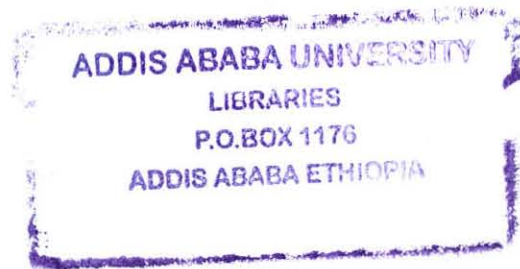


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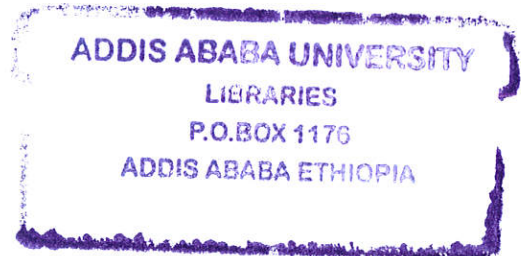


EFFECTS OF HANSEN'S DISEASE STIGMA
ON THE PSYCHOSOCIAL WORLD OF SURVIVORS
AND FAMILY MEMBERS

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JUNE, 2004

**EFFECTS OF HANSEN'S DISEASE STIGMA ON THE
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FAMILY MEMBERS**



BY

WAGANESH ABEJE

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ABSTRACT

This study attempts to examine the effects of HD stigma on the psychosocial world of survivors and family members. Data were collected from 60 survivors (30F&30M) and 60 family members (30F&30M) residing in three different sites in Addis Ababa by means of structured interview schedules. Qualitative research method (case studies) also used to gather in depth individual data. The quantitative data were analyzed using descriptive statistics and t- test.

The result revealed that the survivors and family members experience serious kinds of emotional and behavioral disturbances due to HD stigma. These include depression, anger, anxiety, and hatred towards general community. Termination from job, school dropout, divorce, etc. could also be found as the cost paid of this stigma. However, the t-test result revealed that these effects are more severe in family member than survivors, and in females than males.

Regarding the strategies adopted in managing stigma concealing the disease, denying, displacement, telling unreal stories, social withdraw and restrictions in participating in social functions were used by the respondents. Absence of public education program about the disease or lack of public awareness, lack of cooperation between professional workers and persons with HD, absence of counseling, lack of vocational rehabilitation, and societal negative attitudes towards integration were found to be the major hazards in the reintegration of them into society.

Finally, the importance of counseling for the survivors and family members, health education for the community, promoting the right, wellbeing, and education of females, provision of assertiveness training especially to family members, awareness creation programme, etc. were recommended as strategies for the improvement of HD survivors and family member life.

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Acronyms and Abbreviations

AHRI	Armauer Hansen Research Institute
ALERT	All African Leprosy and Rehabilitation Training Center
ENAELP	Ethiopian National Association of Ex-Leprosy Patients
ETV	Ethiopian Television
GAEL	Global Alliance for the Elimination of leprosy
HD	Hansen's disease
HIV	Human Immune Deficiency Virus
LCP	Leprosy control programs
MOH	Ministry Of Health
MSC	Medhin Social Center
NGO	Non Government Organization
PZWH	Princess Zeneb Work Hospital
SER	Socio-Economic Rehabilitation
SIM	Sudan Interior Mission
SNNP	South Nation Nationalists People
SPSS	Statistical Package for Social Science
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

Background of the Study - Statement of the Problem - Objective of the Study
- Significance of the Study - Delimitation of the Study - Operational Definition
of Key Terms

1.1 Background of the Study:

Hansen's disease (leprosy) is one of the oldest diseases that carry fear and stigma. In the morning of recorded time as early as 1400 B.C., many refer was could be faced to "leprosy" in medical writings; scrutiny of early manuscripts, however, would suggest the term implying more a frame of mind than an actual disease entity (Gussaw, 1989; Flynn, 1991). For instance, Egyptians defined it as a "tumor of the god xenuse ", and coined the phrase, "the death before death"; Chinese writings described a clinical picture only remotely resembling leprosy, ascribing its etiology to good or evil forces known as "feng shui "(Flynn, 1991) and an Indian document also describes it as an "eating disease" called Kushtha. Similar vague descriptions could be identified in other Far and Middle East medical records (Srinivasan, 1993). Beside, 1200AD Europe history indicated that approximately 19,000 leprosaria (leprosy colonies or hospitals where leprosy patients are treated) that are exist all over Europe, usually set apart from towns and communities. Phillip IV, king of France (1285-1312) went up to the extent of suggesting that all persons with leprosy be collected together and burned alive. This spire practice had been continued until the disease was eradicated (ENAELP, 2004).

Though the meaning descriptions varied across geographical divisions, and through time, the one common factor, which gave it forms, was a universal pervasive, negative attitude evoked when the term was applied to a given clinical phenomenon (Flynn, 1991). As to this writer one can virtually differentiate the following five phenomena connected with the term:

- The disease, leprosy, as recognized by modern diagnostic criteria.
- Any condition to which the name “leprosy” is applied.
- The condition itself, under whatever name.
- Any clinical picture which resembles leprosy, and which consequently carries with it notions of disfigurement, progressive mutilation, and threat of transfer by some form of contact with a patient.
- Some type of primitive thought process, something of an almost mystic nature, which is evidenced by mentioning the disease as a transmitted one.

This was seen as an attainment by the medical professionals, who responded in an emotionally primitive fashion in the handling of their patients known to have leprosy.

In summary, one might say that the fear attached to the name and /or to the disease per se, all of which are conceptually some what separable. Even though the attachment is differing, fear of the disease has remained a part of the characteristic of social attitude towards it right to the present day (Zachary, 1989; Flynn, 1991; Tom, 1996).

Ethiopia, as one of the endemic countries throughout the world that has significant prevalence, has given great concern to eliminate leprosy. In the past four decades progress has been made through new methods of outpatient treatment, specialized and

integrated health service and combined treatment (Abera and Shanko, 2000). However, despite the progress achieved, due to the lack of appropriate knowledge about the cause and consequences of the disease, the Ethiopian society holds negative attitude towards the disease. Among widely used irony notations which have negative implication, it is possible to take example such as, “*quomatan quomata kalalut gebto yefetefeta*” (unless the leper is always told about his leprosy, he will seat with you in one dish) which mean that the person affected by “leprosy” is not equal to other healthy citizen, “*bela balgne end abate bequmetgn*” (had I been fortunate, I would have been a person affected by leprosy like my father) its meaning to Ethiopians has negative interpretation which mean persons affected with leprosy are unproductive consumers, earns living in beggary; ” *bequomata bet and etate berkenew*” (a finger is precious to a leper) meaning leprosy patients are poor and selfish because they are equated as life long beggars, indicates the extent of discrimination and stigmatization.

These long aged and deep –rooted wrong attitudes and prejudices have made the survivors and the family members to be the most segregated, stigmatized and social outcasts, which in turn forced them to be vulnerable to various social, economic and psychological problems.

Even today, the stigma attached to Hansen's disease (HD) has been a major constraint –preventing patient from regular attendance for treatment and reintegrating themselves and the family member into the general community even after fully cured. It has also intensive negative effects on patients and the family as well as the community. In many endemic areas of the country there is still prejudice and resentment, which often

makes lives of HD survivors and the family members unbearable (Bergel, 1998; Tirussew, 2000).

The present study is an attempt to explore the effect of this HD stigma on the psychosocial world of the survivors and the family members.

1.2. Statement of the Problem:

In Ethiopia, especially during 1950's and 60's HD had been a very alarming public health problem. To overcome this problem many efforts had been initiated by medical professionals. By now, it is possible to say that HD tends to become under control throughout the country. The number of estimated HD cases in the country has dropped from 150,000 in 1955 to 5,000 in 2002 (Elizabeth, 2004). However the life of many people who have or had the disease and the family members are still sympathetic due to stigma and prejudice.

For a person stick and stones may break his/her bones, but any label with prejudice can severely hurt one forever. The abuse of labeling has been highly observed in the life of HD survivors and the family members throughout the country. They suffer more from the label than did the pain of the disease. They have become a symbol of outcast, the ugly and the feared. For instance, in Addis Ababa (the capital city of Ethiopia), one can simply observe people entering into the city bus No.36 and No. 7 that link the 'lepers' village' and city center and which is being used by HD survivors for transportation, healthy people cover their mouth and nose to protect themselves from being contacted (Waxler,1981). This would have a great impact on their life

circumstance such as on their economic capacity, job opportunity, marriage, socialization, and educational opportunity, utilization of public service as well as emotional and psychological situation. Go to the streets of Addis Ababa and other towns elsewhere in Ethiopia, one can observe that HD survivors constitute a significant portion of the beggar community. Most of them are with observable behavioral problems like aggressiveness, instability and the like and most of them are also illiterate.

On the occasion of the International Leprosy Congress at Bergen (Norway) in 1973, the need to give greater importance to social aspect of leprosy was stressed for the first time. Suisse (1980) cited in Kaufman, Senkenesh and Neville (1986) show the degree of stress by quoting the idea from that occasion. It says:

If the patient is not sought and discovered, how should we take care of him?

If the patient is not cared for psychologically due to the stigmata and prejudices, how will he react to medical care? Finally, if the cured leprosy patient is not reintegrated in society, has the medical care obtained full effectiveness? (p.7)

Since giving due consideration to the social aspect of HD is a very recent trend, its stigma has a profound problem on the psychosocial world of survivors with HD and the family members even today. It is especially a very big problem in developing countries, such as Ethiopia where the knowledge of the people about the disease is not modern or advanced and where culture has more power than policy in bringing public attitude change.

The problem of HD stigma get worst at times and the infected persons including their family have to experience the most agonizing physical and psychological plight of mankind. Though, significant numbers of researches have not been done in Ethiopia, experience shows that the contributions of the medical professionals alone don't bring about significant progress in the life of survivors. Only very limited researches on the psychosocial effects of HD stigma on the life of survivor and the family member had been conducted in the global and Ethiopian scenario. This indeed, implies that more than ever before there is a need to make concerned effort to treat the socio-emotional problems by conducting specialized studies on how this stigma and prejudice affects the psychosocial world of the patients and the family members. To this end, this study searches answers for the following basic questions:

- What major effects does HD stigma impose on the psychosocial world of survivors?
- What major effects does HD stigma impose on the psychosocial world of family members of survivors?
- Is there a significant difference in the effects of HD stigma between the survivors' and the family members' psychosocial world?
- Does gender role differentiation have its own implication in relation to effect of stigma on the psychosocial world of HD survivors and family members?
- What kinds of strategy do HD survivors and family members employ to manage the stigma?
- What problems do HD survivors and family members have in relation to reintegrating themselves into the general community?

1.3. Objectives of the Study:

The study has the following general and specific objectives.

General objective:

The general objective of this study is to examine the effects of HD stigma on the psychosocial world of HD survivors and family members. The study also attempts to assess what strategies they use to manage the stigma and to trace major problems that the subjects face in reintegrating themselves into the general community.

Specific objectives:

The specific objectives of the study are to:

- Identify the major effects that HD stigma imposes on the psychosocial world of survivors.
- Identify the major effects that HD stigma imposes on the psychosocial world of family members.
- Assess the difference in effect of HD stigma between the survivors' and family members' psychosocial world.
- Identify gender differences in effect of HD stigma on the psychosocial world of survivor and family members.
- Assess the strategies that the survivors and family members employ to manage the HD stigma.
- Pinpoint problems faced by HD survivors and family members in relation to reintegrating themselves into the general community.
- Recommend possible intervention and rehabilitation strategies.

1.4. Significance of the Study:

At present, HD is not a major public health concern; however, as the practical experience with the field indicates there is an increasing demand for treatment, prevention of disability, and rehabilitation of the patients and psychosocial intervention of family members. Therefore, this study is expected to hold the following as its significance:

- Help the rehabilitation and welfare programs for the HD survivors and the family members by providing the real psychosocial problems of survivor and the family members.
- Show the implication of HD stigma across sex difference.
- Give insight into the very link existing between the reality and myths.
- Give insight into the psychosocial needs of HD survivors and the family members.
- Suggest viable strategies to curb the problem.

1.5. Delimitation of the study :

The study mainly deals with exploring the effect of HD stigma on the psychosocial world of survivors and the family members across sex difference. In spite of the pervasiveness of the problem it is delimited to three selected sources in Addis Ababa. These are:

Birhan Taye Leprosy Disabled Persons Working Group: It was established by a group of volunteer foreigners and Ethiopian in 1973 at ALERT compound, Addis Ababa with the aim to impart training to women patients in different skills that would

help them engage in income generating activities and also make them productive members of the community. Recently, men HD survivors and their family members have joined the group. The organization comprises of HD survivors who preferred to engage in handicraft rather than begging, which is the fate of their intimates as a means of livelihood.

Region 14 Associations of Ex-Leprosy Patients: It is a branch of the Ethiopian National Association of Ex-Leprosy Patients (ENAELP) and having the aim to protect the rights of persons affected by HD, to promote awareness in the society and alleviating the socio-economic bottlenecks so as to strengthen the life of the survivors in region 14 (Addis Ababa and around). In order to empower the economical capacity of the organization, it involves in different income generating activities. All of the employees who are working at this organization are either HD survivors or family members of HD survivors.

Medhin Social Center (MSC): It is a service giving church based Ethiopian Non Governmental Organization (NGO) established in 1988 in the south western outskirts of Addis Ababa, one of the poorest areas of the capital. It is engaged in socio-economic rehabilitation of HD survivors and the family members through subsidizing school children, welfare service for the elderly survivors, organizes saving and credit association and arranges vocational and higher education for high school graduates.

This study is delimited to Addis Ababa; because, for one thing it is believed that survivors who are living in Addis represent various ethnicity and cultures of different

part of the country than the other cities. Beside, these places were found to be potential setting where one can have easy access to HD survivor and family members.

1.6. Operational Definition of Key Terms:

The key terms used in the study are operationally defined as:

Effects: An individual negative emotional experience such as worry , distinctiveness, isolation, depression , unsuitability , hatred, disinterest, anger , fear , shame, and also the cost paid such as divorce, job termination ,school drop out ,etc due to societal negative reaction towards HD.

Stigma: An attribute which makes a person to be seen with disrespect and disregard and which deprives him or her of the social advantages in life by being considered as a disreputable person.

Psychosocial world: Ones psychological dimension such as self concept, self esteem, self management, emotional management ,etc. and social dimension such as family, marriage, relations, friendship, interaction, socialization, grouping, neighboring, schooling, working ,etc.

HD survivors: Persons who have or had the HD (leprosy).

Family members: Persons with a family member(s) who has /have or had HD and who is not infected by HD

CHAPTER TWO

Review of Related Literature

Introduction - History and Magnitude of Hansen's disease - Hansen's disease and Stigma - Causes and Theoretical Model of Stigma- Psychoanalytic Theory - Social Identity Theory - Social Psychology Theory - The Psychosocial Effect of Stigma - Gender and HD Stigma - Coping Perspective on Stigma.

2.1. Introduction:

Attention to the psychosocial phenomena of HD patients has in no way kept pace with the investigation and progress in medical area for many decades. Since isolating procedure was usually employed following HD diagnosis, the lack of attention on the part of the social scientist has been highly observed. It doesn't have more than six to seven decades of history since it became the principal agenda of social science professionals in addition to Bio-medical professionals (Abera and Shanko, 2000).

HD has struck fear in human minds for thousands of years, and was well organized in the oldest civilizations of China, Egypt, and India (Flynn, 1991; Joplin, 1991; Raja and Reddy, 1995; Bergel, 1998). There are many countries in Asia, Africa and Latin America with a significant number of HD cases (Brand, 1984). HD is an ancient disease, one that has important connotations because of its potential for severe disabilities, and one that has attracted for many years the efforts of civil society and other organizations in an almost unique manner (Srinivasan, 2000).

As to Elissen (1991) and Kikuchi (1994), the prior knowledge of professionals (for example, in the first international congress of leprosy, occurred in 1891 in Berlin,

where it was concluded that leprosy was an incurable disease and that patients had to be isolated (Room, 1995)) and other false beliefs about it such as considering the disease as a curse from the god's or devil's punishment for some sins had great contribution for the existence of the disease with human history until recent days.

Of course the disease might not have been a big deal than any other disease for many centuries, if it was not cloaked in social stigma. Because it is a disease like any other disease and it is totally curable. It isn't a highly contagious disease, as many people believed. Waxler (1981) claimed that it is not as contagious as it was made to be. For example, several health care workers known to be in close contact with HD patient for years are found living, with out getting the disease themselves(Kauffman, Senkenesh and Neville, 1986). Even if the patient has experienced some measure of deformity, it is possible, to correct through chemotherapy, physiotherapy and reconstructive surgery (Bergel, 1998).

Unfortunately, despite its treatable and curability, HD has other attached characteristics such as poverty, discrimination, uncleanness, and stigma. Among all stigma has more power even to substitute the word it self. It is one of the diseases, which are not as in sufferable as the myth and stigma surrounding them. The community has regarded it as contagious mutilating and incurable disease (Freilich, 1982; Srinivasun.2000; Stearns, 2002). From the earliest times until the current days it has been a disease set apart from all the others and in a great many communities its sufferers have been rejected by the society. Even those who are clinically cured still suffer the consignees of their disease (Bainson and Vandeborne, 1998).

According to Deepak (2000), a WHO report in 2000 stated that even today affected person with clear signs or chronic manifestations and their families are often unable to work or marry, becoming dependent for care and financial support, leading to insecurity, shame and consequent economic loss.

In much of the relevant literature, HD stigma is interpreted as the 'chief causes of the social and economical dislocation that people affected by HD experience' (Dogliotti, 1979; Baconcinic, 1991; Nicholls, 2000). In short, there is a chain that follows with its own consequence - leprosy brought stigma, stigma brought social discrimination which has a significant influence on the social and personal life of persons who have or had the disease. A primary impact of discrimination is that it pushes the epidemic underground, forcing people who have anything else associated with the disease in to hiding. It also makes the disease someone else's problem. The disease itself then remains hidden so its perceived threat is reduced. This can facilitate individuals and communities using denial and distancing as a defensive process against the epidemic reducing the need to adopt (Kuar and Vanbrakel, 2002).

Of course, discrimination has much implication than the above-mentioned and it has been a power to prohibit the effectiveness of many leprosy elimination and rehabilitation programs.

2.2. History and Magnitude of Hansen's disease:

Although HD is often referred to as the oldest disease known to man, its origin are lost in the clouds of ancient times. Several lines of evidence throw doubt on such assertions (Ronny, 1986). Bergel (1998) observed that the earliest written records

describing true leprosy, which were most probably proceeded by orally transmitted traditions, come from India, in recessions brought together in about 600B.C. In the western world, many of the assumptions concerning the history of leprosy derive from Christian tradition (Tom, 1996).

At different times in history, leprosy was known by various names throughout the world. For example, in 600 BC, in India, it was called "kushta "; it means it affects the skin of the trunk and extremities (Flynn, 1991). It has also long been thought to be the disease referred to in the Bible as "tzaraat" (Freilich, 1982). Chinese writing described it as " Feng-shui" (Flynn, 1991). It has also various names in Ethiopia. For example in the 4th and 6th century A.D it was known as "lamts" (Mesfin, 1992). Until recently the same name has been used particularly in northern Ethiopia. Other but related names like "quesele sega" (ulcerated body) or "talak dewe" (major disease) or "kurch" (similar meaning to the other, but only used by Oromo people) also used in different part of the country. The commonly used Amharic word "Qumetna" is thought to be derived from the Arabic word "Jadhom" which means "cutting" (Berhan et al., 1990). At present the preferred and legally accepted word is "siga dewe" which means "disease of the flesh". Most of the names of the disease have been covered with stigma and prejudice. In most of the developed countries now days, the preferable term is Hansen's disease than leprosy. In Amharic the equivalent word of HD may be "siga dewe".

In relation to the history of HD stigma in Ethiopia, it is believed that HD was one of the ancient and stigmatized diseases known. Actually, the history of HD in Ethiopia was not clearly documented, but historians have named Ethiopia amongst countries of

origin of the disease (Elizabeth, 2004). As Mesfin (1992) described travelers during and after the 16th century have explained that despite the presence of leprosy stigmata, the Ethiopian society was more tolerant than other contemporary societies of the west where harsh treatment was done to survivors. Despite of this writings there is also found facts that reflect the negative experiences of HD patients in earlier times. For example, in the law of the kings of Ethiopia called "Fetha Negest" it was stated that a leprosy patients couldn't serve the church as a priest, patriarchie or a judge. Though, the Fetha Negest doesn't require the patients to live alone or segregated, it has an implication that may be considered as a pull factor for the society to discriminate HD patients.

The Ethiopian Orthodox Church was said to be operating in accord with Leviticus law and considered the patient as "unclean" but there was no legal provision that prevented marriage or permitted divorce (Berhan et al., 1990). Many writers reported that until the end of the 19th century leprosy patients were regarded as part and parcel of their family and community and were celebrating with other healthy members equally at festival occasion by sharing drinking cups and dining together (Tedla, 1988; Kidanmariam, 1986; Yohannes, 1973). For example, in 1900 when the first attempt form modern care of leprosy patient started in Harare, Freon, a catholic doctor from France, reported that the patients were not segregated from the rests of the population and were taking their medications voluntarily. However, this experience was not continued after the 19th century. Though there is no clear description about the reason for its change several writers such as (Giel and Vanlulisk, 1976) indicated that after this century the patient started to be seen as a dishonored individual who brought a

disgrace to himself, family and even to the seven generations who had lived after him or her. They were treated as not being part of the society: they married among themselves and were forced to leave their family and town (Mesfin, 1992).

The Sudan Interior Mission (SIM) had established the second leprosaria named Princess Zeneb Work Hospital (PZWH), in the suburb of Addis Ababa in 1932. This was considered as "the beginning of specialized hospital care in Ethiopia (Yohannes, 1973). After the establishment of this hospital, until 1955, the formation of the largest residential area of leprosy patients around it was materialized and it paved the way for the creation of these " self built segregation village. To explore this situation Mesfin (1992), said the following

Taking advantage of the spacious compound of the Princess Zeneb Work Hospital patients and their relatives who come for medical help and patients who were rejected by their family and community started to reside on the premises of the hospital compound (P.31)

Then after, the attitude of the people toward leprosy patients is bending to become benevolent, and leprosy seldom leads to complete segregation of patients from their families or villages. This fact was also observed in a story by Waxler (1981) about the universality of stigma and its variation in the degree across Africa, she said that in Ethiopia similar to India, leprosy patients live with negative experience like divorce, migration, begging and rejection from the general community.

Leprosy has a specific history on its magnitude in many part of the world since Before Christ. However, the observation of the WHO (2003) report in the prevalence of HD is

worth mentioning. The prevalence tends to become reduced significantly from decade to decade. In 1951, there were 15 million leprosy sufferers worldwide. About 720,000 new cases were detected during 2000. At the beginning of 2001, the number of leprosy patients in the world was less than 700,000. In 1991, WHO member states resolved to decrease the level of leprosy in the world by over 90%. This has now been accomplished. And to assist in meeting this goal, the WHO and collaborators established the Global Alliance for the Elimination of leprosy (GAEL) in 1999 and GAEL extended the large data for elimination. The aim of the Alliance is "to make a concerted and coordinated effort to achieve the elimination of leprosy as a public health problem from every endemic country, at the national level by 2005." (WHO, 2003).

According to WHO (2003) report, the global leprosy situation, as reported by 110 countries, shows that at the global level there are 534,311 point of prevalence and 620,672 cases detected treated during 2002. Among them 53,888 prevalence points and 48,248 detected cases are from Africa. As to this report, Ethiopia is classified as the country which is in range of 0 to 1 per 1000 prevalence rates. It indicates a very significant improvement when it is compared with the 1991 prevalence rate i.e. 3.1 (Nichollas, 2000).

2.3. Hansen's disease and Stigma:

Wilson (1988) said that stigma drives from ancient Greek word describing the badly signs once used to mark or criminal. This writer defined the word as *a societal reaction which singles out certain attributes, evaluates them as undesirable and*

devalues the persons who possess them. Many other writers also defined stigma from similar societal reaction aspect. Brieger, Oshiname and Ososanya (1998) defined stigma as *social devaluation of a person because of personal attribute leading to an experience of sense of shame, disgrace and social isolation* (P.843). Heijnders (2002) define the word as *discrediting attribute which constitutes a special discrepancy between virtual and actual social identity is what people are in real life.* (P. 32).

Stigma plays a significant role in the development and maintenance of survivors with some condition such as poverty, disease like HIV and HD. Kaufman, Senkenesh and Neville (1986) and Tekelehaimanot (1992) considered certain conditions such as physical deformity, abnormal behavior, race, poverty, gender and disease as the first causes of stigma, which were later extended to broader and more subtle characteristics. It is important to have some scientific understanding of the meaning and role of stigma. For the purposes of the present study stigma has been defined as a deeply discrediting attribute that reduce a person to some one who is in some way tainted and can therefore be denigrated. It is a pervasive problem that affects health of individual, threatening an individual's psychological and physical wellbeing (Appasomy 1996; Stigler, Genus and Heynder, 2000). It is widely recognized that stigmatizing attitudes exist towards HD. Hansen's disease stigma and its implication to rehabilitation to individual who have or had HD have recently attracted attention from researchers and policy makers (Arole, et al., 2002; First, 2000).

According to many writers such as Gillman (1992); Walter (1998); First (2000), it is possible to identify four components as being part of the HD stigma. These include:

- Distinguishing and labeling difference

- Associating human differences with negative attributes
- Separating "us" from "them" and
- Status loss and discrimination.

Though HD stigma is entirely dependent on social economic and political power, as power is required to be able to introduce stigmatization (Scott, 2000), it also removes power from the stigmatized person (Berreman, 1984; Heijnder, 2002).

Stigma plays a role in society by creating "difference" and social hierarchy and then in turn legitimizing and perpetuating this social inequality (Brand, 1984; Room, 1995). It has a shameful history internationally which arises really out of any point of difference. Though, the major focuses for stigma have been illness, age, race, gender, handicap, religion, and other factors no one could be more globally stigmatized than HD (Brand, 1984).

HD can be explained in terms of disease (bio-medical perception), illness (self - perception) or sickness (social perception) (Room, 1995). As far as the social aspects are concerned, it is better to consider HD in terms of illness and sickness. Its illness is experienced by the person and this has its own structure which designed by social and cultural influence. The sickness HD creates if and only if the concern of societies existed. It is the problem as perceived and named by the society, expressed in to social stigma (Gill, 1992; Rodger, Gore and Figueiredo, 1995; Stigler, Gleason and Heynder, 2000).

Other than the impairment and disability caused by the disease, the HD stigma imposed a handicap on the infected to be feared and perceived as dangerous to the

society and exposed him or her to subsequent rejection (Mesfin,1992). The chronics of HD exposed the patient to along stand suffering and the potential deformities (Joplin, 1991; Grant, Blue and Harogan, 2002). The associated implications of incurability lead to a strong negative social reaction. Related to this idea, Scott (2000) said that leprosy has a unique social dimension which is associated with strong social stigma. In both western and eastern cultures, fear of the disease has existed from ancient times.

In no other diseases, individuals have been made to leave their families and communities and be forced to live as out casts in separate colonies or settlement. The word leprosy itself carries prejudice which shades a powerful emotional load. One can possibly say HD is more than biological disease; it is also more characterized by social stigma to the extent that the survivors have experienced it for centuries, the fearful attempts at concealment the trauma of increasing impairment (Joplin, 1991; Mesfin, 1992). As to Gussow and Tracy (1972) the treatment of HD sufferers throughout history is one of the darker examples of inhumanity to man. In spite of the considerable enlightenment and information about HD available today, the fear and prejudices regarding HD and the patients remain to a large extent in grained and persistent (Kamble, Mahanti and Moorthy,2002;Hassan, Khail and Hassan,2002).

HD has become symbolic of highly stigmatized and feared circumstance. In many parts of the endemic areas still has a special position among disease. In relation of the stigma of HD Kikuchi (1994), said:

There is regrettably, deeply entrenched prejudice against patient with leprosy. This is more difficult to combat than that related to any other disease. No other diseases cause such a reaction from the community

and so much distress to the patient and his family. Some times the prejudice is more difficult to treat than the disease. (P.143)

2.4. Causes and Theoretical Model of HD Stigma:

There are many diseases which have more impact on the physical and/or psychological, in human history. HD is one and oldest of them. Despite of its treatable and curable natural, it is more fearful and the patients are suffering more with the stigma.

The root cause for one condition in being stigmatized is the prejudgment of the general community. Prejudice typically includes negative stereotype, undervalue beliefs, hostility and unfavorable treatment that may include aggression. To prejudge individuals in this way is psychologically to stigmatize them rather than to make discriminating judgments about them. Likewise, diagnostic categories are stereotypes that serve a professional function, misusing such labels are prejudice which can be the root cause to stigmatization. Baharath, et al. (2001) also described it as an affective, categorical mode of mental functioning involving rigid prejudgment and misjudgment of human groups.

There are a large number of approaches to the explanation of prejudice and why stigma develops in the individual or groups. It might be useful to discuss three of them- *psychoanalytic, social psychology and identity theory*, just to examine why HD becomes stigmatized than other disease.

2.4.1. Psychoanalytic Theory:

Psychoanalytic theory argued that certain personality traits may incline people toward some form of prejudice (Kushwa, Govia and Kushwa, 1981). The tendency to view prejudice as a manifestation of personality disorders was an early and remains a popular approach. One such effort uses the Freudian defense mechanism of projection as its starting point (Stearn, 2002). According to the followers of this approach, projection is a process where by undesirable personality traits, emotion or impulses are eliminated by attributing them to some one else. Kushwa, Govia and Kushwa(1981) explored this idea as such frequently the unacceptable impulses that are projected have some negative components such as fear, aggression, depression , etc , so the form projection takes is the assumption that others are hostile, mean dirty and immoral.

Many researchers have suggested that projection provides the basis for anti- Semitic prejudicial attitudes. Kushwa, Govia and Kushwa (1981), support for this view is based on the finding that stereotypes of several different groups show the same components: a belief that the group is immoral, dirty and aggressively inclined. When we see this theory of model from HD patients point, since there is a false belief what we called mystery, many people have no knowledge about the disease - its cause, how it could be prevented, how it was transmitted, how it could be cured, why disabilities occurred and how they could be prevented. Even today, despite the great progress that has been made in our knowledge of HD, there are still many important mysteries that often generate an exaggerated sense of insecurity and therefore, fear of the person with the disease.

The other efforts used to express about prejudice from psychoanalytic point of view are the element of hostility, displacement and scapegoating. It is built on the Freudian model of "hydraulics" where aggression and hostility, towards others is seen as a deflection of psychological (libido) from some frustration one's life. For example, people fear HD because it is an infectious disease as well. It means that the diseases deformities, disabilities and ostracism associated with HD can happen. The strength of HD stigma is probably tied to the fact that it can be deforming and contagious. As a result, people feel vulnerable (Kushwa, Govia and Kushwa, 1981; Stearn, 2002). Some one becomes the victim or scapegoats go around of the action. The fundamental attribution error may be involved too.

2.4.2. Identity Theory :

This theory suggests that we have a need for distinctiveness of social identity. We favor our in groups to the exclusion of others (Scott, 2000). To a large extent our self-esteem drives from how we evaluate our in-groups in relation to our out- groups. Thus we tend like able and successful and to favor members of our in groups at the expense of out -group members because of the boasts or self- esteem. Individuals have low self esteem; they may "take it out" on out groups. According to Kushwa, Govia and Kushwa (1981), there may be obvious crookedness of their fingers, or toes (deformities) in HD patients. In the past, deformities were considered a part of the disease process, of course. For this deformity people have strong negative feelings. One reason for this is that persons with deformities usually radically depart from some societal standard of beauty. Besides, deformities imply incapacity and disabled

persons are often viewed as burdens to themselves, their families and to society as a whole.

Finally, according to this approach, people may simply learn some form of prejudice as a cultural norm, passed on from generation to generation. Stigmatizing or discriminating the HD patient probably accepted as a cultural norm by some community or some individuals. The viewers of social identity theory suggest that to reduce the tendency of prejudice creating contact among different groups is essential.

2.4.3. Social Psychology Theory:

Social psychologists have devoted a great deal of effort to identify the factors which developed prejudice. They stated that situation detect what we are and what we do. They stress on examining the particular nature of inter group relations. For most among this theories are those economic or political conflicts. In terms of economic recession groups' indirect competition with each other for jobs resources feel heightened hostility (Denscombe, 1993). For example, the situation of earlier HD patients in the Bible had great contribution to be stigmatized. A religious interpretation of disease in general and leprosy in particular has been common to most world cultures, leprosy has had a particularly prominent place in Judea- Christian literature and traditions and therefore in the countries influenced by them.

In the Old Testament one think of God's can read Mariam with the disease because of striking her sin (Exodus, 12:10); of Jacob played by rotting skin that tradition has often been identified with leprosy; of priests casting out of the camp the victims of the

disease until they were purified; of Nohaman washing in the River Jordan to be cleansed of his leprosy (II Kings, 5:1-10). And the declaration of Moses, the father of Israel in Old Testament also said: ... *And the leper in whom the plug is clothes shall be rent. And the hair of his head shall lose. And he shall cover his upper limp. And shall cry, say unclean, unclean...* (Leviticus, 13:45)

In the New Testament one sees the fearlessness and compassion of Jesus as he healed at the home of "Simon the leper" and as he touched and cured so many persons who had the disease (Matthew, 26:6). In short, leprosy and leper have become religious symbols. On the one hand, they are symbols of some of the worst that can happen to a human being: physical suffering, body decay, ugliness, the loss of worldly goods and perhaps worst of all, the rejection by one's fellow man. Superstition and religious perception of the disease have also played no small part. In many religious books, leprosy or its equivalents have been considered a curse or a result of some divine displeasure or a punishment for some sins committed by the sufferer in his birth or a previous one.

On the other hand the trend of diagnosing HD patients with segregation policy by itself can be a causal factor that leprosy has such stigma. Related to this idea Waxler (1981); Gussaw (1989); Room (1995) have said that it had usually characterized the treatment of the person affected by the disease has been treated through the centuries. The longer such system remains, the longer such mental associations will continue. The results will be the continuation of the public's exaggerated fears of the disease and of the person affected by it. The segregation of people affected by leprosy has been both a major result of and also a major source of fear and stigma.

The other social psychological approaches stress the power relations between groups , noting that prejudices and specific stereotypes may be generated to perpetuate the inferior status of a stigmatized group is profiting (Scott,2000). One of their theories holds that prejudice results when people are in strong competition with each other. Frustration over losing something evolved (such as a desirable prize or the self esteem winning) can help explain this link between competition and prejudice and / or stigma. When people are frustrated by adverse situations they can't change, they often vent their anger and aggression on the most readily available escape goat (Fife and Virright, 2000). This tendency has been demonstrated experimentally. For instance, in earlier times, leprosy was sometimes associated in myth or reality with wealth and powerful persons including famous kings like Constantine. This association, however, is rare today. Although no social group or economic class is immune from HD, today the disease is mainly associated with the developing countries and with the lower classes within these countries. This relationship of the disease with the poor, the uneducated, and the powerless tends to strengthen the public's and the service provider's negative reactions to it and the amount of attention given to it by health and social planners.

In general as far as the stigmatization of leprosy is concerned, the stigma is mainly attached to the dermatological problems and limb deformity, it can cause other factors including the wide spread view of the disease a part, only for dedicated specialists, leads to an atmosphere of fear and stigma regarding the disease and its victims (Tom, 1996; Fife and Virright, 2000).

2.5. The Psychosocial Effect of Stigma:

Stigmatizing actions may differ from community to community and vary depending on the visibility of the leprosy signs and their obtrusiveness, and the extent to which they were recognized as being leprosy. Though the severity of its effect differ depending on various conditions, the survivors under whatever position couldn't escape from suffering in either expected or experienced stigma (Awofeso,1992; Baharath, et al., 2001 ; Hejinder,2002). Those individuals who are suffering from expected stigma may have different experience than those who suffer from enacted stigma. The reality is both of them including their family experience some social, psychological, physical and economical effects in one way or another.

Even today people who have or had HD and their families are experiencing stigma in many aspects of their lives. The impact of stigma is to drive the disease out of the public sight (Aizen, 1988; Benison and Vande, 1998). It also prevents or limits a person's access to treatment, by delaying a person being tested and by the introduction of obstacles to obtaining treatment (Baharath, et al., 2001; Briden and Maguire, 2003). At an individual level the stigma undermines the person's identity and capacity to cope with the disease (Site and Gittens, 1992). It limits the possibility of disclosure even to those close to the person such as family and friends, who could be important supports, stigma also impacts on behaviors.

In short stigma has profound psychological, social, and economical effects not only at individual level but also at family and at community level. The attitude of the public towards the disease is at the root of the social problems arising in leprosy (Bijleved, 1982; Berreman, 1984). In a society where the stigma is high however, the patient

accepts that he /she is the outcast and this attitude of mind is confirmed when he/she is admitted to a leprosy hospital (Scott, 2000). Over all, while leprosy affected each individual differently, it almost always reduced one's social power in some way (Flynn, 1991; Hassan, Khail and Hassan, 2002). Identities which diminish social power are often understood under the rubric stigma (Hudson and Genesse, 1982). Leprosy has served as the basis of social identity in seemingly unconnected places and times ranging from Europe to contemporary Ethiopia (Mesfin, 1992). Most people want to separate themselves from the stigmatized in order to reduce their own risk of acquiring the stigma. By isolating individuals people feel they can also isolate the problem (Chauhan, Dhar and Singh, 1984; Gill, 1992). The fear of leprosy is so great in most communities that often people who contract it either are forced out of their villages and left to fend for themselves or if they are deeply loved by their families are simply locked away - the skeleton in the family closet (Wilson, 1988).

Socially, persons affected by leprosy are not living together within their home communities; they didn't participate with the same rights and duties in the group they would have participated in had they never contracted the disease (Gopalakrishnan, 1986; Site and Gittens, 1992; Heijnder, 2002).

Most of the time particularly where the action of stigma is practiced, the HD patient are segregated directly or indirectly from the general services provided by community institutions like school, church, housing, recreational facilities, hospitals, rehabilitation center, marketing, transportation, homes for the elderly, etc. Lots of terrible stories about negative community behavior are known, persons affected by leprosy were reported to have been buried or burned alive (Fassin, 1990). Many

researchers such as Heijnder (2002); Mesfin (1992), and Waxler (1981) show that persons affected by leprosy experience exclusion from social life. For example, they have to sit and eat separately and are not allowed to use public facilities. They have difficulty in gaining employment they are refused jobs (Mesfin, 1992).

The study carried out by Stigler, Genus and Hinders (2000) demonstrated that when community members were asked to describe the behavior of the community towards a person affected by leprosy who they knew two thirds of them acted negatively towards them. A wide range of community actions was reported, from food restrictions to expulsion from the village. The following actions were those most frequently reported

The person had to sit separately; he or she was not allowed to enter other people's houses; people didn't visit the house of the person affected; the person affected was not allowed to touch others; was not allowed at school; or had problems at work and getting medical care. (P.496)

In short persons affected by leprosy experience unsympathetic reactions, insult, hate abandonment or rejection. Community members also favor some form of segregation; they want persons affected by leprosy to be kept and treated away from their homes and villages (Berreman, 1984).

Some writers said that it is difficult to examine the emotional shock to which HD patients are exposed to and the very great change that takes place in their body as well as in their mind. This is not due to the pain of the disease rather for the consequence of social attitude which follows discrimination from the general community. Discrimination is the immediate process of having that stigma applied, either at an individual or social level. The attachment of discrimination to illness has a long

history with it impairing on people particularly with leprosy (Ji and Saunderson, 2003). Following their being victimized by HD many are rejected by their families on account of the latter's fear of leprosy and isolation or loneliness which is their remaining alternative (Wilson, 1988; Flynn, 1991; Nicholas, 2000).

Since there are certain stigmatization passages in the Bible, some sufferers were isolated because members of the community felt that such patients must be segregated according to the Bible injunction (Wilson, 1988). Fear of rejection by family, friends and the community forced them to develop feeling of distinctiveness with in the leprosy communities and resulting loneliness (ENELPA, 2000; Scott, 2000).

Leprosy can exercise a strong influence on the behavior of a leprosy sufferer. Where the disease has been present since childhood, it can influence a patient's behavior for the rest of life. A variety of emotions are intensely expedited by leprosy sufferers. Grief appears to be the first and most general reaction (Valencia, 1986; First, 2000). Whatever may be the reason, they are debilitated by relatives, neighbors or employers on account of the disease, often, irrespective of the type or stage of the disease. The result of this has been very far-reaching and devastating. At worst, they could force the patient to run away from his family, work place or town or force him for begging or to commit even suicide (Flynn, 1991).

Waxler (1981), in relation to the psychosocial trauma which HD patients received said that a small unnoticed patch on his body, once medically diagnosed leprosy, develop the patient with the cumulative feeling of hopelessness, shame and dependency. Brand (1984) also says about the psychosocial adjustment problems of HD patient as follows,

the leprosy patient would like to be thought of as the victim of a burn and is afraid that his scars will mark him out as a person to be scanned for fear of his diseases (P.48).

As to Ronny (1986) offered, psychodynamic formulation, leprosy patients had an irrational fear produced by the visible bodily blemishes and based on a sense of guilt which he attributed to incest complex. The guilt resulted in masochistic behavior, demonstrated by the patient's neglect of his / her medical regimen. Dreams were infantile and elementary, content extending back to pre-morbidly.

2.5. Gender and HD Stigma:

Most women especially in the developing country lead an existence of extreme sub services with very little control over their own lives. The few (many educated) women who have succeeded and risen to prominence in a completely male-dominated society don't indicate a general improvement at least in the developing area. A disabled woman were suffers a multiple handicap (Thompson, 1994). Marriage accessibility is rare for these women. They are most likely to be condemned to a twilight existence as non-productive adjunct to the house hold of their birth. At best they may be the object of misplaced sympathy which regards them as helpless and unable to do any thing for themselves or for the family or they may well be kept hidden in order not to damage the marriage prospect of siblings alternatively. They may be turned out to beggary. It is small wonder that many disabled female babies don't survive (Coleridge, 1993 in Yeshetela, 1998; Augustine, 1999).

Gender inequality in HD patients was the concern of many researchers. Most of their results indicate that gender could be as big factor to impose psychosocial problem on individuals (Hunter, 2000; Morrison, 2000). Though HD can affect all human beings disregarding race, sex, color, etc., the extent of impact appears to be more among women in terms of isolation, rejection from spouses, children and relatives, loss of freedom to touch and other restrictions (Grant, Blue and Harogan, 2002). The sex difference in the incidence of leprosy is influenced by the population studied, with various African studies reporting male: female ratio from 2:1 to 1:1. In Ethiopia, there is a 2:1 ratio observed (Rao, 1996; Hunter, 2000).

To show the impact of gender on the effect of stigma on ones life, Augustine (1999) said: *In some tropical disease, such as flairs and leprosy, gender inequalities may play larger role, because of their effect on physical appearance and the social stigma associated with it (P.38).*

Men and women may be affected in different ways, be biologically or soico-culturally (Kuar and Ramesh, 1994; Raoand, and Garike, 1996; Zodpey, Tiworid and Salodkar, 2000). Leprosy due to stigma and deformity makes women unable to continue household work and they may lose status in the family and end up leaving their homes (First,2000). Since, women are expected to put their family before themselves and may fail to seek help early in the disease, being unable to find time to leave their family is their major problem (Augustine, 1999).

Morrison (2000) said about the impact of stigma on women's medical history as follows, as to him, they are reluctant to use micro cellular rubber foot wears due to

fear of identification. They are also reluctant to get registered for fear of bad treatments from the family, especially from their husbands. All these might result their irregularity in attending clinics and drug delivery.

Gearochi and Lourdes's (1986) psychosocial need of leprosy patient survey result indicated that the proportions of male and female patients receiving support from their families and communities are shown that females got less family support than male patients. According to this survey, a significantly higher proportion of women patients suffered from low self esteem compared with men.

The other experience of women HD patients related to stigma may be their lack of courage in gathering information about the disease for their fearfulness of discrimination. Zodepy, Tiworid and Salodkark (2000) have observed that many female patients suffer from anxiety, due to lack of sufficient information about leprosy and fear of infecting others with the disease and lack of motivation compared to male patients. Kuar and Ramesh (1994) also supported this by saying that hardship resulting from the disease is probably felt more by women than men, with greater social and marital rejection and loss of self esteem.

Since gender has great role in the accessibility of getting something, women are less able to travel for treatment and seldom do so alone (Rao, 1996). Part of the problem in detection may stem from cultural attitudes to examination of females, particularly young unmarried girls, who keep themselves covered and may hide the signs of the disease (Hunter, 2000). On socio-cultural outcome of the disease, several studies

indicate that women are more affected by leprosy. They suffer more on the social stigma than the pain of the disease and than that of the males’.

2.7. Coping Perspective on Stigma:

The core feature of HD stigma is that a stigmatized person has an attribute that conveys a devalued social identity within a particular context. This devaluation leads to a variety of stressors. A stressor is an event in which environmental or internal demands tax or exceed the adaptive resources of the individual (First, 2000). HD prejudice can increase environmental demands by affecting access to educational and employment opportunities, confining the survivors and their families to the lower rungs of the socioeconomic ladder, and affecting the quantity and quality of health (psychological, social and physical wellbeing) care the survivors and their families receive from their environment. Thus, stress always involves cognitive appraisals about the seriousness of the demand and about the resources the individual has to cope with that demand. This stress could be the source of coping strategies. The vast literature on stress and coping indicates that people have many responses to stress, which include physiological, cognitive, emotional and behavioral responses. There have been several efforts to distinguish conceptually and empirically among the many different responses people may have to stress. Among them as Wilson (1988); Fission (1999) and Nicholls (2000) argued some of the following are observed to use by the HD survivors and their family.

Concealment: The initial response of the patients is to hide about their disease from their family and other community members. They may be able to either collect their

medicines secretly or had informed their family than they have a minor skin disease, which need treatment. In relation to this idea Heijnder (2002) said that in trying to conceal their disease, people employed several strategies to avoid attention.

Avoidance, Denial and Wishful thinking:

Recent research on stigma has given considerable attention to a variety of factors which a stigmatized individual may disengage from the stress. The two main forms of disengagement coping to manage the stigma are physical (displacement) and social avoidance of situation and denial or minimization of prejudice and discrimination (Ji and Savnderson, 2003).

Avoidance coping involves physical and/or social withdrawal. For example, the persons whose disease was exposed to other community members adopt a strategy of covering they took all possible steps to reduce the saliencies of their stigma for others. To do so, they may displace their home place and try to avoid steam-tented situation. This avoidance often goes hand in hand with selective affiliation with other persons affected by the same disease. That is why most of the persons with HD prefer to live in leprosy colony than in other places.

If these people can't avoid or find alternatives to situations in which stigma may create stress, they may withdraw socially. For example they may avoid comparing themselves with non stigmatized people. In relation to this idea Waxler (1981) said that by avoiding social comparisons without group members, stigmatized people are able to avoid the stress that might otherwise result from acknowledging that others are doing better than they are.

Another type of managing stigma is denial or minimization of prejudice and discrimination. Heijnder (2002) demonstrated that stigmatized people do not make claims of discrimination even when the objective evidence points strongly to the possibility that the poor outcomes they have experienced were due to prejudice. This is a strategy to manage the stigma, because it avoids stress by denying the existence of the problem.

There may also be an element of wishful thinking in minimization of prejudice effects. The belief that others have behaved in a discriminatory fashion robs stigmatized people of the sense that they can control and be socially accepted by others. One way to cope with these unsettling perceptions is to wish that those with power are kindly disposed toward stigmatized people and therefore would not discriminate against them(Ashanalla,1987).

CHAPTER THREE

The Method

Introduction - Research Design and Approach - Source of Data – Population-
Sample- Tools – Procedures in Developing Tools - Method of Data Collection -
Procedures Adopted for Data Collection - Analysis of the Data

3.1. Introduction:

To realize the objectives of the study which mentioned in section 1.3, the following research designs and approaches, source of data, tools, procedures for data collection, and method of data analysis were selected.

3.2. Research Design and Approach:

Considering the nature of the research questions, quantitative and qualitative research methods were followed. The quantitative approach was vital to acquire a representative picture of the effect of HD stigma on the psychosocial world of the survivors and the family members. It was equally helpful, however, to apply the qualitative approach in order to be more open to the perspectives of the HD survivors and the family members. Carrying out qualitative research not only allows the investigator to 'get closer to the actor's perspective' but it can also 'confront the constraints of the every day psychosocial world'.

To collect data, interview schedules were constructed keeping the basic research question in mind. Case studies were also conducted to extract in-depth qualitative information.

3.3. Source of Data:

3.3.1. The population: The total population of the study was HD survivors and the family members who are found in Birhan Taye Leprosy Disabled Persons Working Group, Region 14 Association of Ex-leprosy Patient and Medhin Social Center all in Addis Ababa.

3.3.2. Sampling:

To select the sample, both probability and non probability sampling (stratified random sampling and purposive sampling, respectively) techniques were employed. A total of 300 (160 female and 140 male) HD survivors were identified from all the sources – 150 (110 female and 40 male) from Birhan Taye Leprosy Disabled Persons Working Group; 110 (20 female and 90 male) from Region 14 Association of Ex-leprosy Patients and 40(30 female and 10 male) from Medhin social center. From this population, 30 men and 30 women HD survivor were randomly selected. Initially, the group was stratified into two strata comprising of sex. After stratifying, all HD survivors of the three sources were given their own code. The codes were then registered in a separate sampling frame. Finally, the desired sample size was drawn using simple random sampling (lottery method). The same procedures were followed to select 60 (30F and 30M) respondents from 420 family members group. These 420 (170 females and 250 males) family members were drawn from three sources – 320 (120 female and 200 male) from Medhin Social Center, 80 (30 female and 50 male) from Region 14 Association of Ex-leprosy Patients and 20 females from Birhan Taye Leprosy Disabled Persons Working Group.

Besides, after administrating the interview schedules, four respondents (one from each strata) under the selected samples were taken based on purposive sampling. The basic criteria adopted to select these samples were the ability to express their experience verbally and willingness to provide in depth information about themselves.

3.3.3. Sample Descriptions: The total number of respondents selected for the present study was 120 – inclusive of 60 HD survivors and 60 family members. And their socio demographic characteristics are summarized in the following tables.

Table3.1. Age wise Description of Samples (No=120)

Age	HD survivors (No=60)		Family members (No=60)	
	Frequency	%	frequency	%
18-32	7	11.6	38	63.3
33-47	38	63.3	22	36.7
48-62	15	25	-	-
Total	60	100	60	100

As table 3.1. Shows, the majority (63.3%) of HD survivors belonged in the age range of 33-47. Next to this, 25% of them were from the age range of 48-62. The least numbers, i.e. 11.6% of the HD survivors age range was 18-32. In the family members more than half (63.3%) of the cases age was between 18 to 32, while the remaining 36.7% of the cases were in the age range of 33-47.

Table 3.2. Classification of HD Survivors Based on Their Residence (No=60)

Variable		Description	Freq.	%
Place of living	Before onset	Urban	3	5
		Rural	57	95
		Total	60	100
	After onset of the disease	Different from before onset with the general community	7	11.7
		Different from before onset with leprosy community	50	83.3
		The same before onset with general community	1	1.7
		The same before onset with leprosy community	2	3.3
		Total	60	100

As indicated in the table above before onset of the disease the majority of the respondents (95%) were living in rural areas while the number of respondents who lived in urban area before onset was 5%. After the onset of the disease, more than two third of the respondents (83.3%) migrated from their homeland and started living in leprosy colony settlement (with leprosy community). Though 11.7% of the respondents have changed their living place after the onset of the disease, they think that they are living with the general community. On the other hand 3.3% of respondents are living in their original place with leprosy community, and the remaining, 1.7% of them are living in their first place with the general community.

Table 3.3. Ethnic Background of the Samples (No=120)

Variable	Description	HD survivors(No=60)		Family members(No=60)	
		Freq	%	Freq.	%
Ethnic	Amhara	42	70	45	75
	Oromo	9	15	6	10
	Tigrie	2	3.3	-	-
	Wolayta	4	6.6	-	-
	Hadya	2	3.3	-	-
	Harar	1	1.7	-	-
	Not mentioned	-	-	9	15
	Total	60	100	60	100

Though there are a number of ethnic groups in Ethiopia, in this study most of the subjects were found from the Amhara, Oromo, Tigrie, Wolayta, Hadya and Harar. Those who reported they were as Amharas constituted more than half (70%) of the HD survivors group and two third (75%) in Family members. Fifteen percent of HD survivors & 10% of family members' were Oromo. Those from Wolayta accounted for 6.7% and they were HD survivors. Those who were Tigray and Hadya constituted only 3.3 % of the cases of the HD survivor group. The few cases -1.7 % constituted of HD survivor who were Harare. Nine respondents of family members, i.e. 15% of the case were not willing to mention their ethnic background.

Table 3.4. Religious Affiliation of the Samples (No=120)

Variables	Description	HD survivors(No=60)		Family members(No=60)	
		Frequency	%	Frequency	%
Religious affiliation	Orthodox christen	45	75	30	50
	Muslim	13	21.7	9	15
	Catholic	2	3.3	15	25
	Protestant			6	10
	Total	60	100	60	100

Religious affiliation is also an important variable worth mentioning. Two third of HD survivors and half of the family members were Orthodox Tewahedo Christian. Muslim who constituted 21.7 % of HD survivors and 15% of family members are second in number. The rest 3.3 %HD survivors and 25% of the family members were catholic. Ten percent of the family members belonged to protestant.

Table3.5. Marital Status of the Samples (No=120)

Variable	Description	HD survivors (No=60)		Family member (No=60)	
		Freq.	%	Freq.	%
Marital status	Single	6	10	30	50
	Married from leprosy community	26	43.3	20	33.3
	Married from general community	13	21.7	6	10
	Divorced	7	11.7	2	3.3
	Widow	8	13.3	2	3.3
	Total	60	100	60	100

Regarding the marital status of the respondents, a substantial number of respondents 43.3 % in HD survivors group and 33.3 % of family members were married from the

leprosy community, while 11.7% HD survivors and 3.3% of family members have reported to be divorced. Thirteen point three percent from HD survivors group and 3.3% from family members were widowed. Those who reported to be single consisted 10% in HD survivors and 50% in family members. While, 21.7 % of HD survivors and 10% of the family members were married to the general community. Among the reported cases of divorce and separation, more than 60% reported the cause as HD stigma. And it seems that intermarriage among survivors and family members are still in higher percentage.

Table 3.6. Educational Status of the Samples (No=120)

Variable	Description	HD survivors (No=60)		Family members (No=60)	
		Freq.	%	Freq.	%
Education al level	Illiterate	31	51.7	-	-
	Religious	4	6.6	2	3.3
	Primary	12	20	2	3.3
	Junior & secondary	9	15	8	13.3
	Above grade 12	4	6.6	48	80
	Total	60	100	60	100

Regarding their level of education, 80% of the family members replied that they were above grade 12, while, it was only 6.6% in HD survivors case. Among all cases the percentage of illiterates was 51.7% in HD survivors' sample. Fifteen percent of HD survivors & 13.3% of family members and 20% of HD survivors & 3.3% of family members responded that they had attended junior/secondary and primary education, respectively. Six point six percent of HD survivors and 3.3% of the family members also reported that their educational level not further beyond traditional school.

Table 3.7. Occupational Status of the Samples (No= 120)

Variable	Description	HD survivor (No=60)		Family member (No=60)	
		Freq.	%	Freq.	%
Occupational status	Student			20	33.3
	Self employer	9	15	5	8.3
	Vocational	9	15	8	13.3
	Professional	3	5	12	20
	House wife	21	35	3	5
	Begging	15	25	-	-
	Unemployed	3	5	12	20
	Total	60	100	60	100

As the table above indicates, 35% female in HD survivors sample and 5% females in family members sample were house wives. This means that among the total number (30 in each group) of females who were included in the sample, 21 HD survivors and 3 family members were housewives. Those family members who reported to be professionals or unemployed constituted 20% of each in both the cases. While these were 5% of each in the HD survivors group. Those who replayed beggary as their occupation were HD survivors and they constituted 25% of their case. Fifteen percent of HD survivors & 8.3% of the family members and 15% of HD survivors & 13.3% of family members reported that they were self employed and vocational workers, respectively. The remaining 16.7 % of the family members were student.

Table 3.8. Economical Status of the Samples (No=120)

Items	Responses	HD survivor (No=60)		Family member (No=60)	
		Freq.	%	Freq.	%
Economic status	High	2	3.3	5	8.3
	Medium	20	33.3	15	25
	Low	38	63.3	12	20
	Dependent on family economy	-	-	28	46.7
	Total	60	100	60	100

As to the economical status, respondents were asked to respond about their average monthly income. Since the income of most respondents was different from month to month, it became difficult for them to manage to do so. A descriptive statistics computed for this proportion of the cases show that the average monthly income ranges from 25 to 1000 Birr with mean and standard deviation of 150.27 & 27.26 Birr, respectively. Nevertheless, this shouldn't be considered as a representative economic status of the respondents by any parameter. Instead, the respondents were asked to indicate whether they have own some economic status indicators such as electricity, telephone, house, and tap water. In order to make the statistical analysis easier their economic status is operationalized as high for those who have all that above specifics, medium for those having only electricity and tap water and low for those who own specifics other than the aforementioned ones. Accordingly, 63.3% of the HD survivors and 20% of the family members economic status is rated as low. Those who constitute 33.3% of HD survivors and 25% of the family members are under medium economic status and the remaining 3.3 % of the HD survivors & 8.3% of family

members are rated as having high economic status. Forty six point six percent of family members reported as they have no any economic status.

3.4. Tools:

Interview Schedule: Interview schedules were used to collect data as majority of the respondents were either unable to read and write or they were deformed to do so.

Accordingly, two types of comprehensive structured interview schedules - one for HD survivors and the other for family members were constructed to collect data.

3.4.1. Procedures in Developing the Tools: To construct the interview schedules, the following steps were adopted.

Step 1: It involves the following procedures.

- First, the items were constructed in Amharic language by the researcher. Based on the literature review as discussed in chapter 2, and after long discussion with senior experts who are working in the field as well as using the researcher practical experience with the problem and legal documents such as programs which were transmitted about the psychosocial world of HD survivors and family members in ETV and FM Addis radio, interview schedules were developed. And the first items were approximately 120 for each tool.
- Then, these draft items were given to different experts such as the one who is working as a social worker for long time in HD patients' rehabilitation center and the other a medical doctor who is working in leprosy hospital and has got a lot of experience about the HD survivors and their family members' way of

life. These experts made some thematic corrections and then an appropriate modification was made on the instruments.

- Finally, the first interview schedule fifth parts which include 30 open and close-ended and 49 Likert- type effects of stigma measurement scale (see Appendix A). In the first part, a brief description about the study, objectives, its relevance, words of anonymity and words of thanks to the respondents are presented. The second part collects data on socio –demographic details. Items related to medical history of the survivors are contained in the third part. The fourth part was deal on problems that the respondents faced on reintegrating themselves with the general community and strategies in managing stigma. The last part consists about psychosocial effect. Note that the same distinct parts except part three, medical history part which consist 12 items, were included in the second structured interview schedule which was prepared for family members.
- These Amharic preliminary versions were given to an Amharic language expert for corrections of the flaws and the clearness of the items. This expert then made all the necessary thematic and grammatical inspections and corrections.
- Finally, copies of these interview schedules were given to my advisor for further scrutiny and improvement. Based on this the interview schedules were prepared for a pilot study.

Step 2 (pilot study): The first draft of the interview schedules were tried out on twelve HD survivors and the same numbers of the family members of HD survivors

for a pilot test. The pilot study was carried out at Boromeda Leprosy Patients Development Association (Boromeda Rehabilitation Project), 10 KM from Dessie. This site was selected because of its similarity with the way of life and psychosocial experience of HD survivors and their family members who are living at the sites of the main study.

In this association there were 120 HD survivors (80 male and 40 female) and 25 (15 male and 10 female) family members. Since the sample needed (20 % the sample size of the main study) were 24 from both group and 12 from each. Six female and six male HD survivors were selected by stratified random sampling method. The same method of sampling was employed to select six female and six male family members of HD survivors. The age range of the respondents was from 19 to 60 years.

The main purpose of the pilot test was to improve the quality of the interview schedules based on the available information. Accordingly, the following changes were made after the pilot study,

1. The introductory part of the interview schedule which was a bit longer was reduced. As presenting detailed introduction in interview schedules which is being made in a face-to-face interaction between the interviewer and the respondent has been found to be unnecessary.
2. The item on the major problems that in reintegrating the survivors and family members had been rephrased in the form of open-ended from closed question form (see Appedix: A and B).

3. Since a respondent might have possibly been married more than once, the item on this issue has been rephrased in such a way that the subjects could provide some reasons for their divorce.
4. The other change is constructing additional items were formed to enable the respondents to provide their experiences, opinions and attitudes towards managing stigma or prevention of additional psychosocial problems that could come from the stigma. This has been done so by tallying each item against the research questions.
5. Items which were found to be less relevant were dropped and additional ones were generated so as to widen the scope of the interview schedules.
6. Based on the response of the informants the internal consistency (reliability) of part five of the interview schedules (psychosocial effects measurement scale part) were mentioned by calculating coefficient alpha through SPSS software. And its result is presented in the following table

Table 3.9. Alpha value of the Likert-type Scale of the Interview Schedules

Type Tools	Types of Alpha Value		
	Psychosocial Effect	Psychological Effect	Social Effect
Interview schedule I	0.712	0.645	0.718
Interview schedule II	0.768	0.673	0.792

On incorporating all the modification and after establishing the reliability, the final versions of the interview schedules were printed for final data collection.

Until this stage the interview schedules were in Amharic versions because it has also been felt that it is better to translate the instrument after making corrections, testing and modification.

At first the final Amharic versions were translated into English by the researcher and were given to an English language expert for making necessary corrections. This expert then made all the necessary thematic and grammatical corrections. These English versions of the instruments were also given to an Amharic language expert to translate it back into Amharic. Finally, upon receiving this Amharic version of the instrument, the two experts were called upon for a joint discussion and compromised the differences that happened in the processes of the two translations. In the meantime, the researcher took the necessary notes during the discussion and then made appropriate modification on the instrument.

3.5. Method of Data Collection:

For collecting data for the final study, initially, 3 male 4th year regular students from statistics department and a female 6th year extension students of sociology from Addis Ababa university were trained to be research assistants. Things like how to establish rapport before proceeding on to the interview, how to simplify words that could be difficult to understand for some of the respondents and the ways the responses could be written on the interview schedule were discussed between the researcher and the assistants.

Being the next step, permission from all the data sources was secured using the letter issued from the department of psychology. Finally, consent from all the subjects was obtained. Experience reported during case studies are narrated through stories, stories about what happened or -narrations.

3.5.1. Procedures Adopted for Data Collection: since there were two types of data collection instruments-interview schedules and case studies, both of them were applied one by one with the following procedures.

Before beginning an interview schedules, consent was obtained, the persons were assured of the confidentiality of the data and were asked if they had any objection to the interview being tape-recorded (when necessary). In addition, the informants were asked to be interviewed alone, without others present.

Four interviewers conducted the actual interviewing: each of them has 30 informants. After this, the answered interview scheduled, the notes and tape (when there is) were put in an envelope and the next person on the list was interviewed. At the same time the researcher visited each interviewer and collected all the envelopes with the data.

Data Collection through Case Studies: Four respondents representing each strata of the sample were purposely selected for the detailed case studies. Accordingly, in-depth information was gathered in different sessions. Before beginning case studies, consent was obtained; each person was assured of the confidentiality of the data and was asked if she/ he had any objection to the interview being tape recorded.

The tapes were transcribed and translated by the researcher and a language expert in order to check the transcription and translation. And it was printed as case histories with simple interpretations, discussion and self narration (when necessary). The experience of these cases are not simply about establishing the truth of the stories, instead, such responses were treated as indicators of perspectives.

3.6. Analysis of the Data:

Organization of Data: All raw data that was gathered through interview schedules and case studies were edited based on their accuracy, usefulness and completeness. After editing each data the researcher had developed the cognitive mapping diagrams (see next page). Finally the cognitive map were changed in to meaningful and quantified terms, tabulated and narrated

In order to write data of the case studies, the researcher first read the summaries of the interviews, the note taken during the interviews and the transcribed and translated tape. While, Reading these, notes the researcher wrote different notes or memos. These notes related to e.g. interesting new insight, ideas for analysis, suggestions for key themes and any thing else that had attracted the researcher attention.

Table 3.10. Categories Emerged from Cognitive Mapping Exercise

1. Socio demographic and case histories
2. Medical treatment history; their belief on the cause, reason for defaulting and relationship with medical professional
3. Help gained: from family, friend, and local community
4. Action taken: by themselves, by family and community
5. Psychosocial effect: psychological effect, social effect, individual negative reaction, societal negative reaction, gender.
6. Coping strategies related to stigma: withdrawal, restriction, concealing from other, stories told, triggers experienced (for HD survivors); concealing, denying, story telling, leave the area, isolation (for Family members)
7. Problems in reintegration process: lack of people's knowledge about the disease, absence of counseling, lack of attention from the government, resource limitation
8. Situation at time of the interview

NB. The classification differs from group to group.

Analysis of Data: Both quantitative and qualitative data analyses were employed to analyze data.

With regard to the quantitative method, variables, which would identify and coded response, were entered into the computer for analysis. The statistical analysis is then made using the SPSS software program for data analysis in percentage, and t- tests. Percentage is used to describe the socio-demographic characteristics, cause and nature of stigmatized behavior, coping strategies related to stigma and problems, which they

faced in reintegrating themselves with the general, community of HD survivors and the family members.

T-tests were used for testing the significant mean difference between HD survivors and family members in the effect of HD stigma on their psychosocial world in general and on their psychological and social world in particular. The significant mean difference between sexes of each group was also calculated

CHAPTER FOUR

Results and Discussion

Introduction – Socio-demographic Characteristics and Case Stories - Nature and Causes of Stigmatized Behavior – Effects of Stigma on Adherence to Treatment of HD Survivors - Psychosocial Effect of HD Stigma - Psychological Effect of HD Stigma - Social Effect of HD Stigma - Individual Negative Reaction on Social Functioning - Societal Negative Reaction - Gender and Effects of HD Stigma - Strategies Employed in Managing Stigma - Problems in Reintegration of HD Survivors and Their Family Members

4.1. Introduction:

The purpose of this study was ‘to hear the voices’ of the people affected by HD and the family members, in order to understand how HD stigma affects their psychosocial world.

Thus, to assess this, the data gathered are analyzed and discussed in this chapter, in the following five sub-sections. The first section focuses on the socio-demographic information and case stories: the central question is what psychosocial experience does HD survivors and family members had in related to stigma? The second section looks at the nature and causes of stigmatization from the perspective of the HD survivors (the “perceiver”): the central questions are how HD survivors and their family are stigmatized? And what were the root causes of this stigmatized behavior lies? The third section focuses on the effect of stigma on adherence to treatment and relationship with environment such as family, friend, local community and health workers. The central question is what was their medical history? Fourth section focuses on psychosocial effect in general and psychological and social effect, in particular. Beside it also focused on effect of stigma and gender. The last section of this chapter looks at solutions of stigma problem. The central questions are; what strategies do the survivors and family members’ use in managing stigma? And what problem do they face in reintegrating themselves into the general community?

4.2. Socio-demographic Information and Case Stories:

As indicated in the previous chapter, case studies were conducted with two HD survivors and two family members. The data gathered from the four respondents is presented one after the other and discussed below. Their background information is summarized in the following table.

Table 4.1. Background Information of the Respondents for the Case Studies

Group	Code	Sex	Age	Occupation	Institutional affiliation
HD survivors	EB	M	59	Handcraft	Region14 Ex-leprosy Patient Association
	SE	F	46	Handcraft	Birhan Tay Leprosy Disabled Working Group
Family members	SM	M	25	University student	Medhin social center
	AS	F	24	Tutorial teacher	Medhin social center

Case 1 (EB):

EB is 59 years old and a crafts man. He is a member of Region 14 Ex-leprosy Patient Association. He was born to a peasant family in Debrebrehan – Jiru province (farmers association). When he was 18 years old some strange coin- like spots started to appear all over his body especially around his hands. Knowing not what they were, he showed them to his father but his father neglected it as if it was some thing to disappear shortly. Yet later some a strange sense of inability to order his fingers and

absence of pain in time of injury made him more than curious and his father took him to a known magician in the vicinity who was supposed to give the best possible treatment for the disease. The magician told them that he was a victim of a so-called 'kifu Gela', which according to the magician, will gradually tear EB's body apart, if not given the necessary medication quickly. And for his services he asked EB's father to pay a lot of money but they had to go for chancing the holy waters, as the money asked by the Magician was more than what his father can pay. Thus left with the only option EB spent for some time at the holy waters where he got baptized for quit some time but with no avail. The situation was rather worsened. This was more than a dozen of trouble his family could bear and hopelessly took him leave home. But EB's return was the beginning of series of misfortunes that changed his life once and for all for the worst. For one thing he had to limit himself to his childhood activity –'shepherd' as his hands are no longer strong enough to till the land like his age mates. Secondly he was denied his wife to -be who according to the tradition in their culture was selected by his family and with the consent of her families. Yet her family forbade the wedding, as they have put it '*they will not give their daughter for a leper and would like to pay what ever compensation*'.

When his disease became know amongst the people in the village, the family started faced social repercussions because of it. After all this, life could never be the same for EB. His village was no longer easier for him to live. No one wanted to be with him not even his former friends. Some even detested seeing him in their surrounding and what was devastating was his families were no more ready to have him with them. That was a punishment enough for him to got so upset and flee to the nearby Afar desert

knowing not what will happen to expect for him next. Luckily he met some nomads who allowed him to be their shepherd and never gave him look down for what he was suffering from. That gave him a relative ease as no one was giving him a cold shoulder. And he lived there for 15 years.

The disease, however, was spreading all over his body that he lost all his fingers and continued to his toes. Observing his situation one of the nomads for whom he worked, told EB to go to Addis Ababa where he could find some help. Then he came to Addis with the help of this Nomad and got the medical treatment at ALERT. After the treatment he was left with begging as the only option for survival. But later taking some training on the handicraft with other people of the same background (HD survivor) EB was able to manage enough income for him and get married with a woman who was HD survivor and fathered two sons. Though after the treatment his life has been changed, the disease has not only deprived him of social life but has taken the simplicity of life from his children as they don't want to be seen with him or their mother and they always feel unhappy for having such a family. As EB said his sons feel guilty on being born to him. Especially the youngest one, frequently request him to be able to attend his education in some other place where no one knows about his family history. EB also came up to his own conclusion after he noticed his sons reaction , he said, *I realize that the disease has made some deformations on my hand and toes while on my sons it has brought deformations of their sprite, personality.*

Case 2(SE):

The second case from the HD group is a 44 years soft-spoken woman, called SE. She starts her history from her mother's background that had similar problem like her. SE's mother was born in Debark –Gondar. It was after she gave birth to SE that the symptoms of the disease started to appear it on her. This fact was more than a reason for her brothers who tried to kill her for more than three times for if the villagers know the story of her disease they will be labeled as a family of leper and will be segregated by the society. What was more important was that they will not have chance to be married in the future, because in their culture to get married, the primary issue is checking the descendants biography of both couples just either to accept or reject the marriage. SE's mother survived death because her husband (SE's father) saved her because he knew of their plan of killing her. Then SE and her parents came to Addis and her mother started her treatments at ALERT (Zenebework). While on medication SE's father disappeared and life was difficult for SE and her mother. SE's mother was forced to serve as housemaid at different places with no hint of her problem. After they stayed in such situation for about 4 years SE's mother got married with a man of the same background and moved to a place where they live now (Zenebework). Yet their marriage ended with the death of this man. Two children survived him. SE was seven then and that was the time she knew of her being the victim of the same disease. Thanks to medication it didn't give her deformed body as she took the medicine on time.

A school in their vicinity established with the goal of helping children from unfortunate families gave her the opportunity for education. The school offers these

children with feeding service. Later as the students got to know each other a big rift started to claim its place between those who are from the family with HD and others from healthy family back ground. Those who came from health families refused to eat and learn with SE and other children with similar background for fear of transmission of the disease. Later the problem was solved with the intervention of their families. When SE passed to secondary school, it was an ideal place for her to hide her identity as no one knew of it. None of her friends knew about her family and her disease. But that was momentary for some thing was waiting to happen when she was 11th grade. It was an accidental fire shot near her school whose story was told to most of the students' family who came to see the students' safety. Her mother who came along with many neighbors (most of them HD survivors) was one of them and SE was called in the class to talk to her mother and neighbors. The secret that she withheld for three years was uncovered before the whole school. And it took her only 30 minute to decide quitting class-it was not however out of fear of segregation but because it just happened the moment her class mates saw her mother and the rest with her. All friends who used to sit with her on the same desk immediately changed their seats. And that was the last day she went to school.

After she dropped out, she had no choice but to help her mother at home. At this time there was an HD survivor who used to see her every day when he passes around her home. Though, SE's mother didn't accept his proposal to marry SE, he kidnapped her in a day when her mother was not there. SE gave birth to two children with him and within some years she divorced him. Six years ago her mother passed away. That was the last day she met her brothers. In relation to her present family she says, *I heard*

that one of my brothers who lives around 'Kasanches' got married last year, but I was not invited to attend the ceremony. The cause is nothing except that I am an HD survivor and he has hidden his family history from his spouse.

As SE claims, though, her brothers are living in the same city- i.e. Addis Ababa and they are economically well to do, they never share their life with her just to mention their social relationship. Generally SE narrated her life story very emotionally. She prays to God that it shouldn't happen to any body else.

Case 3(SM):

SM is a young man of 25 years of age living in Zenebework village with his parents who are both HD survivors. He is a 4th year University student. He has a lot of experience with HD stigma since he was in junior school. The first experience of SM happened when he was at school. He told his situation as follows

When I was in grade 7, there was a full day academic trip to 'Entoto' which was organized by our science teachers in which I was one of the participants. During lunch time we seat in different group for dining. In my group there were 6 students including me. After we sat, one of the girls told to me "you have to eat after we finished, we will leave your share, as your parents are lepers. I will not eat, if you eat together with us ..." At that time I was very nervous and bite her shoulder. Even after school I cried bitterly and when my mother asked me why, I told her all that happened. Then she too cried with me" That time on I developed fear towards touching other students and started to live secluded. Still now I have no friends. And I

students were from healthy families, the HD stigma started to affect her psychosocial world. In relation to this she said,

It was when I was a 10th grader that my families background started to haunt me. One day our English teacher asked us to make oral presentation about our parent and their role in our education. When it was my turn, I was speaking about my family. I told them about my mother's and father's deformed hands and feet. Immediately I started to read negative reaction printed on the face of many students, even the teacher was not interested to pursue in listening my speech. This discouraged me a lot class participation in any subject. And most of my class mates start to show me a disgusted face and cold shoulder. Starting from that time on wards I never told any person about my parents.

Her friendship also seems affected by the stigma. For instance, currently in the college she has friends while she never told them even about her real place. Her reason is just to maintain her relationship with them. Her current experience appears as:

I have two class mates whose place is around 'Ayer Tena' (passed Zenebework). We use city bus daily for transportation. Since I told them as I am living in 'Total' (one fermata before Zenebework), I always drop at that place and walk the remaining distance on foot. Because I know how much they disgust my village. Why should I tell them the fact? It is better for me to walk on foot that much distance than telling the reality.

Actually the effect of stigma is not restricted to her academic and social world. Rather it extends beyond as she said *I am worried about my parents' disease and the society's negative reaction. Since it has a great influence on my over all wellbeing, such as psychological, social and educational development. Before a year I introduced my self*

to a young man and we fell in love with each other. He asked me to be his girl friend. My response was negative because he is from healthy family. And I knew we can't continue until marriage as our relationship will break after he learns where I am from. Still my position is that if I get married, in the first place he has to be from HD survivor family.

4.3. Nature and Causes of Stigmatized Behavior:

The present section attempts to examine the experiences of HD survivors and their family members with stigmatized behavior. It depicts how HD stigma affected the survivors and family members and how the community expressed stigmatized behavior. From the case studies an attempt is being made to show how the survivors and their family members were experiencing the stigmatized behavior by pinpointing their common social and psychological experience.

Social Experience: The negative social functioning in the life of the two HD survivors' cases was started from their family relationship. In both of the cases families were the first to react negatively or to isolate them. In EB's case after the family recognized that their son's disease could segregate them from the society they had forced him to leave their home. This is also true in SE's mother's case that she was targeted to be killed by her own brothers. In both of the two cases, displacement of the home land is observed and it had happened due to societal stigmatized reaction rather than by their choice. All of the four case stories showed that they were alienated from their friends due to HD stigma. Of course, the survivors had faced this problem since their friends didn't want them, while the family members' alienated them due to fear

of stigmatized behavior. SM, for instance, is an isolated young man since he didn't want to make friendship with those from normal family. This is also AS's experience as she believes friendship and marriage relationship should make from similar background. Marital problem could also be identified as one of the social problems of not only the two survivors' but also the two family members. EB was denied his wife due to his disease; SE's father had disappeared from her mother by the same reason. SE herself also got unwanted marriage as a consequence of her disease stigma. Though, the way they experience was changed AS, one of family members cases, also couldn't able to make friendship with whom she loved one due to felt stigma.

Psychological Experience: Both EB and SE were upset and angry on their family's reaction towards their disease. And it pushed them to be disinterested in social participation. For instance, EB and SE's mother might be able to live in the center of the city with the society after they came to Addis, but they never try rather they preferred to live in leprosy colony where there was no discrimination. Feeling guilty, worry, stress, etc. could also be observed in both of the two family members' cases. To protect the stigmatized behavior of the society they also reached at concealing their living area and their parent.

In order to know the state of experience with the stigmatized behaviors, 60 HD survivors were asked and their response is summarized in the following two tables.

Table 4.2. Societal Reaction of Stigmatized Behavior as Perceived by HD Survivors (No=60)

Items	Response	Freq.	%
How did your community react to your diseases since knowing it?	Forbid me to seat together for dinning	59	98.3
	Fire me from job/ work	36	60
	Restricted me in social participation	40	66.7
	Termination of friendship	45	75
	Outlaw me to get marriage with loved one	30	50
	Stop to exchange material with me	5	8.3

Stigmatized behaviors may be complex and this study is not aimed at examining that. However it is better to inspect it in order to see the effect of stigma in different direction. When the respondents were asked about what was the society's reaction after knowing the disease, all most all of the cases (98.3%) said that as they are forbidden to seat together for dinning either by their family or by the local community. Sixty percent of the respondents also fired from their job or work. Sixty six point seven percent of the cases expressed what happened after people or their family knows the disease was restricted them from social participation. Those who constituted 75% of the respondents had an experience of friendship termination. Outlawing to get marriage with loved one due to the disease was the first experience of 50% of the cases. Among all cases very few (8.3%) reported as their local community including their family were stopped to exchange and share material with them. Actually this restrictions are not settled formally as a rule or regulation in any structured form, rather it was in community's mind and manifested thorough their reaction. Changes in the stigmatized behavior of the community were also analyzed over time positive actions started to increase and the negative mentioned began to decrease. But the fear

of expulsion and separation as expressed by the affected person and their family members is based on narratives that are still in circulation and not solely base on old stories from the past. As persons affected by HD including families are members of their own society, it is understandable that they know the narratives that are being told and are afraid that the same will happen to them. This result is also in line with Heijnder (2002) study about the nature of stigmatized behavior. Her finding shows that when the community was asked about what they had seen happening and the action towards person affected by HD, they stated that the infected persons were not allowed to attend public festivals; were not allowed to use a public well; problems at school and at work, were not allowed to inter in holy place and not allowed to get marriage with people having non-infected ancestor and difficult in getting medical and monetary exchange. The people's negative behavior is strong in many of the Ethiopian people, particularly with regard to marriage association, sharing of accommodation and any other physical contact with the affected person. As Kuar and Brakel (2002) said, *in Ethiopia, about 95% of the populations were found unwilling to employ or work with leprosy-affected person (p.346).*

Table 4.3. Beliefs of HD Survivors on Causes of HD Stigma (No=60)

Items	Response	Freq.	%
What are the causes of HD stigma?	Hereditary	13	21.7
	Culture of stigmatizing HD survivors	9	15
	God's punishment	25	41.7
	The society links it with Poverty and poor hygiene	4	6.6
	It has deformity nature	6	10

It could be seen from the above table that 41.7% of the cases believed that they are stigmatized; because their disease is a result of God's punishment. A significant numbers of the respondents' i.e. 21.7% also believed that the fear of the people to the disease comes as the disease is hereditary one. Ten percent of the cases also believed that stigmatized behavior of the society comes due to the deformity nature of the disease. Those who constituted 15% and 6.6% of the cases believed that culture, and poverty as well as poor hygiene are the main reason of stigmatized behavior, respectively. These perceptions of the survivors show that the listed factor could be the cause of stigmatized behavior and the detail is presented below:

Lack of knowledge: As the above table shows even a significant numbers of the HD survivors have no enough or real knowledge about the disease. The data which is presented under the table 4.3., show that most of survivors believed that the hereditary nature of the disease could be the cause of the stigma. And most of them not only consider the disease as a hereditary but also as communicable. And this impression of survivors leads them to accept society's segregation of affected person by HD and to react negatively on their social functioning.

Traditional belief: During the previous time, in most world cultures, HD was considered as an outcome of sin or it was considered as a punishment from God than a disease which gets manifested due to bacteria, like any other disease. The result of the present study also shows that a significant number of respondents believe that their disease is the result of God's punishment. This implies that if the patient who suffers from HD is considered as a person who is hated by God, the tendency to discriminate himself will live on.

Deformity and Disability Nature: The other prominent factor which may play a great role to happen stigmatized behavior toward the disease is the deformity and disability nature of the disease. Unless early treatment is provided, there is a possibility to deformity and disability which may force the individual to lose his self esteem winning (Flynn, 1991). In relation to this Tom(1996) said that there is a relationship of the disease with the poor , the uneducated and the powerless that tends to strengthen the public's and the service provider's negative reactions to it . In a study conducted in Nepal about leprosy stigma and adherence for treatment by Heijnder (2002) also show that when people were asked about what should happen, most of them thought of HD as a disease which is very contagious and which leads to deformed hand and feet. Consequently most of the people suggested that separation would be the most appropriate action.

4.4. Effects of Stigma on Adherence to Treatment and on Support gained:

Table 4.4. Way of Taking Medical Treatment and Reason for Withdrawing

Items	Response	Freq.	%
Way of taking medicine	By concealing the disease from every body	33	55
	Inform only family members and took it in secret	7	11.7
	In other place where no one knew	16	26.7
	Openly like any other disease medicine	4	6.6
	Total	60	100
Reason in withdrawing the treatment	Feared of probable stigma	25	41.7
	Distance of health institution	3	5
	Other persons' decision	15	25
	Unfair treatment	6	10
	Not mentioned	11	18.3
	Total	60	100

As table 4.4 depicts that majority (55%) of the respondents were taking medicines secretly and concealing the disease from every body. The second largest group of respondents (26.7%) was forced to displace their first place in order to take the medicine freely. This is also in line with the data in Table 3.3 that majority (83%) of the HD survivors reported as they are displaced from their home land after the onset of the disease. The remaining 11.7 % of the cases had their way of taking medicine- by informing their family members only while keeping it as a top secret and 6.6% of them took it as free as other diseases medicine. As the figure shows, more than half of the cases were taken their medicine with keeping it as a top secret. This indicated that persons affected by HD face difficulty to tolerate their problem freely. They are not free to talk about their disease for their neighbor, friend or relative because they felt to be stigmatized. The following words from case 2(SE) indicates how her mother try to tolerate her problems by concealing not only her disease but also her medicine and exemplifies this problems

People in the village think that this disease is contagious. They neglect people suffering from it. My mother (who was HD survivor too) was becoming out of job if her employer know about her disease. (Meaning that there was a tendency to fire infected persons if the administrators discovered that their employee had leprosy). My mother didn't tell them (her administrators) about her condition while she took medicine. So they behaved as they behave for normal house maid.

Another salient feature is the reason why some of the respondents had withdrawn the treatment or discouraged to adhere to treatment. This is especially important to see

whether the impacts of stigma also exist in their medical treatment or not. Accordingly, most of the respondents were dropping out their treatment at least for one time. Among the cases, 25% of the respondents also had withdrawn their treatment due to other person's decision. This seems especially females' problem as the descriptive statistics of this item revealed as among 15 (25%) who withdraw the treatment 12(20%) of them are females while the remaining are males. It also reveals in different literature, for instance, Mesfin(1992) said that in Ethiopia, women specially married and uneducated women have no right to make decision even on her health and wellbeing, most of the time it is restricted either on their husband (if they are married) or on their father and/ or brother (if they are not married).

On the effect of stigma to adhere for treatment, the largest group, 41.6% of the cases had reserved from treatment due to fear of the probable stigma or discrimination that comes after knowing about the treatment by anybody. In describing about the impact of felt stigma Heijnder (2002) on her studies find that the first reaction of people who were affected by the HD has worry about the public reaction to their disease than the disease reaction to their body. As a result they are discouraged to start the treatment to reduce their stress towards societal negative reaction. The reason for withdrawing the treatment for 5% of the respondents is distance of health institution respectively. Some of those barriers which were highlighted by vast literature on the continuity of medical treatment of HD were related to the distance to health post and the physical barriers to getting there. Some times the costs traveling to the health institution were unimaginable for those who have low economical status. As the response of 10% of the respondents indicates, the behavior of health worker to treat the HD patients could

be crucial factors which play a role on the wellbeing of the patients. The remaining 18.3% of the cases were not mentioned about their treatment experience.

Table 4.5. Support Gained and Relationship of HD Survivors with Health Workers (N=60)

Items	Responses	Freq.	%
Family Support	Concealing the disease from other person	22	36.7
	Encouraged to finish the treatment	18	30
	Financial support for medicine and transport	10	16.7
	Nothing	20	33.3
Friends Support	Concealing the disease from other person	3	5
	Encouraged to finish the treatment	2	3.3
	Financial (lent money for transport or medicine...)	4	6.6
	Nothing	56	93.3
Neighbors and Local Community Support	Not discriminating me	2	3.3
	Encouragement to finish the treatment	2	3.3
	Nothing	58	96.7
Relationship with Health Worker	Like any other patients	10	16.7
	Disgusted to me	5	8.3
	With out love and respect	1	1.6
	Ill-treated	4	6.7
	With love and respect	40	66.7

To address the existence of support in time they need, the respondents were asked whether they got support from others such as family, friends, neighbors and other local community (see table 4.5). In response to support from family the majority of the cases stated that they had received support from family members. Among them, 36.7% of the cases reported that their family support have been limited on concealing the

disease from other person. This indicates that family help in concealing the disease from the community served as a buffer against life-stress. As Mhasawase (1983) cited in Heijnder (2002) the people who gave such support have been defined by others as 'stigma coaches'. Family members being willing to conceal the disease and its treatment helped the survivor to reduce his/ her stress which comes due to felt stigma. Thirty three point three percent of the cases reported that they haven't got any kind of support from their family, while 30% of them responded as the support was not more than encouraging to finish the medical treatment. The remaining 16.7% of the respondent have got financial support from their family

Regarding friends support, Most of the respondents (93.3%) reported that they couldn't get any support from their friends during medical treatment. This condition was similar to the neighbors or local community cases, where 96.7% of the respondents claimed as they were not supported by their local community. Six point six percent of the respondents said that their friends' supports were laid on lending money for transport or medicine, while 5% of the cases responded as they got friends' support in concealing their disease from other persons. Those who got encouragement from friends' constituted 3.3% of the cases. This indicates that the persons affected by HD may break their interaction and communication with both friends and local community or vise verse. In Ethiopian culture, supporting each other at bad time is a very common trend. In relation to this Abera and Shanko (2000) said that Ethiopian have great intimacy in sharing life with each other. While, the result of this study shows that this fact of supporting each other was not much practical in the life of HD survivors. Those who got support such as not discrimination, and encouragement

from the local communities constituted 3.3% of cases each. Generally community support was rarely mentioned. In relation to their way of communication or interaction with health workers (the medical professionals) during treatment, significant number of respondents (66.7%) reported that they had positive relationship with love and respect. Where as, 16.7% of the respondents considered their relationship like other patients who are affected by other diseases. While 8.3 and 6.7% of the cases responded that their relationships had a tendency of disgust by the professional and consider themselves as ill-treated, respectively. The remaining, a very few case (1.6%) reported that their relationship were with out of love and respect.

4.5. Psychosocial Effect of HD Stigma:

As it is viewed in the section dealing with the nature and causes of stigmatized behavior (section 4.3), HD survivors and family members experienced either felt stigma (a primary fear of discrimination) or enacted stigma (actual discrimination). These stigmas impose different negative impacts upon their psychosocial world. Both survivors and family members were asked to respond to the psychosocial effects of stigma. The following tables show the details:

Table 4.6. Data and Result of t-test on Psychosocial Effect between HD Survivors and Family Members

Groups	Mean	SD	t-value
HD survivors	156.9	17.4	2.79*
Family members	169	14.5	

* Significant at 0.01 level

As indicated in table 4.5, the t-value (2.79), with 99% confidence interval and 118 degree of free dam, reveled that there is a significant difference between the means value of survivors and family members. Since the family members scored relatively higher mean (169) than the HD survivors (156.9) in related to the psychosocial effects of the stigma, the HD stigma has affected more the psychosocial world of the family members than the survivors. The detail of this general analysis is presented in the following sub-analysis parts.

4.5.1. Psychological Effect of HD Stigma:

In this study “ psychological effect” means the negative psychological state such as depression, aggression, anxiety, isolation (being alone), sadness, hatred, negative attitude towards the general community, low self-concept, etc. of an individual that comes as a result of societal negative reaction towards HD

Table4.7. Data and Result of t-test on Psychological Effect between HD Survivors and Family Members

Groups	Mean	SD	t-value
HD survivors	77.96	15.6	1.69*
Family members	81.4	12.9	

*Not significant at 0.05 level

It could be seen that the t-test result of the groups on the psychological effects of stigma was1.69, with a 95% confidence interval and 118 degrees of freedom. Though there is a slight difference (3.44) between mean scores of the two groups, the t-

statistics indicated that there is no significant difference among the groups, which means that both of the HD survivors and the family members are affected by stigma in their psychological functioning with similar level or conditions as they scored higher mean- 77.96 and 81.4, respectively.

As far as, the psychological effect of HD stigma is concerned, vast number of literature highlights that it is difficult to examine the emotional shock to which HD patients are exposed to and the very great change that takes place in their body as well as in their mind. This is not due to the pain of the disease rather for the consequence of social attitude, which follows discrimination from the general community (Waxler, 1981; First, 2000; Arole S, et al. 2002). The values that the society place on appearance and image have an effect on those who are different. Many writers such as Scott (2000) and Waxler (1981) argue that labeling person as deviant and unacceptable may influence their self-concept, behaviors, cognition and psychological health. This argument is found to be consistent with the present study result, which shows the HD survivors high level of negative psychological functioning.

As we notice from the mean value of the respondents of the family members the stigma didn't affect only the survivors rather extend to their family members.

Different factors may be attributed for each group to be affected psychologically by the stigma. The role of cognition or educational level of the subjects, for instance, could be the reason for high mean scoring on the psychological effects of family members than the survivors. Since the family members are educated than the survivors (See table 3 6), the probability to recognize and analyze the societal

negative reaction may be higher on family members than survivors. As they have reported, most family members believe in logic and they are searching any scientific justifications for segregation. Unfortunately there is no and it leads them to get anger, guilty, hatred to the general community. While the survivor with no or less education may not have found the reason beyond the society reaction, rather they have a tendency to accept it. This was observed on their response as most of them have negative self-concept, considering themselves as inferiors with low self-esteem (see table 4.3). They have less compliance for the society's disgusting reaction than the family members. Even on question of acceptance (esteem need), respect and love by the society doesn't bother them as it did to family members. This was noticed from the survivors' tendency to accept the traditional beliefs, which classified the HD survivors as a beggar, unclean, poor and inferior. The following narration by EB' could be one of examples in relation to the self-concept of HD survivors

Not only me but also many of HD survivors know that he/she is a result of punishment and accept his/ her inferiority. Since we are not clean and have deformed hand, how can we seat with one dish with others. Even it gives me discomfort to eat in front of others with these deformed fingers.

Self-presentation is at the heart of social anxiety. Persons who have strong intentions about presenting themselves in a certain way may become anxious about their ability to self present adequately, they will find obstructions to this presentation very stressful. Heijnder (2002) also found that social isolation leads to loneliness, low self-esteem, and negative self-concept, and ill health, changes in processing of social information, anxiety, and even criminality.

On the other side, due to difference in experiences survivors psychological functioning should be affected more than the family members. The HD survivors passed through two different way of life, before and after infection. They could notice how the disease changes their life, how the society including their neighbors, family, friends, and relatives were near to them and how now they neglect. The memory was in their mind and all these drastically change should force them to develop anger, depression, and aggressiveness than the family members. As SE said: *we can endure losing, fingers and toes, eyes and nose but we can't endure is to be rejected by those nearest and dearest.* This result is consistent with Scott (2000) finding. She argues that the psychological effects reported by leprosy patients include increased depression and anxiety, attributed to the social effects of the disease.

4.5.2. Social Effect of HD Stigma:

Persons with HD or HD family's experience many disadvantages in society, because of stigma. These disadvantages are called 'social effect or participation restriction'. The participation restrictions experienced by HD survivors and their family members in this study include unemployment or job termination, loss of social status, divorce, displacement, friends alienation, school drop out, not participating in Ider, Mehaber and public holidays, etc.

The psychosocial effects of stigma measurement scale were administered to the survivors and the family members and the result is analyzed through t-test and presented in the following tables.

Table4.8. Data and Result of t-test on Social Effect between HD Survivors and Family Members

Groups	Mean	SD	t-value
HD survivors	79	16.57	2.12*
Family members	87.6	12.8	

* Significant at 0.01 level

As the table above shows the t-value was 2.12 with 99% confidence interval and 118 degree of free dam. This indicates that significant difference is existed between the two means; the mean difference between these two groups was 8.6. It means that the family members were affected on their social world due to HD stigma than the survivors. This is inconsistent with the result of Yeshetela (1998) studies, which shows that children of HD survivors got more social acceptance and less social problem than the survivors. But in line with First (2000) which stated that even though other members of the HD survivors family may be in perfect health, because of association with all “unclean” person, family members are often refused employment, access to public transport, shops, offices, schools, etc probably more than their parent. This may be happened due to the degree of exposure to involve with the general community. In relation to this Flynn (1991) said that after segregating themselves from the society, most of persons with HD create their own world and their socialization will not go further their colony.

Persons who are survivors with HD and family members are part of the general society and they expected to have all social functioning, which contribute some useful asset to the society. However, the result of this study shows, this notation is too much

ideal in which they lose an opportunity to perform social functions based on their capacity in the first place. They have lots of problems in their social life including hatred by the society, and have little or no chance of participation in social gathering, making friends, marrying whom they love or desire, have unequal citizenship and lack of job opportunity. Their problem goes to the extent of prohibiting eating or drinking from the same dish or container using separate kitchen, and other as it was described in section 4.2 and section 4.3. This is also in line with the research result which carried out by Halok (1998) cited in Yeshetela (1998). It showed that HD survivors have been stigmatized by the funded public fear of illness and have been denied rights. It says, *In the carry days of the hospital they didn't have the use of telephone couldn't vote and their out going mail was sterilized for fear of contagion (p: 78).*

The other probable reasons for the family members' negative social functioning than the survivors may be the level of awareness about the general community reaction, the capacity of recognizing esteem needs and others. Since family members are more aware on the societal reaction and high esteem needs than their HD survivors (see section 4.5.1.), it may lead them to react negatively on their social functioning. Actually it may be difficult to state the reason, but possible to show how the stigma affects each group's social world through different social functioning of both groups. Displacement, having negative family and marriage relationship, lack of job opportunity, restriction on social participation and other problems were noticed in their day to day activities.

The HD survivors displace their home place mainly in two ways. One before the information dispatch that he/she is affected by HD to others. Because the name

“Leprosy” has a terrifying image in the minds of persons affected with leprosy. The memory of mutation, rejection and exclusion, the person developed fear of discrimination, i.e. a felt stigma. The consequence will be leaving the home place. The second one is after recognizing the practical discrimination of the society (after experiencing the enacted stigma). The family members too forced to displace their home place due to felt or enacted stigma. Since they have fear of public rejection due to their parent’s disease, they leave their parents place and began to live in place where no one know about their parents and stigmatized them. Here forced displacement is observed in both of them. The difference lies on the reason of displacing, the survivors displacement is just to adopt the new situation what happened or to avoid the situation which serves as a cue to memorize what they had. While the family members’ displacement is mainly to start new life by denying or concealing their family history.

The other social effect is observed in the family relationship of the respondents. In Ethiopian culture, where the family relationship is extended it is common to share every day life experience among the family members. For instance, if one is attacked by others the offence is considered as if it is committed on other members of family too (Yeshetela,1998).But this intimacy, responsibility and accountability do not functional for persons affected with HD and family members.

The persons affected by HD were sharing intimacy and responsibility among their family before the disease infected them. However it became history after infection. Their relationships faded daily as the disease grows severely (see section4.2). On the research about the integration of stigmatized people in case of Besidimo Leprosy

Relief center, most of the respondents were informed that their families were the first to isolate them. A case who was treated in this study states her experience about family rejection as follows:

My families were the first to isolate me, insulted me restrict me not to go outside or told me to cover my body to hide the symptom.... (Yeshetela, 1998:42)

It is also equally difficult to find intimacy and accountability in family relationship of family members of HD survivors. The family members may experience or they may have fear of societal negative reaction due to the parents' disease and it creates stress in them. Therefore, avoiding intimacy with their parent is one type of the defense mechanisms to cope up with the stress. For instance EB's say:

Though after the treatment my life has been changed, the disease has not only depriver my social life but has taken the simplicity of life from my children's as they don't want to be seen with me or their mother and are always feel unhappy for having such family.

This EB's and his sons relation indicates that how family members especially children have a tendency to far apart from their HD survivors parent.

Societal exclusion was also found to be prominent social effect on survivors and their family members as interpreted as the chief causes of the social dislocation that people affected by HD and their family experience in much of the literature (Nicholls, 2000). It denotes either a situation of marginalization experienced by individual or as a structural process that occurs in societies as a result of malfunctioning of their institutions. Exclusion from security, justice, representation and citizenship can be explored by considering the institution and rules, formal and informal which enable

and constrain human interaction. As Yeshetela (1998) argued based on his finding, there is no positive side persons affected by HD and the family members feel proud of their social interaction. Rather considered as morally inferior and discriminated, in all areas of social life. This is also found to be true in the present study, since the survivors and family members on the social effects score high mean value-79 and 89.6, respectively.

Regarding to the marriage life of the respondents, the great challenge either to get marriage or to mention the marriage relationship is observed in both group's life experience. Many people believe persons affected with HD including their family members should not have a loving relationship, get married or have children and some think the question of marriage relationship is disgusting (Scott, 2000). The public attitude towards marriage is mainly due to believe- "HD is hereditary". This is observed not only cultural marriage relation (an agreement to live together decide by relatives) but also by educated (civilized) persons' marriage relation (an agreement is decided by couples).

Another area to show the effects of stigma on the social world of survivors and family members is their participation in social interaction such as in Ider, Mehaber and other public organization. It is possible to generalize their level of acceptance or rejection. Ider is a cooperative organization where members share all happiness and sorrow in-group. It is considered as insurance to its membership and it is center of socialization. However, the involvement of persons affected by HD including their family members is found to be restricted among them (see table 4.3 result and discussion). This is attributed to reasons such as feeling of shame on their manner of eating with deformed

hand in front of the health people at good or bad time, absence of participation in funeral process due to disability, or lack of health society's interest to involve with them in any form of public organization were provided from HD survivors group on to why they prefer to have their own social involvement only. The family members' too have their own reason for such reaction in relation to social involvement. Among them, fear of negative reaction of the society towards their family is the most, which is shared by many of the family members' reasons. The following SM, a young man from HD survivors' family, thought may be showed that how much they are restricted in social participation.

Always it is better by far that I should being alone and miss the benefit of interaction than I should involve with dissimilar social group and suffer on their negative reaction.

His followed principle seems there is no way with out similarity in back ground and way of live, like "birds of a feather flock together". This implies that the possible way to share life is come with the sameness than in different background.

This may show specifically through the mean values and t-test results in the individual and societal negative reaction on the social functioning that presented in the following two tables

4.5.2.1. Individual Negative Reaction on Social Functioning:

The individual negative reaction indicates that the individuals actions on his socialization such as preference to restrict his friendship with certain group (similar back ground), stopping socialization(involvement into public) , keeping as a secret

about himself or his family back ground to friends, avoiding new friendship than introducing oneself as a survivor with HD or as a family members of HD survivors , prefer to drop out of school, dislike to be member of Ider, Mehaber with the general community, not attending funeral ceremony of the general community , discourage to bring himself to public or religious holyday ceremony ,etc.

Table4.9. Data and Result of t-test on Individual Negative Reaction between HD Survivors and Family Members

Groups	Mean	SD	t-value
HD survivors	32.3	13.9	2.45*
family members	43.6	18	

*Significant at 0.01 level

The t-test result (2.45), with 99% confidence interval and 118 degree of free dam, reveled that the difference between the two means is significant. And the mean of family members is higher than HD survivors mean value by 11.3. This shows that the family members were reacting negatively on their socialization than the HD survivors group.

Since the family members have more exposure than the survivor to interact with the general community, they may see or notice the society's negative reaction in every day of their life. As a consequence, their negative reaction on their social functioning tends to be high. Kamble, Govia and Kuswah (1981) in their study on the nature of interaction between non-stigmatized and stigmatized individuals; argue that the societal negative reaction towards stigmatized individuals increase the likelihood of antisocial reaction of stigmatized persons, too. This states that there is a direct

relationship between the societal negative reaction and the individual negative reaction. The result of this study is consistent with Heijnder (2002) results, which indicated the family members' of the patient socialization problem is worse than the survivor who mostly accept the stigma and create their own world.

4.5.2.2. Societal Negative Reaction:

Societal negative reaction indicates that the general community's reactions that push the survivors and the family members away from socializing with the general community.

Table 4.10. Data and Result of t-test on Societal Negative Reaction between HD Survivors and Family Members

Groups	Mean	SD	t-value
HD survivors	49.5	14.6	2.01*
Family members	45	17	

* Significant at 0.01 level

This condition seems reverse on the societal negative reaction on the socialization of survivors or family members. The t-test result (2.01) showed the existence of significant different between two group's mean on the effects of society negative reaction on their social involvement. The societal negative reaction which forced to displacement, depart from family , divorce, discriminated in Ider , Mehaber, not inviting in wedding or funeral ceremony, prohibiting monetary exchange ,etc. are more experienced by the survivors than the family members, as the mean difference (4.5) among the groups indicated. However, it doesn't mean that the societal negative

reaction didn't affect the social functioning of the family members. As their mean score (45) indicated their social functioning also gets affected by the society's reaction. It indicates that the society negative reaction towards the HD forced both the survivors and their family members to be alienated from Ider, Mehaber, displaced from home land, segregated from public area, divorce, terminate from job, drop out from school etc. But these social dysfunctions are manifested more on the HD survivors than the family members.

When people experience problems in social participation or participation restriction for a long time, they increasingly devalue and gradually pull out of society. They are forced to leave their families and community due to the rejection they face. Some leave themselves to try and spare their families from social rejection. Ultimately, they go and live with other persons devalued like themselves, mostly in leprosy colonies. This was what happened in EB's case. When the societies reject him and his family began to face social repercussions he left his homeland to Afar desert. Even after coming to Addis Ababa for treatment, he was having an exposure to live at the center of the city but he didn't want to do, since once he experienced social participation restriction while he was in his homeland. To explain how the societal negative reaction forced the stigmatized person to segregate him/ her self. He says,

I could be able to live in the center of the city, before 20 years ago, but I didn't want to see the society which is not willing to share their life with person like me. I knew if I were, I would be very lonely. My decision to live here (in leprosy colony) was correct. Here at least there is no isolation and no one can show you stigmatized behavior.

4.6. Gender and Effects of HD Stigma:

Though HD can affect all human beings disregarding race, sex, color, etc., the extent of impact appears to be more among women in terms of isolation, rejection from spouses, children and relatives, loss of freedom to touch and other restrictions (Grant, Blue and Harogan, 2002). Accordingly the results of the present study also show this difference is existed in family members and in HD survivors. The data and the result are presented in the following table.

Table 4.11. **Data and Result of t-test on Psychosocial Effect between Sexes of HD Survivors**

Variable	Male (30)		Female(30)		t-value
	Mean	SD	Mean	SD	
Psychosocial effect	150.9	17.6	156.4	16.3	1.99**
Psychological effect	73.4	15.8	76.4	14.9	1.6*
Social effect	75.5	16.4	80.0	12.6	1.97**

* Not significant at 0.05 level

** Significant at 0.05 level

The t- test result on the psychosocial effects of stigma between two sex was 1.99, with 95% confidence interval and 118 degree of free dam. This result revealed that the difference is statistically significant. And their means difference was 5.5 which indicates that females' survivor psychosocial world is more affected by HD stigma than male survivors. However, the t-value(1.6), with 95% confidence interval and 118 degree of freedom, on the psychological effect of HD stigma on females and male survivors showed that the mean difference(3) which exist between two groups was not statistically significant.

Regarding to the social effects of stigma, the t-test result was 1.97, with 95% confidence interval and 118 degree of free dam. This means that the difference between two means (males and females mean) on the social effect (4.5) is statistically significant. This led to female HD survivors to have more affected social world than males.

Table 4.12. Data and Result of t-test on Psychosocial Effect between Sexes of Family Members

Variable	Male (30)		Female (30)		t-vale
	Mean	SD	Mean	SD	
Psychosocial effect	162.7	19.6	175.8	15.3	3.1**
Psychological effect	79.4	18	86.9	12	2.0**
Social effect	83.3	16	88.9	14.5	1.99*

** Significant at 0.01 level

* Significant at 0.05 level

As table 4.10 indicates, in the psychosocial effect of HD stigma, the t-statistics result (3.1), with 99% confidence interval and 118 degree of free dam, revealed that there is a significant difference between sexes. And female family members scored higher mean (175.8) than males who scored 162.7. This implies that females' family member psychosocial world was more affected by the HD stigma than male family members.

This difference was also observed in the psychological and social effects of HD stigma as the t-values of these two variables were, 2.0 and 1.99, respectively, and showed the existence of statistically significant difference between the two means. Females were

more affected than male in both their psychological and social functioning, since they have high mean score than males.

The above two tables (Table 4.11. and Table 4.12.) statistical results tell that though females' and males' of HD survivors and the family member psychosocial world is affected by the HD stigma, it is more in females who are already socially and economically inferior to men in such matters as receiving health education, access to treatment and mobility. This result is consistent with many research findings which conclude that the problem of stigma is severe in women HD survivors and family members than men. Most of them such as Morrison (2000) and Heijnder (2002) conclude that women with leprosy or with leprosy family are in a double jeopardy or in a double handicap. Based on the result of the present study, it may be possible to say that problems of stigma on females with HD or HD family's life could be seen like "mumps on goiter". Because, a woman who has been stigmatized by her or her family disease also have additional psychosocial problem such as rare chance to get marriage, to make friendship, to get social acceptance etc. First (2000) in her study about the socio-cultural aspects of leprosy disease in women, also found that leprosy due to stigma and deformity , makes women unable to continue house hold work, and they may lose status in the family and end up leaving their homes.

Women are expected to put their family before themselves, and may fail to seek help early in the disease, being unable to find time to leave their family (Augustine, 1999). They are less able to travel for treatment and seldom do so alone, usually accompanied by a male companion. A psychosocial survey was conducted among male and female leprosy patients to asses their emotional status by First (2000). And the result of this

study shows that a substantial number and a slightly more number lack of sufficient information about leprosy and fear of infecting others with the disease, lack of motivation and fear compared with the male patients. In order to reduce this problem many researcher such as Ashanalla(1987) and Heijnder (2002) said that the rehabilitations program which focused on leprosy elimination shall give great emphasis for women's problem which come to not only due to the disease but also due to the socio-cultural aspects.

4.7. Strategies Employed in Managing Stigma:

Since the stress which developed by survivors and family members due to stigma differ, they also adopted different strategies in order to cope either being stigmatized or from its effect. The respondents were asked which kind of strategies did they use to manage the stigma and their response were summarized in the following tables.

Table 4.13. HD Survivors' Strategies in Managing the Stigma

Item	Response	Frequency	%
What strategies did you employ to manage the stigma of HD?	Discontinued the treatment	32	53.3
	Leaving the village together with family	21	35
	Leaving the village alone	40	66.7
	Social participation Restriction	52	86.7
	Concealing the disease	49	81.7
	Unreal Stories told	46	76.7
	Withdrawing from social life	45	75

After they came to know which disease they had, the majority of the survivors reported that a pattern of strategies were employed to manage stigma. These strategies were used either for expected (felt) stigma or experienced (enacted) stigma. The felt stigma means an individual's fear of exposure and expectation to be treated negatively by family and community members (Heijnder, 2002). Accordingly, 81.7% of the respondents were trying to conceal their disease. As far as concealment is reported as a coping strategy, Heijnder (2002) provide case story which states as follows:

People in the village think that this disease is contagious. They neglect people suffering from it.... I don't tell them about my son condition out of fear, so they behave as before. If they know my son's disease is leprosy, they will stop coming to my house" (P.139).

Because of these expectations, felt stigma leads to a strategy of concealment that has the effect of reducing the incidence of enacted stigma. Seventy five percent of the respondents reported that they were avoiding questions being asked by withdrawing from social life by going to their fields in the early morning, by working outside the village, in order to diminish triggers to exposure. Some people, when they had visible signs of leprosy, withdrew temporarily until their symptoms are improved. When questions were asked as 76.7% of the respondents reported they answered by telling unreal 'stories' which are used to hide their real diseases or to distract attention.

In managing the enacted stigma (experienced negative behavior from other community members) 53.3% of respondents mentioned that in order to stop their community members 'waiting to see' what would happen, they discontinue their medical treatment. If the sign of the disease were visible and the local community

reacts negatively such as stop interaction, hesitate to share materials, etc., the infected person will leave the village either together with their family or alone. These happened to 35% and 66.7% of the respondents, respectively. In relation to the experience of restriction SE said,

I have two healthy neighbors, they know about my mother disease but not mine. Some times when I get into an argument they said bad things which are related to me. At that moment I feel rally bad, and I became to limit my interaction with them. Even I didn't allow to my children to be with their children.

More than two third (86.7%) of the respondents reported that they were living in their village by limiting their interaction with their neighbors and the local community. Their restriction includes not making intimacy, not allowing their child to play with healthy family child, making friendship with those who are affected by the disease only, or by avoiding confrontation, by sitting apart, not sharing tools, not visiting public gathering, etc.

Table 4.14. Family Members' Strategies in Managing the HD Stigma

Item	Response	Frequency	%
What strategies did you employ to manage the stigma of HD?	Concealing parent's disease	45	75
	Denying family back ground	24	40
	Leaving the village where the parent's alive	40	66.7
	Concealing the village where they live	45	75
	Make friends with similar group	48	80
	Telling unreal Stories	46	76.7
	Abstain to talk about family history	30	50
	Learn in leprosy colony around only	30	50
	Learn far from the village	9	15

The family members of HD survivors also were asked how they managed stigma. And they described various coping mechanisms in response to either to what they felt (which has the effect of reducing the incidence) or to enacted stigma (the negative behavior of other community members towards their parent disease)

Two third of the respondent had used concealment as a strategy. In trying to conceal their parent's or family's disease, they employed several strategies. When questions asked about their family background and their living place, many respondents mentioned that they told 'fictitious stories' or concealing the place where they live or escaped the question (abstain to talk about the family history) or denying family's disease. This had happened with 76.7%, 75%, 50%, and 40% respondents of the cases, respectively.

Another way of managing stigma was to avoid situations in which stigma could be triggered or to diminish the number of triggers. Some symptoms such as making friendship with HD survivors family (80% of the case), leaving the village where the parents are living (66.7% of the cases belief), stay in schools which is located in the leprosy colony and most of the students are from HD survivors family only (50% of the cases) and stay in schools which is far from their village (15%of the cases) had reported.

In the general literature on the adaptiveness of different coping responses suggests that disengagement have all poor track records. They are related to increased psychological distress, including maladjustment and physical symptoms.

4.8. Problems of HD Survivors and Family Members in Making Reintegration :

People who are recovering from HD often hear the word "Reintegration." It refers to all the things they do from the time before they affected by the disease. Due to stigma these people including their family members are segregated from the general community and affected their psychosocial world. In order to reduce or eliminate these effects of stigma, there is a need to do a lot in prevention and rehabilitation program which actually go hand in hand. The current trend towards rehabilitating of persons affected by HD is focused on reintegration issue which helps them to reduce the effect of stigma on their psychological, social and economical wellbeing. The reintegration principle is started from integrating HD treatment in to the general health treatment

and it should be extended into reintegrating the segregated people in to the general community.

The respondents of the study were asked to indicate which kind of problems they have in reintegrating themselves into the general community. And their responses are summarized in the following tables.

Table 4.15. HD Survivors and Family Members' Problems in Reintegrating Themselves into the General Community (No=120)

Item	Response	HD Survivors		Family members	
		Freq	%	Freq.	%
What problem did you face in making reintegration with the general community?	Absence of public education program about the disease or Lack of public awareness	30	50	48	80
	Absence of counseling and efforts to motivate them to live a socially responsible life	45	75	55	91.6
	Lack of cooperation between professional workers and persons with HD	35	58.3	45	75
	Lack of vocational rehabilitation including job opportunity	55	91.7	42	70
	Societal negative attitude to wards reintegration	37	61.6	51	85

As the above table shows the HD survivors reported some crucial factors which hinder them to make reintegration with the general community. Among these lack of vocational rehabilitation which reported by 55 (91.7%) of HD survivors and 42(70%) of family members respondents scored the first. The next scored problem was absence

of counseling and efforts to motivate the survivors and the family members to live a socially responsible life and it was reported by 45(75%) HD survivors and 55(91.6%) family members. Absence of public education program about the disease or lack of public awareness, and lack of cooperation between professional workers and persons with HD were reported as the major problem in reintegration processes by 30(50%) HD survivors & 48 (80%) family members and 35 (58.3%) HD survivors & 45 (75%) of family members, respectively. The societal negative attitude also listed as a problem by 37(61.6%) HD survivors and 51(85%) of family members' respondents.

As most of the respondents shared in their report, there is a tendency to integrated the HD care in few health center, and treatments now become bring closer to the patient's home community, however, there is no successful public education or awareness campaigns, patient education programs or counseling, or in crating a spirit of cooperation between care providers, people affected by the disease and the public.

Nor has there been as much success in integrating leprosy work into non-medical program that serve the general population. However in many of the country through out the world, it took long time when integrating HD treatment in to the general health system is very much concern of health care planners. One prime reason started for this is to reduced stigma attached to this disease. How ever this is the first step which can be taken to go in to reintegrating the stigmatized and segregated people into the general community. The study which conducted by Kuar and Vanbrakel(2002) shows that to make reintegration effectively , it is important to work not only on preventing physical impairments of the patient but also to eliminate the social stigma which can be prevalent causing for social participation restriction among the stigmatized

individual. As Heijnder (2002) said health education on HD in society can reduce the prevalent of stigma and would also help in the acceptance of the affected persons and their family member in the society. As far as reintegration concept concerned, Kushwa, Govia and Kushwa (1981), states that there should be mutual understanding between the segregated group and the general community. To do so the counseling service for the segregated one and health education for general community is essential. However, these activities are not effectively materialized in the case of the present study's informants.

CHAPTER FIVE

SUMMARY AND CONCLUSION

Summary and Conclusion - Recommendations

5.1. Summary and Conclusion:

This study was conducted to investigate the effect of HD stigma on the psychosocial world of HD survivors and the family members. It also has attempted to explore different strategies that they adopted to manage the stigma and the problems that they had encountered in reintegrating themselves with the general community.

The review of literature has highlighted that HD stigma is reported to be the pervasive problem in most of developing countries even in the present day. The situation is more serious and tragic in Ethiopia too. The absence of preventive and rehabilitative measures makes the problem more aggravate not only to the survivors but also the family members. The HD survivors and their family members suffer from many psychosocial and economical problems stemming from the stigma.

All HD survivors and family members who are members of the three sources namely Birhan Tay Leprosy Disabled Persons Working Group, Medhin Social Center and Region 14 Ex leprosy Patients Association, in Addis Ababa were enrolled in the study and data were collected from 120 stratified randomly selected including 60 HD survivors and 60 family members. Four (2 HD survivors and 2 family member) were

purposely identified and extensive case studies were conducted on them. The data were then analyzed quantitatively and qualitatively.

The analysis of data has thrown light on the following findings and conclusions:

- Lack of public knowledge, traditional belief about the nature and cause of the disease, associating the disease with sin or god's punishment, the disabling nature of the disease, and association of the disease with poverty were listed by most of the respondents as the cause of the HD stigma.
- A descriptive statistics revealed that HD stigma has virtually affected the psychosocial world of HD survivors and the family members. However, the t-test revealed that the family members are the most affected by the stigma than the HD survivors. This could also be found true with females' than males.
- A high level of psychological effects such as depression , anxiety, isolation , hatred, low self esteem, negative self concept, low self confidence, etc were observed among both the groups. The result of t-test between HD survivors and family members had revealed that there was no significant difference existed between the groups.
- On the social effect such as school drop out, job termination, outlawing marriage or divorce, etc, the t- test result revealed that the family members' social functioning is more affected by the stigma than the HD survivors.
- On the individual negative reaction towards socialization, t-test result also showed that the family members react negatively than the HD survivors on their social functioning. However, the reverse was true on the societal negative reaction.

- The family members especially, females have low self confidence to bring themselves to public such as to make friendship, to get married or to work together with the general society. They have also negative self concept about themselves, considering themselves as if they can't do any thing before they try. Even their need of acceptance and being respected by others are also low and restricted among inter group (those who have similar back ground). This also confirmed by most of the survivors' parent who frequently said "The disease destroys our outer limbs but for our children, the damages are deep inside".
- On the strategies what they adopt in managing stigma, HD survivors used the following strategies : withdraw the treatment, displacement together with family, displacement alone, restricted social participation, concealing their disease, telling unreal story and withdrawing from social life. The family members used concealing parent's disease, denying family background, displacement, concealing the village where they live, make friends with similar group, telling unreal stories to others, abstain to talk about family history, learn in leprosy colony area only and learn far from the village.
- The study also revealed that absence of public education program about the disease or lack of public awareness, lack of cooperation between professional workers and persons with HD, absence of counseling and efforts to motivate the survivors to live a socially responsible life, lack of vocational rehabilitation, and societal negative attitudes towards integration are the major problems which hinder the HD survivors and family members to reintegrate themselves in to the general community.

5.2. Recommendations:

In light of the aforementioned conclusions the following recommendations are put forth:

- Since the leprosy control programs (LCP) in Ethiopia are now integrating into the general health service, in these setting, the Ministry of Health (MOH) should develop a socio-economic rehabilitation (SER) program which should be flexible to address individual psychosocial and economical needs and to monitor response to assistance by ensuring that the most needy target groups are reached.
- In order to bring effective and significant change in responding to the overall need of the populations and to coordinate initiatives being under taken in the field of psychosocial and economical rehabilitation of HD survivors and their family members throughout the country, a national leprosy rehabilitation coordination committee should be established by the government.
- Further, the government, particularly Ministry of Health (MOH) should develop standardization in the measurement of HD stigma to aid further research and program monitoring.
- To see the over all problem of these stigmatized people further research with more scope of including more variables, especial the socio-cultural variables should be undertaken

(Since the largest population of the HD survivors and family members are reside in villages around ALERT than any where else in Ethiopia (ENAELP, 2000), the

following recommendation are forwarded for organizations which are working on this area in order to bring significant change without taking long time).

- ❖ The needs of the population in the villages around ALERT are diverse and several social service providers are working towards satisfying it; however, the psychosocial needs of the villagers are not seriously addressed by most of them. Therefore, the following suggestions are forwarded for those organization operating in the area:
 - All agencies working in the area should develop models of rehabilitation and re-integration through provision of educational and social activities. These programs should be focused at strengthening and developing community structures which help the population with especial emphasis on women survivors, female and youth family members to empower their capacity through group therapy, assertive training, working counseling and psychosocial intervention, a case in point being the practice at Medhin Social Center (MSC) base its programme. This approach and the considerable success achieved so far in promoting social participation of HD survivors and family members can lead to the recommendation that MSC can be a model for other agencies working in the area.
 - NGOs' working in the area should also break social exclusion (effects of HD stigma) through promotion of self help community in the area. For instance, despite the fact that much of the products which are produced by Berhan Tay Leprosy Disabled Working Group and Region 14 Ex-leprosy Association are accepted by the general society they have entertained lesser market return.

Therefore, if the NGOs' or the government takes same part in advertising and promoting of these self help community product, it will be possible to create opportunities in which the general community and the leprosy village community interact and communicate each other.

- Elimination of HD (leprosy) should go hand in hand with the psychosocial rehabilitation of those who are already stigmatized and segregated. Programme should be developed for the psychosocial rehabilitation with the following feature:
 - Vocational rehabilitation including job opportunity and formation of working groups as per the abilities of the individual
 - Counseling efforts to motivate survivors and family members to live a socially responsible life.
 - Establishment of a community center that would act as a focal point in which members of the community could involve in developing their own self help programme with the assistance and backing of the responsible organization.
 - Education of society for the acceptance of HD survivors and family members through both print and mass media and different awareness creation programs.

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Appendices

Appendix- A

Addis Ababa University School of Graduate Studies Department of
Psychology

Interview Schedule I*

(Prepared for HD survivors)

Waganesh Abeje
Senior Graduate student

Code no _____

Date _____

Place _____

The principal purpose of this interview schedule is to obtain data for a study intended to investigate the psychosocial effects of stigma on the life of Hansen's disease survivors. The study will be useful for the leprosy control and rehabilitation programme and various professionals who are working for the welfare of the survivors and their family members who need rehabilitation. You were selected for this project because you could give enough information on the issue. Therefore, your unreserved cooperation in providing the most genuine information will have a greater significance to the solution of the problem.

I am interested in all your ideas, comments and suggestions. I understand that the questions might be very sensitive. However, from the practical importance of your views for the total program planning I truly need to ask you such questions.

Dear respondents, please note that:

- Any information that you give is confidential
- You are not required to write your name in the interview schedule and you will not be asked to specify your name anywhere in the interview.
- Please return the interview schedule to the person who interviewed you

Thank you in advance!

Direction:

Listen to the following items and its response categories containing your reactions, opinions and feelings given against each item. And then provide the necessary information orally to the person interviewing you.

*Was original in Amharic

Part I Socio-demographic Section

1. Sex _____
2. Age _____
3. Birth place _____
4. Living place:
 - 4.1. Before on set of the disease _____
 - 4.2. After onset of the disease _____
5. When did you infected ? _____
6. Educational status
 - 6.1. Illiterate
 - 6.2. Literate (reading and writing)
 - 6.3. Elementary school (first cycle i.e. Grade 1-4)
 - 6.4. Elementary school(second cycle ,grade 7-8)
 - 6.5. Secondary school (grade 9 to 10)
 - 6.6. Colleges preparatory (grade 11to 12)
 - 6.7. Others, specify _____
7. Marital status
 - 7.1. Never married
 - 7.2. Married
 - 7.3. Divorced
 - 7.4. Widowed
 - 7.5. Separated
8. What is your predominant ethnic back ground?

8.1 Amhara	8.5. Somali	8.10 Kembata
8.2. Oromo	8.6. Agew	8.11. Gamo
8..3. Tigrie	8.7. Sidama	8.12. Dawro
8.4. Wolayta	8.8. Gurghe	8.13. Konsa
	8.9. Hadya	8.14 others, specify _____
9. What is your current occupation?

9.1. Student	9.5 government or NGO employee
9.2. Daily laborer	9.6 hand craft

9.3. House maid

9.7. Business man /woman

9.4. House wife

9.8 others, specify _____

10. What is your religion?

10.1 orthodox tewahido-Christian

10.2. Islam

10.3. Catholic

10.4. Protestant

10.5 other, specify _____

11. What is your average monthly income? (E.g. Birr 100 or 150 etc.)

If you don't know it in cash, check whether one or more of the following facilities are available (write 'yes', if it is available and 'no' if it is not.)

Own electricity _____

Own telephone _____

Pair of oxen _____

Own tap water _____

Own house _____

Enough farm land _____

12. Are there any people with this disease in your family history?

12.1 yes

12.2 No

13. If your answer for question no. 12 is yes, how many? And what is their relationship? _____

Part II Medical History

14. How you and your community react to your diseases since knowing it?

14.1. Forbid me to seat together for dinning

14.2. Fire me from job/ work

14.3. Restricted me in social participation

14.4. Termination of friendship

14.5 Outlaw me to get marriage with loved one

14.6. Stop to exchange material with me

14.7. Other, specify _____

15. What is the cause of stigma of your disease?

15.1 Hereditary (since we have leprosy in our family history)

15.2. Culture of stigmatizing HD survivors

15.3. God's punishment

15.5. The society links it with Poverty

15.6. It is a result of poor hygiene

15.7. Other, specify

16. Have you properly followed all process of medical treatment?

16.1 yes

16.2 No

17. If your answer for question No. 16 is yes, how did you take medicine?

17.1. I concealed my disease from every body and took medicine secretly

17.2. I informed only my family about it and I took medicine secretly

17.3. I took the medicine in other places where no one knew me

17.4. I took the medicine openly

17.5. Other way, specify _____

18. If your answer for question No. 16 is 'no', why did you withdraw the treatment?

18.1 I feared the probable stigma and discrimination of my neighbors, and other community

18.2. Due to the distance of the health institution

18.3. Due to economical constraints

18.4. Due to my father's/ husband's/ or other persons decision

18.5. Due to unfair treatment by health workers

18.6 Other, specify _____

19. How did your family support you during your treatment?

19.1 They supported me by concealing my disease from other people

19.2. They encouraged me to finish the treatment.

19.3. They supported me financially

19.4. They didn't support me in any way.

19.5 Others, specify _____

20. How did your friends support you during your treatment?

21.1 They supported me by concealing my disease from other people

21.2. They encouraged me to finish the treatment.

22.3. They supported me financially

23.4. They didn't support me in any way.

24.5. Others, specify _____

21. How did your neighbors and other local community support you during your treatment?

21.1 They supported me by concealing my disease from other people

21.2. They encouraged me to finish the treatment.

21.3. They supported me financially

21.4. They didn't support me in any way.

21.5. Others, specify _____

22. How was your relationship with your physicians and other medical professionals at hospital?

22.1. They treated me like any other patients.

22.2. Since my disease was Hansen's, they were disgusted by me

22.3. They examined me without love and respect

22.4. They examined me with love and respect

22.5. They ill-treated me

22.6. Others, specify _____

23. Did you have any real knowledge about the disease before you were infected?

23.1. Yes

23.2. No

24. What about after you were infected?

24.1. Yes

24.2. No

24.3 If yes, can you please share with me your knowledge?

25. Did you take some care to prevent the infection to other persons?

25.1. Yes

25.2. No

25.3. If yes, on what way

26. Did you try to infect it to others?

26.1. Yes

26.2. No

26.3. If yes,

why? _____

26.4. If no, why? _____

Part III State Of Experience in Managing Stigma and Reintegration

27. What kind of strategies do you use to manage the stigma when you learnt one of your family members had HD? (You can choose more than one)

27.1. I concealed the disease from every body except my family.

27.2. I didn't accept the disease as Hansen's

27.3. I didn't give any attention for society's negative reaction.

27.4. I took elders/ professional advice to adjust my self with the problem

27.5 others, specify _____

28. What do you advise if you meet a person with Hansen's disease and affected more by the social stigma?

29. Do you face any problem to make reintegration with the general society?

29.1. Yes

29.2. No

29.3. If yes, what kind of problem did you face from the local community?

29.4. What about from professionals?

29.5. What about from government?

30. From your experience, what is the best way to make reintegration?

Part IV State of Experience with Stigma and Psychosocial Aspects

No	The following questions are about some of your experiences, feelings, and opinions as to how people with Hansen's disease feel for the society's reaction towards the disease and how they are treated. There is no right or wrong answers. Please answer all questions	SD	D	N	A	SA
	I. State of Social Functioning					
	a. Societal Negative Reaction					
1	I have stopped socializing with some people because of their stigmatized reactions to the Hansen's disease					
2	I was forced to displace my home town/ zone/worda due to the stigma of Hansen's disease					
3	I was forced to depart from my family due to the stigma of HD					
4	I lost my friends after they learnt that I had HD					
5	I got divorce because I had HD					
6	I have no power of decision making either in my home or in my local community for I have HD					
7	Since knowing that I had HD my friends were set apart and isolated me from their world					
8	I had never been invited to attend wedding ceremony of persons who aren't victims in HD					
9	For me it is forbidden to be spiritual servant for the followers belief in HD is the result of sin or the survivors are unclean					
10	It is difficult for me to use public service such as public telephone, city bus or any recreational center like other people due to society's attitude towards my disease					
11	I was forced to drop of out my education due to stigma and discrimination of the school community					
12	I had never been visited by the healthy community neither in good nor in bad time					

13	Most people don't want to have monetary exchange with me					
	b. Individual Negative Reaction					
14	I send my children to school which is far from us just to protect them from being discriminated.					
15	Mostly I don't like to go church, market and Eder to keep myself from being ill treated by other people					
16	I really prefer to have friends who have /had HD than those who don't					
17	I am prefer to become neighbors with those who have the disease					
18	I couldn't marry with a person who is free from the disease					
19	I have a big problem in the relationship with my spouse/my children/my family/ my neighbors due to Hansen's disease stigma					
20	I worked hard to keep my disease a secret from my friends, neighbors, etc for maintaining of our relationship					
21	I was terminated from my job due to the stigma and discrimination of my collogues.					
22	I discouraged to bring myself in to public institute because of peoples' discrimination					
23	I don't attained the funeral ceremony of the general society					
24	I don't participate in religious holy days' (Meskel, Epiphany , Christmas, Id Al Adhad, etc) celebration with the general community					
25	I don't participate in public holy days' (victory of Adowa comm. International Labors Day ,etc.) celebration with the general community					
	II. State of Psychological Functioning					
26	I feel guilty because I have HD					
27	I feel I am not as good a person as others because I have/or had HD					

28	I feel free when I am with persons like me than with person with out HD					
29	Having HD makes me feel that I am a bad person					
30	Since knowing I have HD , I worry about people discriminating against me					
31	I worry that people may judge me as a sinner when they learn I have HD					
32	I have been hurt by the way people reacted to after knowing that I had HD					
33	People's attitudes towards HD make me feel worse about myself					
34	I have no self confidence because most people believe that I am a dirty					
35	Mostly I got anger when most people show disgusted to by me					
36	I have been hurt by how people reacted to see my deformed body/ after knowing I had HD					
37	I worry that people who knew I have/had HD will tell others					
38	I feel hopeless about my future when people have told me that getting HD is what I or my family deserve for all sins that we did					
39	I became pessimistic after infection by the disease					
40	I believe that all Hansen's disease patients should be treated in the general Hospital where all kinds of diseases are examined					
41	I allow myself to get too much worried about people's discrimination					
42	I didn't motivate to have my own work because I didn't think to be successful as far as most of our local people expect me to become a beggar					
43	When ever I noticed that people didn't want their children around me feel totally dejected.					
44	I have been lonely for most of the time since no one didn't want to make friendship with me					
45	I felt like committing suicide after I learnt that most people					

	outcaste the Hansen's disease survivors					
46	I feel sad when some people avoid touching me once they knew I had HD					
47	I consider that having HD is disgusting to me					
48	I feel ashamed because some people who knew I had HD have grown more distant					
49	I prefer to be alone than to tell others that I have or had HD					

SD = Strongly disagree

A = Agree

D = Disagree

SA = Strongly agree

N = Neutral

Appendix - B

Addis Ababa University School of Graduate Studies Department of
Psychology

Interview Schedule II* **(Prepared for Family member)**

Waganesh Abeje

Code no _____

Senior Graduate student

Date _____

Place _____

The principal purpose of this interview schedule is to obtain data for a study intended to investigate the psychosocial effects of stigma on the life of family members of survivors. The study will be useful for the leprosy control and rehabilitation programme and various professionals who are working for the welfare of the survivors and their family members who need rehabilitation. You were selected for this project because you could give enough information on the issue. Therefore, your unreserved cooperation in providing the most genuine information will have a greater significance to the solution of the problem.

I am interested in all your ideas, comments and suggestions. I understand that the questions might be very sensitive. However, from the practical importance of your views for the total program planning I truly need to ask you such questions.

Dear respondents, please note that:

- Any information that you give is confidential
- You are not required to write your name in the interview schedule and you will not be asked to specify your name any where in the interview.
- Please return the interview schedule to the person who interviewed you

Thank you in advance!

Direction:

Listen to the following items and its response categories containing your reactions, opinions and feelings given against each item. And then provide the necessary information orally to the person interviewing you.

*Was original in Amharic

Part I Socio-demographic Section

8. Sex _____

9. Age _____

10. Birth place _____

11. Who is infected by HD in your family? _____

12. Educational status

12.1. Illiterate

12.2. Literate (reading and writing)

12.3. Elementary school (first cycle i.e. Grade 1-4)

12.4. Elementary school(second cycle ,grade 7-8)

12.5. Secondary school (grade 9 to 10)

12.6. Colleges preparatory (grade 11to 12)

12.7. Others, specify _____

13. Marital status

6.1. Never married

6.2. Married

6.3. Divorced

6.4. Widowed

6.5. Separated

7. What is your current occupation?

7.1. Student

7.5 government or NGO employee

7.2. Daily laborer

7.6 hand craft

7.3. House maid

7.7. Business man /woman

7.4. House wife

7.8 others, specify _____

8. What is your religion?

8.1 orthodox tewahido Christian

8.2. Islam

8.3. Catholic

8.4. Protestant

8.5 other, specify _____

9. What is your predominant ethnic back ground?

9.1 Amhara

9.5. Somali

9.10 Kembata

9.2. Oromo

9.6. Agew

9.11. Gamo

9.3. Tigrie

9.7. Sidama

9.12. Dawro

9.4. Wolayta

9.8. Gurghe

9.13. Konsa

9.9. Hadya

9.14 others, specify _____

10. What is the average monthly income of your family? (E.g. Birr 100 or 150 etc.)

If you don't know it in cash, check whether one or more of the following facilities are available (write 'yes', if it is available and 'no' if it is not.)

Own electricity _____

Own telephone _____

Pair of oxen _____

Own tap water _____

Own house _____

Enough farm land _____

Part II State Of Experience in Managing Stigma and Reintegration

11. What kind of strategies do you use to manage the stigma when you learnt one of your family members had HD? (You can choose more than one)

11.1. I concealed the disease from every body except my family.

11.2. I didn't accept the disease as Hansen's

11.3. I didn't give any attention for society's negative reaction.

11.4. I took elders/ professional advice to adjust my self with the problem

11.5 others, specify _____

12. What do you advise if you meet a person with Hansen's disease and affected more by the social stigma?

13. Do you face any problem to make reintegration with the general society?

13.1. Yes

13.2. No

13.3. If yes, what kind of problem did you face from the local community?

13.4. What about from professionals?

13.5. What about from government?

14. From your experience, what is the best way to make reintegration?

Part III State Of Experience with Stigma and Psychosocial Aspects

No	The following questions are about some of your experiences, feelings, and opinions as to how people with Hansen's disease feel for the society's reaction towards the disease and how they are treated. There is no right or wrong answers. Please answer all question	SD	D	N	A	SA
	I. State of Social Functioning					
	a. Individual Reaction					
1	I have stopped socializing with some people because of their stigmatized reactions to the Hansen's disease					
2	I worked hard to keep my family disease a secret from my friends, neighbors, etc for the sake of the maintaining of our relationship					
3	It is easier for me to avoid new friendships than to introduce myself as one who has a family history of HD					
4	I really prefer to have friends who are from a family with HD than those who don't					
5	I don't participate in public holidays' (victory of Adowa comm. International Labors Day ,etc.) celebration with the general community					
6	I don't participate in religious holidays' (Meskel, Epiphany , Christmas, Id Al Adhad, etc) celebration with the general community					

7	I don't attend the funeral ceremony of the general society					
8	I preferred to avoid bringing myself into public institutes because of peoples' discrimination					
9	Mostly I don't like to go church, market and Eder to keep myself from being ill-treated by other people					
10	I send my children to school which is far from us just to protect them from being discriminated against my parent's disease					
11	I prefer to become neighbors with those who have or had the disease					
12	I couldn't marry with a person who is free from the family history of the disease					
	b. Societal Negative Reaction					
13	I have no power of decision making either in my school/work place or in my local community for I am from a family with HD					
11	I was forced to displace my home town/ zone/worda due to the stigma of Hansen's disease					
14	Since knowing that I have a parent with HD I felt set apart and isolated from the rest of the world					
15	I have no opportunity to be a spiritual servant in a church which I follow since the church doesn't allow for HD survivors and their family to serve					
16	It is difficult for me to use public service such as public telephone, city bus or any recreational center like other people due to society's attitude towards Hansen's disease					
17	I was forced to drop out of my education due to stigma and discrimination of the school community					

18	I had never been visited by the non-victim local community neither in good nor in bad time					
19	Most people don't want to have monetary exchange with me					
20	I was terminated from my job due to the stigma and discrimination of my colleagues					
21	I had never been invited to attend wedding ceremony of persons who aren't victims of HD					
22	I lost my friends after they learnt that I have a family with HD					
23	I got divorce because there is HD in my family history					
24	I was forced to depart from my family due to the stigma of HD					
25	I have a scattered in the relationship with my spouse/my children/my family/ my neighbors due to Hansen's disease stigma					
	II. State of Psychological Functioning					
26	I feel guilty because there is HD in my family history					
27	I feel I am not as good a person as others because I have/or had a family with HD					
28	I feel free when I am with persons like me than with person who are from a family without HD					
29	Having a family with HD makes me feel that I am a bad person					
30	Since knowing I have a family with HD , I worry about people discriminating against me					
31	I worry that people may judge me as a sinner when they learn my parents have HD					

32	I have been hurt by the way people reacted after knowing my parents have or had the HD					
33	People's attitudes towards HD make me feel worse about myself					
34	I have no self confidence because most people believe that I am dirty					
35	Mostly I get anger when most people show their disgust to me					
36	I have been hurt by the way people reacted after seeing my parent's deformed body/ after knowing that my parent have or had HD					
37	I worry that people who knew I have a family with HD will tell others					
38	I feel hopeless about my future when people have told me that getting HD in family history is what my family deserve for all sins that they did					
39	I became pessimistic after recognizing society's attitudes towards a person who is affected by the disease					
40	I believe that all Hansen's disease patients should be treated in the general Hospital where all kinds of diseases are examined					
41	I allow myself to get too much worried about peoples discrimination					
42	I am not motivate to do my own work because I don't think that I will be successful as most of our local people expect me to become a beggar					
43	When ever I noticed that people didn't want their children around me , I feel totally dejected					
44	I have been lonely for most of the time since no one didn't want to make friend ship with me					

45	I felt like committing suicide after I learnt that most people outcaste my family members					
46	I feel sad when some people avoid touching me once they knew I am from a family with the history of HD					
47	Having HD in my family history is disgusting to me					
48	I feel ashamed because some people who knew I had a family with HD have grown more distant					
49	I prefer to be alone than to tell others that I have a family with HD					

SD = Strongly disagree

A = Agree

D = Disagree

SA = Strongly agree

N = Neutral

Appendix C: Interview Guide *

1. Introduction
 - Aim of the study
 - socio-demographic of cases
2. The problem of stigma
 - Its cause
 - Its nature
 - Its severity
3. Person's reaction after onset of the disease
 - Family reaction
 - friend's reaction
 - community reaction
4. Personal experience with the stigma
5. Fear of communities action and what they really did
6. Change in person's live
7. Closing remark
8. Suggestion for reducing the stigma

Declaration

I, the undersigned declare that this thesis is my original work, has not been presented for a degree in any other university and that all sources of materials used for the thesis have been duly acknowledged.

Waganesh Abeje Zeleke

This thesis has been submitted for examination with my approval as university advisor.

Dr. R. Sreevalsa Kumar

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