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HISTORICAL AND SOCIAL ASPECTS OF LEPROSY
IN ETHIOPIA

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Historical and Social Aspects of Leprosy
in Ethiopia

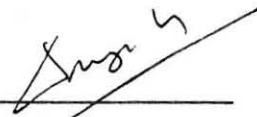
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List of Abbreviations

Note: The abbreviations listed below are only the ones that are frequently used in the thesis.

1. ALERT All Africa Leprosy and Rehabilitation Training Center. It is located in Addis Ababa, Ethiopia.
2. MDT Multiple Drug Therapy. Recommended by the World Health Organization in 1982. The multiple drug regiments are 1) Dapsone 2) Rifampicin 3) clofazimine.
3. MOH Ministry of Health, Ethiopia.
4. NLCP National Leprosy Control Programme, Ethiopia
5. Post MDT Post Multiple Drug Therapy. This 'Name' is only chosen to indicate the period after January 1, 1983. It is used inter-changeably with post - 1983. In some places it is cited as the second group.
6. Pre - MDT Pre Multiple Drug therapy period. This 'name' is only chosen to indicate the period before December 31, 1982. This 'name' is also used inter-changeably with pre-1983. In some places it is cited as the first group.
7. WHO The World Health Organization.

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ABSTRACT

A qualitative study based on individual interview was carried out in Tekle Haimanot and adjacent Awrajas and at the All African Leprosy Rehabilitation and Training Centre (ALERT). A total of 54 respondents were interviewed out of whom 20 were leprosy patients and the rest were religious leaders, high school students, high school teachers, general health workers at Tekle Haimanot Health Centre, health workers at ALERT and non leprosy patients. In this study the patterns and trends of leprosy stigmata were reviewed. Through the in-depth interviews it was observed that the negative reactions to leprosy were very prevalent, including among the leprosy patients, and had a serious impact on the control of leprosy. Though not conclusive, it was found out that there were very strong, high similarities in the patterns and trends of social responses regarding leprosy over the last 35 years. Leprosy was perceived as a unique, chronic, non-fatal but progressively deforming disease with doubtful curability and especially a disease which could cause a disgrace to the victims and their families. The findings of this study strongly showed the importance of addressing the psychological and social issues of leprosy patients and the general perceptions of the society regarding leprosy before implementing or initiating integration of leprosy control program into the general health service. In-service training to health workers, health education about current knowledge of leprosy to the patients and studies on knowledge, attitude and behaviour of leprosy patients and the public are recommended.

Introduction

Throughout history leprosy has been feared in most parts of the world for its devastating deformities and its victims have been feared and subjected to the cruelest forms of social treatment and isolation(1). Unlike other diseases leprosy is a disease known for its peculiarity of evoking a long standing negative social reaction (2) and is a global health problem which has an intense psychological impact on the patient(3).

Although prevalence data are very limited in many countries, it is estimated that there are about 10-12 million patients in the world, especially in Africa, South East Asia and Latin America (4). The number of leprosy cases as well as its impact on mortality is not higher than from many of the diseases which are common in the developing countries where leprosy is endemic. Rather, the stigmata attached to the disease have intensely negative effects on patients and their families and the community(5).

Despite the considerable success achieved in the Dapsone (Diamino diphenyl sulphone) monotherapy period, the stigma of leprosy has been a major constraint preventing patients from early reporting and regular attendance for treatment (6).

Even more recently, after Multiple Drug Therapy (MDT) started, for many health professionals, world wide control of leprosy seemed to be more realistic.

Furthermore, there is a fall in the prevalence of actively registered cases and an increase in early self reporting and

regular attendance at treatment(7). Nevertheless, leprosy is still one of the most complicated diseases especially when the age-old stigma attached to it are examined

The fears by the patient of being stigmatized on one side, and the society's negative attitude towards leprosy patients, though not universal, on the other side, are the main factors which are hampering the control of leprosy, particularly, early case detection and case holding.

For example, since the 1960's it has been estimated that the registered patients represent only between one-fourth and one third of the estimated cases (8). Compared to the true prevalence the percentages of cases reported to be registered were 2,788,298 (25.6%) in 1966, 3,600,000 (34%) in 1976, 5,400,000 (36%) in 1985, (30.8%) in 1990 (4). In most parts of the world the patients who were getting regular therapy accounted only for 20-30% of the registered patients (5).

Considering the magnitude of the effect of the social stigmata, the WHO repeatedly stresses the importance of studying the social and cultural factors in promoting control programs. The prejudice against leprosy patients and their families and the social and cultural factors must be considered in efforts to promote the control programs as well as in the integration of leprosy control programs into the general health services (9,10).

Despite the problems, the social perceptions of leprosy in a given community and society and the effect of these perceptions on the control program as well as on the epidemiological study of the

disease are usually given little emphasis (11). Many researchers believe that unless the issues of the stigmata surrounding leprosy are addressed, to control leprosy is no more than a "dream" (12).

There is no single widely held belief about leprosy even in a given community and it is mandatory to study different perceptions at different levels, from the individual to the national level. Such types of study help to involve the patients in the leprosy control program as well as in the community and with the general health workers who at present are far from the control program.

In Ethiopia there is no reliable information on factors that show changes on the social perception of leprosy since the control program started in the 1950's. It is imperative to review such changes and social perceptions if one wants to integrate such a 'unique' disease into the general health service where a large part of the hate and fear is reflected in the public's attitudes.

The purpose of this study is to review the historical patterns and trends of the social stigmata and prejudice regarding leprosy over a period of 35 years in relation to policy and program issues in integrating leprosy control program into the general health system.

The study was done by interviewing twenty leprosy patients, eight religious leaders, twelve health workers, five high school teachers, five high school students and four non-leprosy patients. The study was mainly conducted in Tekle Haimanot Awraja (which was one of the residential areas of leprosy patients during the Italian

invasion of Ethiopia, 1935-41) of Addis Ababa Administrative Region and at the All Africa Leprosy and Rehabilitation Training Center (ALERT) and in four neighbouring Awrajas.

The study's aims were to generate hypotheses or study areas for further research and to point out certain ideas about how leprosy is perceived by leprosy patients and the public and the impact it has on the policy of integration.

Current World Situation

Leprosy is a major public health problem in many developing countries of Africa, Latin America and Asia. The adverse impact of the social stigmata that clings to leprosy is of greater importance than the disease itself. Leprosy stigmata have very negative implications for the patient, the society, and the success of the leprosy control program. Leprosy, as a disease with unique social problems, requires understanding of the disease from a social science perspective in order to formulate strategies that are applicable to a given community or country.

Magnitude of the Leprosy problem

Leprosy is distributed in many parts of the world where about 1,600 million people are exposed to it (10). This is the third largest number of population exposed to tropical and mycobacterial diseases next to tuberculosis (3,000 million) and malaria (1,800 million) (8). Even though the magnitude of leprosy is very serious in tropical and sub-tropical countries, for unexplained reasons the distribution is uneven and patchy even within the same country and has a marked difference in prevalence among two adjacent countries (13).

Today among the 12 million estimated cases, only 3.5 million (31.%) are registered for treatment (4). In the most affected areas of the world, South and South-East Asia, Africa and Latin America the registered prevalence rate ranges from less than 0.1 to

3 or more per thousand population (7). The highest prevalence rates of 20 per 10,000 are reported from endemic areas of South-East Asia; the prevalence reaches 9 or more in Africa(4).

In the year 1990 annual case detection ranged from 37.2 per 100,000 population, in South East Asia, to 0.9 in Western Pacific. Africa has a case detection rate of 8 per 100,000 population. And the overall global case detection rate is 10.9 per 100,000 population.

Among the registered cases, about 82% are found in five countries (Brazil, India, Indonesia, Myanmar and Nigeria) and 91% of all registered cases of the world are found in only 15 countries (7). In Africa, Nigeria alone contributes to 40% of registered patients (4). The concentration of cases in certain countries shows the problems to be associated with case detection and case holding.

Even though there are limited data, the global disability rate is estimated to be 20-30% (5) and in many parts of the world leprosy is taken as one of the major causes of physical handicapping. The size of the social problem the patient would face and the economic loss due to disabilities are some of the major problems which need strong attention from any control programs.

After puberty it is reported that males are more susceptible to all types of leprosy, especially the lepromatous type, than females. Although all ages are equally affected by the disease, it is rarely seen in children under five years of age (13). In Africa

children under fifteen constituted 9% of new cases (4) while in Brazil, out of the total cases, children under 15 constitute 10 or more percent(14). The distribution of leprosy in terms of geography, age and sex shows the extent of morbidity inflicted by leprosy. Above all, the large area distribution which makes every individual, residing in the area, at risk and its predominance in the developing countries magnifies the problems of leprosy (10).

Leprosy Stigmata

A stigma is 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 (15). Other than the impairment and disability caused by the disease, the leprosy stigma imposes a handicap on the victim to be feared and perceived as dangerous to the society and exposes him or her to subsequent rejection (16).

The chronicity of leprosy which exposes the patient to a long standing suffering and the potential deformities(17) with the associated implications of incurability leads to a strong negative social reactions (8,17).

Like in the prehistoric and middle ages, even today leprosy is considered the worst of all human being's fate(18) and the most frightful disease that can befall a person (19).

Like the previous "cruel" oaths "the pox upon you" (20) today in some parts of Africa one sometimes says "mean as a leper" and leprosy is called " the great disease" while another fearful

disease, measles, is called "the great mother"(11). The word "leper" is always associated in many Anglophone countries with a devastating and repulsive disease(21).

Volinn stated that he has become accustomed to people rejecting any person with AIDS related signs and symptoms as a "leper"(15). This juxtaposition shows us that leprosy is a disease whose 'name' and stigma have not changed over centuries; rather the negative reactions have survived and persisted up to the present day with additional stigmatization over the ages (22).

The leprosy stigmata which create social rejection and many types of cruel actions are usually justified by the patient (8) and reach to the point of regarding the self with disgust(10). Beside the disabilities, the lack of knowledge about the disease makes the patients spoil their own self-image (18). Patients are influenced by the perceptions and understanding of the society in which they were born and grew and by all social conditions that surround them (17).

In 1991 it was reported that there were three suicide attempts in England after the diagnosis of leprosy was made and one Indian scientist who was working in London confessed that he would have committed suicide had the diagnosis been made in India (15).

The leprosy stigmata inhibit patients from coming early for treatment and in most cases patients come in the advanced stages of the disease at which time the disease is easily recognizable(3,9).

Unlike many diseases there is no reliable way of primary prevention of leprosy (13). Lack of knowledge on factors that put

a certain population at risk, absence of an intermediate host, the lack of an effective vaccine and the difficulties on chemoprophylaxis limit the detection of the disease and protection of the population at risk (3). For these reasons the control of leprosy is mainly dependent on the third method of case finding and contact. The general purpose of leprosy control is to reduce infection and transmission by chemotherapy, to provide early and sufficient treatment for all detectable cases and preventing disabilities (10,13).

Different studies have confirmed that many victims of leprosy prefer the risk of being disabled to losing their job and social status in family and community (19). As a result one of the serious effects of leprosy stigmata is the problem it creates on the early detection of cases, either passive or active.

The strategy of control through case detection was reported to be successful in decreasing the incidence and prevalence of leprosy in a very few countries like Burma, Burkina Faso and China (5,9,15). Pearson reported that in areas where active case finding is done, usually not more than 50% come by themselves(13).

The effectiveness of early detection and the fear of leprosy stigmata can be measured by the frequency of deformities, which have been seen in about 20-30% of patients in many countries.

In Africa, in the year 1990, among the very few registered patients alone, there were 25-40% disabled patients. Disability among the newly diagnosed cases throughout the continent is believed to be 10% (4). The disabilities, which may have been

prevented by early diagnosis if the stigmata had not been there, lead to loss of family, job and self respect. A recent study done in Bombay showed that out of the 129 leprosy patients more than 50% of the patients had lost their job after they developed deformities (23). The loss of a job after being diagnosed is a very common experience among factory workers. Apart from the patients' own fears these social factors hamper active case detection including the simplest form of contact tracing (13).

In spite of the acclaimed success of MDT in increasing self reporting, the WHO reported that one of the present and future problems of leprosy control programs is early case detection.

Another world wide problem in the control of leprosy is the extent of regularity for treatment which is considered to be not more than 20% in most parts of the world(18). In the 1960's Porter reported that regularity of domiciliary drug intake (Dapsone) in England was much lower than 50% (24). Koticha and Nair, in 1972 found out that only 20% of the patients were regular attendants out of 42,000 patients (25) and, in 1976, regularity in drug intake was 42% in 22 African countries (8). For fear of being known as a "leper" by their family, work mates and other members of the society, patients usually decided not to comply fully or became irregular attendants (18).

In both developing countries where the disease is endemic, or, in the western countries, leprosy patients' practices and attitudes towards leprosy and treatment are dependent upon the socio-cultural belief systems their society has towards leprosy (17). A study

which focused on the social perception of leprosy in the outskirts of Dakar, Senegal, in 1986 found that the different clans in the study area had unique socio-cultural beliefs and attitude regarding leprosy and leprosy patients. Based on these cultural and social peculiarities the activities of the leprosy control program in Senegal were met with success. In Caramance, Senegal, where there is a traditional grouping and treatment of leprosy patients, the modern way of treatment in the therapeutic villages was readily accepted. The same was true for patients who were rejected from their family and community. But, this kind of treatment couldn't be successful in the Senegal River Valley where the patients were allowed to live together and the society was not willing to let their patients go. Based on these findings the author stated that acceptance and a great deal of compliance can only be achieved when the method of leprosy treatment is correlated with cultural beliefs and practices(11).

Similarly, a study in Northern Thailand showed the importance of studying indigenous healing practices which can be associated with modern care. Leprosy's causation is associated with "Karma" and "resistance" which have valuable and meaningful explanations for populations of Northern Thailand including the patients. Based on these findings the authors suggest that these local terms can be used together with the idea of bacteria infection in order to introduce the crucial concept of chronicity and, hence the importance of the long term treatment.

T. Neylan stated that mutual understanding between the leprosy patient and the health worker regarding treatment practices and goals are crucial for increasing compliance and for the overall success of the leprosy control program (26). A study which assessed patterns of drug compliance in 485 patients in Bombay, India, has resulted in making 52% of the patients from irregular to regular attendants in repeated counselling (27).

Many patients do not have the knowledge of how long they will have the disease or the need for prolonged therapy (26,27). In India it was found out that lack of knowledge about the disease, treatment and its effect on disability was one of the causes of non-compliance (25). Patients without deformity and, as a result, who don't want to be known as leprosy patient and patients who are found by active case finding are among the groups which are highly non-complaint.

Since Multiple Drug Treatment(MDT) started, it is repeatedly reported to be superior than the Dapsone monotherapy by increasing compliance, self-reporting of patients with early disease and better motivation of health workers (4,7,10). From 1985 onwards there has been a decline in many countries in the number of registered cases which is attributed to the effect of MDT (7). In some areas the mass release of patients after screening, in preparation for the MDT program was the reason for the reduction in the number of cases in the three years prior to 1985. Many authors argue that the main function of the leprosy control program should not be limited only two with the promotion of MDT, neglecting the

main focus of attention, which is the patient and the stigma that makes him or her non-compliant (17).

In Indonesia where the leprosy control program is said to be integrated from the central to the lower level, the MDT coverage among the registered patients was about 26% in 1988. The same low coverage is seen in Vietnam (38% of registered cases) in a country where full integration is said to be achieved. In the WHO's African region 55.7% of those registered (17.8% of the estimated) were under treatment in 1990 (4).

These figures of estimated and registered; patients and non-compliance indicate the need for addressing the problems that prevent patients from beginning and continuing treatment. In a study done in the Philippines in 1986, out of the 100 non-leprosy individuals (50 men and 50 women) interviewed, more than 90% expressed their wish not to live in the same community with leprosy patients who were in the early stages of their disease, while 97% expressed their wish not to live with patients in the advanced stage. Almost all the respondents answered that they were are not willing to let their children play or marry the offspring of a leprosy patient (29).

In Karachi, Pakistan, in 1988, out of 83 diagnosed leprosy patients 28 had been shunned by their neighbours, 16 had been fired from their jobs, 9 had been unable to marry and two had been unable to find a husband for a sister or daughter. In one case the

victim's parents were forced to leave for Pakistan (from Bangladesh) in order not to disclose the illness to other people who might want to marry the patient's sister (1).

The problems of leprosy should be seen as a problem of the community as well as problem of the victim who is inseparable from the disease (30). But in many countries health policy makers and health workers who encourages the integration of leprosy into the PHC system usually do not address the question of social stigmata which surround the health workers (17). Missalek studied the discriminatory behaviour of general practitioners towards leprosy patients. This study showed that among the respondents, 56% refused to treat any leprosy patients and about 90% refused to treat a patient in advanced stage. Based on this study, done in Pakistan, the author commented that this type of discrimination is usually seen in health workers who are not involved in leprosy control programs (31). R. Bloom and T. Godal stated that integration of leprosy into the general health service is not only resisted by the general public, but by the health workers who at present are in almost total opposition to be received into the field of leprosy (5).

Beliefs In Causes of Leprosy

Since time immemorial a lot of erroneous knowledge about the cause and transmission of leprosy surrounds leprosy and has been causing negative attitudes towards leprosy and leprosy patients. (1,18).

In China, leprosy was believed to be a punishment for having sexual intercourse with a prostitute (15) and sexual misbehaviour was also implicated as a cause of leprosy in Greece (32).

The Caraka Samhita, an Indian medical text, dating from around the first century A.D explained that "antagonistic diet" as well as untruthfulness, ingratitude, blasphemy against the gods, deriding of ones elders sinful actions, and "the accumulated evil acts of past lives" are the factors that cause leprosy" (1).

Theodoric of Cervia (1205-1298) who was a prominent surgeon believed in the evil nature of leprosy due to its relation to sex and considered it to be a venereal disease. He also believed that "leprosy comes as a result of corrupted blood and can be congenitally acquired" (33).

Even after Hansen's discovery of *Mycobacterium leprae* as a cause of leprosy in 1873 many physicians couldn't accept his findings and persisted in the belief that leprosy was not caused by anything except being hereditary (22). Leprosy is still surrounded by different beliefs and myths not less than it used to be (34). In many parts of the world leprosy is still believed to be caused as a result of sexual intercourse during menstruation (35), marriage between two different groups for example, between a

blacksmith and a weaver (11) or due to the evil wish of another person (1), or as a result of eating eggs as a child (36). In Zambia people believed it to be caused by a witch, (37) while in Uganda mistreatment of a leprosy patient is implicated to cause leprosy through evil spirits (38).

Certain types of food like fish or mixing of food are also implicated as causes of leprosy (1,39). In certain countries people are reported avoiding water from a well a leprosy patient was using to drink for fear of transmission (40).

The hereditary nature of leprosy is believed in many countries (37,40). In religions like Hinduism even nowadays it is believed that leprosy and its subsequent deformity is a divine punishment (15).

In a study done in the Philippines in 1986 among employees of leprosy control program about 12% believed it to be caused by uncleanliness of the blood, soul and by witchcraft. 89.3% stated that leprosy is contagious and 69.6% stated that casual skin contact was the main route of transmission. 35.7% of them confessed that they preferred to avoid contact with leprosy patients (41).

Joping quoted about the SUN, a British daily news paper, which issue of 28 September 1989 warned the Princess of Wales from shaking hands with leprosy patients by saying "Di to shake hands with a leper" and "Don't do it". The paper's assumption was that the princess would contract leprosy by just shaking hands with leprosy patients (15).

Like the general population, patients also had inadequate information about leprosy (17,18,38). In Karachi, Pakistan, a study (1987) showed that out of 94 patients more than half answered that a combination of food, especially fish with milk causes leprosy. Out of 128 patients, 87 patients held the belief that leprosy is a punishment from God, usually for the victim's own sin, and occasionally for ancestral transgressions. Thirty one respondents agreed that leprosy is hereditary, while 36 patients believed it to be caused by an ill-wisher who projects the disease upon a person (1).

In a study in Thailand about illness beliefs of leprosy patients, only two patients identified bacteria, out of 61 patients, as a causative factor for leprosy. While other patients stated humoral disorders, circumstantial events, sin, curses and venereal disease as factors (26). These findings suggest the negative attitudes the patients had towards leprosy and their lack of knowledge about their disease.

Ethiopians Beliefs about the Causes of Leprosy

There were very different perceptions regarding leprosy's cause and transmission like in many parts of the world. Leprosy is believed to be a punishment for sin (35,37). Evil spirits are also frequently blamed as the causes of leprosy. To have sexual intercourse in the open (57,58,59) to uncover ones body outdoors and coming out on the sunshine from a very hot environment (58), coming near to the river, washing with water kept uncovered during the night are usually associated with evil spirits which subsequently are variously blamed to lead to leprosy (37,59). Leprosy is also considered to be a sign which warns when the end of the world comes nearer (57) or as a sure sign of the end (58).

In spite of these various perceptions of causation, the intense belief in miraculous cures and in the non-contagious nature of leprosy contributed to minimizing the very negative social attitudes (50).

One of the reasons for the relative social tolerance for leprosy was the belief of the Ethiopians in the hereditary nature of leprosy (50). In Ethiopia leprosy has usually been associated with "Lalibellas" who sometimes are called "Haminas" or 'the great beggars', whose origin is assumed to be from Wello (a Northern province of Ethiopia) (35).

The previous "Lalibellas" were thought to be leprosy patients (35) and some have the thought that they were 'healthy' people like today's "Lalibellas" who beg to prevent leprosy (57). Both the previous and today's "Lalibellas" were seen throughout the country,

going in pairs, and begging by singing in a loud voice at the gates of houses before the sun rises (35). They believe that the early morning cold air is one of the factors that prevents them from being deformed.

There is a folk tale which associates the origin in the belief of hereditary nature of leprosy by the "Lalibellas" with a boy who got deformed ignoring the advice of his friend, who advised him to wander around and beg not to have his father's disease (leprosy) (57).

On the contrary leprosy is said to be sent by God to test the faith of the victim (58) or to a person who is chosen by God to show His grace. These latter beliefs are directly or indirectly related to the history of St. Gebre Christos (57).

Other than the common people's view of hereditary transmission many writers at the turn of the century reported that leprosy was more common among the Amharas than the Oromo people (50). This view was further strengthened in 1969 by Price who commented that Amharas might be genetically more susceptible to leprosy (60).

Current Knowledge of Transmission

Despite being the first bacterial pathogen to be discovered, in 1873, It is not yet possible to cultivate the bacteria in a non-bacteriological medium and this greatly hampers the study of the disease. Until now the only proven source of infection are humans (3,5,10,42,43) but the significant prevalence of leprosy in wild armadillos increases the assumption that exposure to armadillos can be a source of leprosy in humans. Naturally acquired leprosy has also been reported in a chimpanzee (in Sierra Leone) and in a mangabey monkey (in Nigeria) (44). Different studies showed the detection of large number of viable *M. Leprae* in the nasal discharges of leprosy patients has increased the belief that multi-bacillary patients can be the main source of infection (3,18).

The portal of entry of the bacilli is still less known than the portal of exit of the bacilli (10). The gastrointestinal tract, broken skin (3) breast milk, bedbugs, fleas and scabies mites that feed on lepromatous leprosy patients have been suspected (43). But there is no scientific proof for the age old belief of skin-to-skin contact in transmitting the disease (3,45)

In endemic areas a large part of the population shows immunologic conversion to antigens of *M. leprae*. This type of immunologic conversion is also seen among the leprosy health workers (13). Only 5 - 10% of the infected population develop a clinical picture of leprosy (43) Whose potential of transmitting the disease or infectivity is very minimal if treated (42). Overcrowding (43), malnutrition in children (46), and poor

sanitation are suggested as the possible risk factors that contribute to the speed and transmission of the disease.

The findings of leprosy in monozygotic twins (3) and the reported association between tuberculoid leprosy and HLA-DR2 antigen (13) has increased the suspicion of genetic susceptibility to leprosy.

The uncertainty of the current knowledge about leprosy is said to contribute to increasing the social stigmata towards leprosy.

(18)

Background History

Many historians suggested that leprosy was endemic in India, China, Japan, Africa and the Mediterranean regions and its surrounding lowlands several centuries before Christ (47).

Even though the first indubitable descriptions of the disease date back to 600 B.C, the archaeological finding in Egypt is regarded as an evidence to the existence of leprosy as early as 4000 B.C (16).

The earliest written references to leprosy as we know it today are found in Indian, Chinese and Japanese writings of the sixth century B.C (48,49). The medical texts of the time also gave the clinical picture of the disease that it caused numbness of the skin and made the patient to have a feeling of sensation that "a worm is crawling under his skin" (49). Some writers believed that the disease was present in Nubia by 480 B.C; some argue that the disease was spread into Athens after the third century B.C (32). There is an assumption that leprosy was brought to the rest of Africa countries by migrating Cushitic tribes (35).

Brown suggested that leprosy was introduced into Europe around 327 B.C by the returning armies of Alexander the Great after his campaign in India(32). The disease is said to have been brought to the USA by French settlers who were expelled from Canada (15). But, some historians argue that it was probably brought by slaves from Africa (20).

Authors like Peter Richards blame the church for the fear and stigma by its teachings that a "leper" is spiritually

'unclean'(22). The third book of Moses, Leviticus, which many people associate with the fear and stigma attached to leprosy has a part which describes certain skin infections. Chapter 13 and 14 of Leviticus states that:

Depending on the extent and types of infection patients should be put in isolation for seven or more days. Patients who are cured would return to the community after having some 'rituals of purification and sacrifice'(49).

But many writers stated that it is wrong and unjustifiable to attribute the stigma of leprosy to the teachings of the church (21). Because the earliest descriptions as well as the dread and fear for leprosy were also prevalent in the non-Christian lands (32). In the Hindu belief system leprosy is a punishment for sin (15). Many Indians believed the sin of the victims or their parents caused leprosy (15,21). In China it was a price paid for moral degradation. In Iran patients were considered to be sinners against the sun (16).

In Western Europe at the time of the Middle Ages leprosy patients were denied their civil rights and were forced to live alone in a hospital or outside the city wall(15). The European churches declared the leprosy patients to be "dead to the world" and denied them the rights of marriage or property (22). A law proclaimed in 1375 prevented the leprosy patients from entering into the city of London and penalties were issued on all those who allowed the entry of the patients to the city (20). In Finland, in the 17th century, patients were forced to go to the Islands of

Gloskar where there was no medical or nursing care. Patients who were forced to these islands had to bring or were provided with "wood and nails for his or her own coffin" (22).

In the 19th century Russian patients were usually expelled from their communities and lived in the forests. They were not even allowed to come to their family for fetching of food which usually was dropped by their relatives at certain places in the forest (15).

LEPROSY IN ETHIOPIA

Leprosy is believed to be one of the oldest diseases known to Ethiopians (35,50) The contact between the ancient civilizations of Egypt and Ethiopia during and before the Axumite empire is believed to be one of the means which brought leprosy to Ethiopia (35).

It was also suggested that the geographical location of Ethiopia, which made it the land and sea link between Asia and Africa, might have caused the early introduction of leprosy to this country(51), as the disease was supposed to be present in Egypt and North Africa before Christ (32).

At different times in history, leprosy was known by various names in Ethiopia. In the 4th to 6th century A.D. it was known as 'lamts' like the contemporary Tigregna (Northern Ethiopian language) "lamtsi" and by other but related names like "Quesela Sega" (ulcerated body) or "Talak Dewe" (major disease). In areas of Oromo people it is known as "Kurchi" which has a related meaning similar to the others (50). The commonly used Amharic word, "Qumetena" is thought to be derived from the Arabic word "Jadham" which means "cutting" (37). At present the preferred but not widely used word is "Sega Dewe" which means "disease of the flesh".

Travellers 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 leprosy patients. In the law of the kings of Ethiopia called "Fetha Negest" it was stated

that a leprosy patient couldn't serve the church as a priest, patriarch or a judge. Even though the Orthodox Church of Ethiopia was said to be operating in accord with the Leviticus law and considered the patient as "unclean" there was no legal provision that prevented marriage or permitted divorce. In general there was no rule written in the 'Fetha Negest' that required patients to live alone or segregated (50). The Orthodox Church believed in St. Gebre Christos as being the patron saint of leprosy patients (50,51). Some people also associated leprosy with another saint, Abune Aregawi, and believed that both names are the names of one saint and are used interchangeably. The church near ALERT which was built by the Ethiopia Orthodox church and the saint's day of Tekemt (October) 19 are commonly called as Gebre Christos or Abune Aregawi (51,52).

Abdel Meseih, which means Gebre Christos, was the only son of King Thewodosios of Constantinople (now Turkey) and Queen Merkeza. When he was a child Gebre Christos was taught about the Bible, the deeds of the Saints and the tales of Christ, as his parents were very religious. At the age of 15 he disappeared from his father's palace on the night of his wedding, wishing to serve God by leaving all the happiness behind far from his home. After a one year journey he started to live with the poorest people of the poor, fasting all days except for Sundays.

Feeling in deep sorrow, his father sent his messengers throughout his empire to search for G/Christos, but couldn't succeed in finding him. According to some writers the reason for

his not being recognized by his father's troops was the prayer he made to God to make the internal part of his skin like the outer part and viceversa. His father's troops failed to recognize him because their only encounter occurred after 15 years, at which time Gebre Christos no more had a royal appearance, as a result of 15 years of fasting and suffering.

Gebre Christos returned to his father's palace after 20 years, by the will of God who changed the direction of the ship to Constantinople, and lived there for 15 years with the servants without being recognized. It was only known who he was after his death.

Why did Gebre Christos become the patron saint of leprosy patients? In the last days of Gebre Christos, Jesus Christ, with all the angels and saints was sent to Gebre Christos and told him that he gave him all the power to cure by His name all the leprosy patients, the blind, the deaf and all other patients who have skin disease. Jesus also told Gebre Christos that all his prayers were heard and would reward him for all his patience and good deeds in spite of his bad fortune and suffering and would go to the Holy place of Heaven.

Concerning the celebration or the Holy day of Tekemt 14 there are two opinions among the followers of the Ethiopian Orthodox Church. The first one is that the day is the date of Gebre Christos death and before his death Gebre Christos asked Jesus Christ to bless all those who would go to church on his memorial day and Christ accepted him and promised to give all his blessings

to all who celebrate the day and they started to celebrate Tekemt 14 as a day of St. Gebre Christos (51).

On the other hand those who call the day (Tekemt 14) Abune Aregawi state the following. Abune Aregawi was one of the 9 monks who were exiled to Ethiopia in the year 480 A.D from Syria and Asia Minor as a result of the repression imposed on Christians by the Byzantine kings of the time. These 9 monks were welcomed by the then king Alameda and the Ethiopian people and were able to expand the words of Christ and Christianity throughout Ethiopia. As a result of their holy contribution, the then Ethiopian Church decided to celebrate as a holy day the date of death of each of the 9 holy men. Abune Aregawi died on Tekemt 14 and the day was declared to be holy (52). In either case the history of the two saints can be taken as another witness that the Ethiopian people were well accustomed to leprosy for a very long time.

Until the 19th century many writers reported that leprosy patients were regarded as part and parcel of their family and community and were celebrating with other healthy members equally at festive occasion by sharing drinking cups and dining together.

After the 19th century the patient started to be seen as a 'dishonoured' individual who brought a disgrace to himself, family and for the seven generations who had lived before him or her. Patients were treated as not being part of the society; they married among themselves and were forced to leave their family and town. Towards the end of the last century the negative attitude was seen throughout the country, particularly in the northern

province of the country, in Tigray, where the rejection and segregation was very harsh (50).

One of the earliest medical professionals who described treating leprosy patients was the English surgeon Dr. Kirk who reported of treating 26 patients with the "complaints of Lepra" in the year 1841 and 1842. Dr. Henry Blank, who was one of the prisoners of Emperor Theodros II (1855-68) also described leprosy as one of the commonest diseases he was treating. The high prevalence of leprosy around Lake Tana was also reported by Arthur Hayes who was also reported treating many leprosy patients. In the reports of the Russian Red Cross it was documented that the mission had treated 143 cases in Harar and 233 leprosy patients in Addis Ababa between May and October of 1896 (53).

The first attempt for modern care of leprosy patients started in Harar town in 1900, with the establishment of the first leprosarium in Ethiopia (51,53). Dr. Feron, a Catholic doctor from France, named it the St. Antoine leprosy home after the patron saint of leprosy patients in the Catholic Church (51).

The missionaries at the time reported that the patients were not segregated from the rest of the population and were taking their medications voluntarily.

The physicians of the leprosarium believed that leprosy was a disease which was no doubt a contagious disease. Even though they were not certain of the hereditary transmission of the disease, they strongly believed that husband and wife could transmit the disease to one another and their union would produce the severest

form of the disease (53). This belief of the missionaries is considered to be one of the earliest accounts of the belief in the contagious nature of leprosy in Ethiopia (50).

The second leprosarium was built by the Sudan Interior Mission (SIM) in the suburb of Addis Ababa in 1932. The establishment of this hospital, named Princess Zeneb Work Hospital (PZWH), was considered as "the beginning of specialized Hospital care in Ethiopia" (54). One of the important aspects of leprosy in the pre 1955 period was the formation of the largest residential area of leprosy patients around Princess Zeneb Work Hospital which establishment, in 1932 paves the way for this 'self' built segregation village (55).

Taking advantage of the spacious compound of the hospital, patients and their relatives who came for medical help and patients who were rejected by their families and communities started to reside on the premises of the Hospital compound. In spite of the very high number of patients and relatives, the SIM and the American Missions for Assistance were reported to be giving good care for those in the hospital as well as for those outside the hospital (56).

In the early 1960's to rehabilitate these patients, by transferring them to agricultural settlements and farms, with the cooperation of MOH and other missionary and voluntary organizations, many cured patients were transferred to settle at

Gende Beret (Shoa), Addis Hiwot (Arussi) and Shashemene (55,56). Patients who were courageous enough to return back to their native areas were allowed to go (47).

The large number of patients who remained and settled around the premises of the PZWH formed a new neighbourhood which they called 'Addis Ketema' (a new town) and named Gebre Christos by the other people (55).

Leprosy Control Programme in Ethiopia

Leprosy was the first disease in Ethiopia to which a planned control programme was directed. It was also the first disease which led the Ministry of Health to arrange a control programme with the World Health Organization (WHO) (51).

Since the control programme started in the 1950's the MOH used different methods and strategies over the last 35 years.

1. Period of Specialized services in fixed Clinics 1956 - 61

This control programme started in July 1956 with the help of UNICEF. The programme was planned for 3 years with the objectives of :

- establishing 30 provincial centers in the high prevalence areas of the central highlands.
- Maintaining three leprosaria to house 3000 patients
- training 88 'leper dressers' mostly chosen from among the patients .
- Treating 15,000 patients (51).

During this period care of leprosy patients was carried out at the Princes Zenebe Work Hospital, St. Antoine's in Harrar, the leprosarium in Shashemene and 12 provincial clinics located in Fiche, Debre Brehan, Dejen, Bichena, Debre Marcos, Fenote Selam, Dangela, Bahr Dar, Lekemt, Gonder and Jimma (51,54).

A WHO consultant came to Ethiopia in 1958 to assess the progress of the program. He strongly criticized the "fixed clinic" approach which he claimed shouldn't have been attempted without a previous survey and situational analysis. This consultant's comments were given a deaf ear until the second WHO consultant came in 1960 and expressed his disappointment in the overall progress of the programme. He was very critical of the health workers "Just waiting for the patients at the door of the clinic" and was

disappointed in the irregularity of the patients in taking their treatment. At the end of his visit the WHO consultant recommended that the control programme should be integrated into the basic health services and advised to establish provincial leprosy clinics with mobile units.

After the consultant's advice a decision was reached to abandon the control programme by the "fixed clinics" method. At the end of December 1961, out of the estimated cases of 200,000, about 61,000 patients were said to have been registered out of whom only 20,000 were getting treatment. For this period the Ethiopian Government's expenditure was about US\$ 115,000 while UNICEF's amounted to US\$23,000 (51).

Period of Attempted Integration into the
General Health Service 1962 - 64

The control of leprosy became part of the services of all health centers and health stations after the gradual transfer of health personnel and as budget was given to the health officer in charge of the health center of a given area and to the regional manager of health.

According to the Ministry of Health report, the number of patients registered in 3 years was only 2415. Even in the high prevalence areas of Gojjam there were only 299 registered patients.

Almost in all clinics regularity was very low. For example, in Shambo Health Center, Wellega, regularity was 9% and 126 (40%) came only once. In Gore Hospital, Ilubabor, 9% were regulars while

about 70% (240) came only once. In general regularity of attendance in the country was below 10%.

During this three years period, out of the 57 health centers in 13 provinces, 22 health centers reported in 1962 to register no patients at all throughout the year while the highest number of patients registered was at the Buno Bedele health Center which registered 81 patients. In 1964, 14 health centers registered no patient, 15 registered less than ten patients and the highest number registered was 87 at Karakore Health Center.

The report of the MOH stated that the reasons given by the patients for their non attendance were:

- "The health center personnel do not like us"
- "The other patients don't like us"
- "They have no Dapsone"
- "The Dapsone is not the same as that which we used to get"
- "It is too far" (51,60).

These reasons were good indicators of the importance of studying the social perceptions of the society for the success of a leprosy control programme.

According to MOH the causes of failure were:

- Lack of knowledge about leprosy by the general health workers and a very low motivation for the control programme.
- The planning of the control programme which didn't consider local situations and methods which could be acceptable by the patients.

HISTORY OF ALERT

The conception of establishing the All Africa Leprosy and Rehabilitation Center started in the early 1960's. Brand wrote that "in the early 1960's the International Society for the Rehabilitation of the Disabled (now called Rehabilitation International) established "The World Committee on Leprosy Rehabilitation" and asked me to be its chairman,.....at a meeting of the committee, held at Carville in 1963, we had an open discussion to try to define the greatest single need in the field of leprosy rehabilitation world wide..... It was agreed that, in this field knowledge was ahead of practice, we know better than we were doing. The greatest need was to train personnel to implement what was already known. The next question was, where? It was agreed that Africa was the continent in which the need for training was greatest" (61).

Brand and Browne (Leprosy Mission, London) during their visit in Ethiopia in 1964 agreed that Addis Ababa and PZWH fulfilled all their criteria, one of which was the strong political support which they got from the MOH and the Medical Faculty of Addis Ababa University(AAU) (58).

During the meeting on December 11, 1965 the formation of a new training institution was declared, which was named All African Leprosy Rehabilitation and Training Center (ALERT) (61).

The organization was founded by :

1. The Ministry of Health,
2. The University of Addis Ababa,

3. The International Society for the Rehabilitation of the Disabled,
4. The American Leprosy Mission,
5. The Leprosy Mission International (TLMI).

The main purpose of ALERT was specified in 1965 as follows: "to train men and women in all aspects of leprosy with special emphasis on control, treatment and rehabilitation, for work in Africa countries" (56,61,62).

The agreement reached by all participants also intended "to build up a leprosy service in a limited rural area, which shall demonstrate comprehensive medical care and rehabilitation of leprosy patients as part of a national an Anti-leprosy campaign and linked with general public health services" (62).

To play its role in the national anti leprosy campaign, and for training purpose, ALERT took up the leprosy control programme in Shoa administrative region and Addis Ababa city.

In 1967 after an exploratory visit had been made, the north-eastern parts of Shoa including Menz and Yifat, Tagulet and Bulga, with a center at Debre Berhan were selected for training of leprosy field workers in the methodology of survey and leprosy control.

In the early phase of its foundation, other than the in-service training courses on leprosy for nurses and advanced dressers for ALERT staff, courses for leprosy field workers were given and the graduates were assigned at Debre Berhan and at PZWH.

By 1985 ALERT had given training courses for 379 Ethiopian medical students, 840 nursing students, 21 tutors and 407 health assistants. The courses which stressed leprosy control gave priority for the prevention of deformity and for the rehabilitation of the disabled (56).

Up to 1972 4,830 patients from Addis Ababa and 4,193 patients from the rural (North Shoa) areas were served by ALERT (60) and for these patients or areas regularity of attendance was 74% and 64%, respectively. At the time (1972) the overall national regularity of attendance was estimated to be 71%.

The leprosy clinics under ALERT in Debre Berhan, Molale health Center (H.C), Mehal Meda H,C, Globe Health station (H.S) Sheno H.S, Fiche H.C, Gebre Guracha H.S, Guha Tsion H.S with a total of 952 registered patients were reported by the MOH to be "semi-integrated" by 1972 (60).

The data collected in Addis Ababa on Dapsone compliance on outpatient daily self administration showed that, in 1974, 16% were irregular and the 1981 collection showed the same trend (78 out of 368) of 11% irregularity (6).

Due to the increasing number of patients coming from urban and rural areas to ALERT, which created problems for treatment, the MOH and ALERT agreed to open 14 leprosy clinics which could be attached to the existing health centers and stations in Addis Ababa in 1974.

Since then It was recorded that about 6997 patients were registered for treatment in the 14 clinics other than ALERT. The highest number of patients were registered in Arada and Tekle Haimanot H. centers respectively (47).

3. The Period of Control by Mobile Clinics:

The Method of "Seek and Treat" (1964 -69)

The "seek and treat" method was started with the objective "to treat as many patients as possible as near to their homes as possible as early in the disease as possible" (51).

The programme used certain principles as the basis for its control activities. To bring the Dapsone as near as possible to the patient the programme focused on places where regular attendance were expected. Even though one of the areas selected was the local church as a means of distributing the drug, for various reasons success couldn't be met; on the other hand the local markets proved to be successful, where the treatments and examination was done on market days in rooms hired for that specific day, and examination was done under a tree in the absence of a room.

The 'seek and treat' method control programme was also made to be part of the general health service of the respective regions and contact and cooperation of the control programme and the regional office was stressed as one of the basis for success.

The method of seek and treat had been most highly developed in the central highlands. (Begemder, Gojjam, Wollo) under the control

of a leprosy supervisory team, but smaller and similar areas were controlled by ALERT (example, Debre Berhan) and by the provincial medical offices (Wollega).

In the central highlands the number of patients registered up to December 1968 were 8063 with a regular attendance of 75%.

Other areas with specialized mobile units (Wollega, Debre Berhan, Harar and parts of Wollo) had a high number of patients registered with a maximum regular attendance of 65% and a minimum attendance of 36% (51).

Due to the success of this method in 1970, the MOH approved a policy of leprosy control for the whole country, based on a system of market clinics.

The leprosy control project of the Medical Services Division of the MOH was established in order to co-ordinate the work of all agencies engaged in leprosy control.

The policy document of the MOH stated the general principles of control as follows:-

1. Areas of low prevalence will be served by the existing health services
2. Resources are concentrated in areas of high prevalence
3. These areas are served by specially developed services, related to the General Health Services.
4. The method depends on regular treatment posts in all market places in the area, served by mobile health aids.

- * 6. The work of philanthropic organizations is incorporated to the general programs.
- 7. Supervision and coordination in provinces with low prevalence is done by the provincial medical officer of health.
- 8. Co-ordination in provinces with high prevalence, (Begemdir, Wollo, Wellega, Gojjam, Shoa, Harar) is assured by a provincial leprosy control officer, attached to the provincial health department.
- 10. Responsibility for all leprosy matters is assigned to the chief of the leprosy control project, at the MOH.

One year later (1972) the number of patients registered for treatment in the basic health services was much lower in all provinces when compared to those registered in leprosy control project of the MOH and other voluntary agencies like missions and ALERT. In 1972 out of the reported 48,352 registered patients only 2792 were registered in the basic health services. 16,259 and 29,301 patients were registered by MOH and other voluntary agencies respectively.

The extent of regularity of patients in the BHS was not reported in all provinces; on the other hand the overall regularity of patients registered in the L.C.P and voluntary agencies was 71%.

During this period, as the figures showed, the establishment of ALERT contributed a lot for those areas (Addis Ababa and Northern Shoa) the organization took responsibility. There were

4,830 registered in Addis Ababa and 4,1193 patients in the rural areas with regularity of 74% and 64% respectively.

When commenting upon the failures of the integration program of the 1960's, Price said that "... integration has many advantages of centralizing the work with economy, in personnel and material. It also helps (in theory, at least) to break down prejudice. But it is useful to recall that there can be a wide gap between the plans of administration and the realities of the local situation"(60).

In the early 1970's two strategies of control were proposed.

1. "Semi-Integration"

" In areas where there isn't total opposition to the treatment of leprosy in general clinics, but, where the existing personnel are not willing to undertake the work which they consider additional, it has been found acceptable to place a specialized leprosy aide at that health unit, on market days in order to hold a leprosy clinic. Under the conditions, the Health Aid remains part of the leprosy control project and not of the Health Unit.

2. **Total Integration**

Leprosy control is considered totally integrated when the responsible personnel (Health Officer) of the unit accepts responsibility for the leprosy health aid, for the mobile service which they ensure and the supervision of the workers" (60).

In 1978 the Ministry of Health issued directing principles concerning the policy of gradual integration of leprosy control activities into the Basic Health Services with the objectives of

- increasing coverage.
- improving quality of services offered, and
- reducing the prevalence and incidence rates of the disease (54).

To accomplish these objectives a health assistants' school was established at the Shashemane Hospital to upgrade the existing leprosy health workers to become Health Assistants. The graduates were assigned to different health facilities to do general health service with emphasis on leprosy (54).

In areas with low prevalence leprosy control was carried out by the General Health services of the regional medical offices in coordination with the National Leprosy Control Program.

In moderate and high prevalence areas control program was mainly done by a leprosy health assistant who was a staff member of the General Health Services.

In Ethiopia from 1978 to 1982 the highest prevalence was recorded in the year 1981 with overall prevalence of 2.7 per thousand. In this same period the highest number of patients registered was in 1982 and the number was 84,627 patients (43).

After the WHO recommendations had been published in May 1982 (63) the National leprosy control programme and ALERT produced the first draft manual for the implementation of Multiple Drug Therapy (MDT) in Ethiopia (54,64).

4. 1983 - to Present

According to the WHO classification, depending on leprosy endemicity and leprosy control, Ethiopia is included among the countries in level IIB, where medium endemicity is found and the coverage of MDT is less than 75% of registered cases (4).

It is estimated that there are almost 120,000 patients throughout the country and that the disease is spread unevenly (43). The highland areas are highly affected where in some parts prevalence upto 7 per thousand have been reported(65).

The country has three distinct areas according to prevalence rates: low prevalence (1 or less per thousand), moderate prevalence (2-4 per thousand) and high prevalence (5 or more per thousand) (43). At present there are 31,753 registered cases and the overall prevalence rate is 0.7 per thousand population for Ethiopia as a whole and case detection rate is 1.1 per ten thousand population(4).

After the National Leprosy Control Programm's workshop, in December 1982, five pilot areas were selected for the application of the recommended dosages of MDT. After the leprosy workers were given retraining (37) the programme of MDT was launched in the five selected areas in 1983. The areas were in Bichena (Gojjam) in nine clinics in Hararge, in Shashemene (Shoa), at Gambo (Arsi) and at Debre Berhan (Shoa) (54).

In March 1984 implementation of the MDT programme started in Sidama (Sidamo) Menagesha (Shoa). In that year out of the total of 12,361 patients under MDT 2627 (21%) completed their treatment

and were released (43). These areas including Addis Ababa and Yererere and Kereyu Distracts are the first areas where the procedures described in the " Manual for Implementation of MDT in Ethiopia" got started. (43,66).

The programme in Addis Ababa area, which was started in March 1984, included 47 centers. 1500 patients started MDT and in that year the compliance of the patients in all clinics was reported to be above 90%(65).

In Ethiopia five years after the MDT programme was started the prevalence has been reduced to 75% of the previous total and in 1990 the total MDT coverage was reported to include 54% known cases (4).

In 1984, after MDT started , " 10,521 (13%) leprosy patients were fully integrated in 134 treatment centers: while 48,732 (60%) were partially integrated in 407 treatment centers. And 27% (21,674) patients were said to get their treatment in 282 specialized leprosy clinics" (54).

In the same document for the implementation of integration the following points were suggested:-

- continuous training for all health workers about leprosy.
- Health education about leprosy for the public.

But five years after MDT began, in spite of the efforts of the NLCP for integration, in 1988 there were only 5881 patients fully integrated into the 90 treatment centers, while 45,177 were partially integrated in 282 treatment centers.

Again in 1988, suggestions were made that better knowledge of leprosy and its control on the part of the general population is clearly needed. The message also stressed that without the consent and assistance of patients, and patients' education in both medical and social aspects of leprosy and in the presence of many staff of the general health Services who still consider leprosy "a disease apart" the NLCP can't meet its goals (54).

OBJECTIVES

General Objectives

To review the historical patterns and trends of social stigma and prejudice regarding leprosy over a period of 35 years in relation to policy and programme issues in integrating leprosy control programme into the general health system.

Specific Objectives

1. To examine the history of 20 leprosy patients' medical, social and personal life since diagnosis.
2. To describe social factors which facilitate or constrain the integration of leprosy control programme into the general health system.
3. To learn the attitudes beliefs knowledge, and behaviour of 6 general health workers, 6 leprosy health workers in ALERT, 8 religious leaders, 5 high school teachers and 5 high school students, four non leprosy patients towards leprosy and to identify areas of rejection or acceptance of integration of leprosy control programme.
4. To understand the different leprosy control programmes and the policies of integration and how these might have affected social perceptions of leprosy in the past 35 years.

Study's Relevance and Utility

- a) It enables the leprosy control programme to gain insights into attitudes, beliefs, knowledge and behaviours of the target population in order to make relevant decisions.

- b) To delineate some of the areas in which policies and programmes might be formed so as to positively assist the control programme.
- c) To see this public health problem from the leprosy patients' and the public's points of view and to give the control programme certain concrete ideas how the leprosy patients and the public want to solve problems of leprosy.
- d) To bring out certain important practical implications for the future by seeing the past.
- e) Due to leprosy's similarity with AIDS regarding social perception, the study may give some ideas in handling the social problems of AIDS

Materials and Methods

The purpose of this study is to review the historical patterns and trends of social stigma and prejudice regarding leprosy over a period of 35 years by comparing the knowledge, attitude and behaviour of non-leprosy respondents and the medical, social and personal life and knowledge and attitude of leprosy patients before and after 1983, when Multiple Drug Treatment started in Ethiopia. The reasons for taking MDT as a demarcating period were:

1. Due to the ease of finding patients who were still taking treatment after starting treatment in the mono-therapy period.
2. MDT was widely accepted and it is said to be helpful for integration of leprosy control programme into the General Health Service and in decreasing the stigma attached to leprosy.

A total of 54 respondents were interviewed in the first three and half months of the study period. The respondents consisted of 20 leprosy patients, 10 patients diagnosed before December 1982, and 10 patients after January 1983, 8 religious leaders (two from each of the four religions considered to be the main religions who have large number of followers; namely, Orthodox Christian, Muslim, Catholic and Protestant;) 6 health workers at ALERT, 6 General Health workers, 5 High School students, 5 high school teachers and four non-leprosy patients.

The two groups, the pre-MDT and the Post - MDT, were made to have 27 respondents in each group with comparable numbers of respondents in each category.

Selection of Respondents - Enrollment

From the source population all the respondents were selected by judgement and expert sampling.

Before the selection of leprosy patients started, discussions were held with responsible individuals at ALERT and in particular with the supervisor of leprosy clinics of Addis Ababa and leprosy health workers responsible for the different clinics about the objectives of the study.

Because of the monthly schedule of the leprosy clinics it was not possible to get all the respondents from Tekle Haimanot Health center.

For the purpose of increasing the response rate and decreasing the drop out rates, selection of patients was mainly done by the Leprosy Health workers and the patients' ability to express their views was taken as a criterion to select the leprosy patients for interview.

After selection patients were individually briefed about the study by the principal investigator and the leprosy health workers and after obtaining informed consent the date and place of the interview was arranged between the principal investigator and the leprosy patient.

Among the 20 leprosy patients, 17 were outpatients who were taking their medications at the time of the study and three were

patients who had been released from treatment. 10 patients were from Tekle Haimanot Health center, 2 from Gulele Clinic, 3 from Arada Clinic, 2 from Kazanchis Clinic and 3 were from ALERT. Selection of patients from the different Clinics was dependant on the availability of patients fulfilling the criteria.

After discussion about the purpose of the study with the heads of the different churches and the only mosque in the Awraja and the Catholic church in the neighbouring Awraja, (there is no Catholic church in the Awraja) respondents were selected, two from each, based on the criteria given to them by the principal investigator. Heads of the Orthodox Church and the head of the Mosque presented themselves as volunteers while the Protestant and the Catholic churches' Heads selected other respondents. All the respondents were at first informed individually about the purpose of the study and the date and place of interview was arranged after they gave their informed consent.

Because of the school administration (Kefteгна 4 High School) change of opening new classes for grade 11 and 12 students, High School teachers and students were selected from Tikur Anbessa High school which is found in the adjacent Arada Awraja. After discussing the purpose of the study with the director of the school, the selection of students from grade 12 was conducted through the Unit Leader of grade 12. All grade 12 students were told about the purpose of the study and among those presented to be interviewed voluntarily two females and three males were selected by the Unit Leader and the principal investigator. The selected

students were briefed about the purpose of the date study and the time and date of the interviews were settled by themselves.

Respondents were selected among the grade 12 teachers by discussing with individual teachers at different times and finally five teachers were selected, one from the different departments of the school. All the teachers selected had started to teach before 1983 G.C.

The non-leprosy patients were selected from the patients who were waiting at an outpatient department of the Tekle Haimanot Health Center for treatment the early morning hours.

The four non-leprosy patients were selected on different days and when the selected ones had agreed to be interviewed after being told about the purpose of the study, the interviews were conducted on the same morning. All the respondents were non-leprosy patients who came for minor complaints (as defined by the patients themselves) and antenatal care in one case. To decrease the patients' suspicion of why being elected for this "Leprosy" interview the interview was conducted before having their examination (this was also decided when they agreed to do so) and before the interview the patient were told that they were not selected for any other reason except fulfilling the criteria like age, sex and not being seriously ill.

The six general health workers who participated in this study were all from the Tekle Haimanot Health Center. After considering the sex, age and time of graduation of the health workers, selection was made by the Awraja Health Manager, the Head Nurse and

the principal investigator. All the health workers were told about the purpose of the study and their consent to participate in the study obtained a day before the planned day of the interview in order to minimize the discussion among the health workers, as all are from the same health center.

Selection of the respondents among the Health workers at ALERT was mainly done by the leprosy control supervisor of Addis Ababa and the respondents included those who were employed as leprosy health workers and those who were assigned to ALERT after working in other Health institutions. Like the General Health workers, respondents were asked to participate in the study on an individual basis a day before of the planned interview day. Among the Health workers at ALERT one Health worker who was a leprosy patient was selected for the interview.

Pre - Testing:- Before the study the prepared English question formats were translated into Amharic by three people and were translated back to English in order to avoid ambiguity and to have reliability. Pretesting was conducted in a population assumed to represent the study population and as a result some phrases and questions were dropped and some questions were added in the question formats.

The question formats were generally prepared to focus on knowledge, attitude and practice of the respondents on leprosy and to evoke the medical history and social experiences of leprosy patients after diagnosis.

All the interviews were conducted at the date and time set by the respondents and in places where the respondents felt at ease to talk. Except for two leprosy patients who were willing to be interviewed in the presence of their family members, all interviews were held in private settings with the principal investigator and the project coordinator.

Three leprosy patients agreed to be interviewed at home and one of them refused to be interviewed in the presence of her neighbours. The interview was conducted at a later date at her home in private. Ten patients were interviewed at Tekle Haimanot health center and 2 patients at the Arada Clinic and 3 patients at the Gulele Clinic. Two patients were interviewed in the backyard of Gola Michael church very late in the afternoon when they considered it to be deserted.

Some of the leprosy patients were constantly in need of encouragement and comforting due to their depressed moods. Almost all the leprosy patients needed extensive probing and time to discuss their experience without denial or repression of their emotions and feelings.

The interview covered illness beliefs of the leprosy patients concerning etiology, mode of transmission, health seeking practices and the patients medical and social life after illness and their previous expectation and evaluations of their treatment outcome and future expectations. All the formats of the other categories contained questions concerning the knowledge, attitudes, beliefs and practices of the respondents towards leprosy.

Interviews with the religious leaders, high school teachers, general health workers, and leprosy health workers were conducted in their respective working places on the date and time the respondents chose. The high school students and the non-leprosy patients were interviewed at Tekle Haimanot Health center.

Before the interview a prepared one page paper about the purpose of the study was read and all the respondents were assured of anonymity. All interviews were started after the respondents agreed to be interviewed and tape recorded.

Data Collection:- All the interviews were held in private setting and the interviews lasted between 45 minutes and 120 minutes. The questions progressed in a conversational tone and questions were forwarded from general to specific and from easy to difficult. Because the questions were open-ended and the respondents were given the opportunity to do most of the talking, the wording and sequence of questions were adjusted to meet the needs of the circumstance and to go with the emotions and moods of the respondents.

Following the main focus of the study, the respondents were asked at appropriate times of the interview about socio-demographic aspects, family history and to tell a story they knew about the life of a leprosy patient. Each respondent was asked to define terms he or she used to define illness concepts and treatments and was invited to suggest about his/her feeling at the end of the interview. Each respondent was also given the address and telephone number of the investigator to call back and discuss

again. Two respondents, one student and one religious leader called back.

Twelve respondents, out of whom were nine leprosy patients, one religious leader and two high school teachers were interviewed a second time. Many respondents were asked some questions which were not clear during the interview wherever there was an opportunity to meet them.

All the interviews were conducted by the principal investigator and all interviews were tape recorded. One additional written commentary was submitted by a Catholic priest.

All the tape-recorded interviews were listened to by the principal investigator and the project coordinator with the aim of improving the quality of the subsequent interviews.

Because of the repeated mistakes seen in typewritten transcriptions, the tape-recorded interviews were written by hand in Amharic. Then transcriptions were then translated into English. After repeated interviews and transcriptions the commonly used words, phrases and other expressions were given standard and equivalent English words or phrases to maintain the quality, reliability and consistency of the Amharic expressions when translated into English. All the translations were made by the principal investigator.

The literature review on the history of the leprosy control programme of Ethiopia, was done from materials available at ALERT, the National Leprosy control programme, the Institute of Ethiopian studies and the J.F Kennedy Library.

Data Analysis:- After the interviews were completed and translations were done, common factors and questions were selected for each category and these questions in turn were selected and arranged in such a form to represent:

1) The leprosy patients' medical, social and personal life and their knowledge and attitudes towards leprosy.

2) The different categories '(other than the leprosy patients, all are represented as non-leprosy respondents) knowledge and their attitudes and behaviour towards leprosy.

Due to the problem of overlap, particularly the questions regarding non-leprosy respondents behaviour and attitude, the results of the study on the non leprosy respondents were presented in two sections: knowledge in one part, and attitude and behaviour mixed in the other part.

Leprosy patients responses are presented in the same way except for additional medical, social and personal aspects of their lives.

All the responses were analyzed by comparing the responses of the pre-MDT group with the responses of the post-MDT group. Simple quantification of responses were made to clarify some important issues. Otherwise the analysis was made solely on descriptive and explorative style in order to meet the purpose of this qualitative study and to generate further hypothesis or study areas for further research.

RESULTS**Part I**

Out of the 20 indepth interviews conducted, six abstracted case studies are presented below. The major information included are the social, medical and personal histories of the leprosy patients. The purpose of presenting these case studies is to reflect the emotions felt by the patients, the impact on their lives and what the diagnosis of leprosy meant to the patients.

Sociological Background

I.D. No Lp 1	Sex. Male	Age 61
Birth place	Jiru (North Shoa)	
Present residence	Addis Ababa	
Marital status	Divorced (twice)	
Number of children	Two	
Ethnicity	Amhara	
Level of education	Read and write	
Occupation	Priest	

Medical Background

Year of diagnosis	1965
Type of leprosy	Lepromatous leprosy
Treatment received	Rifampicin, DDS (Dapsone), clofazimine
Current status	On treatment
Handicaps present	Severe absorption of fingers and toes
Attendance at treatment session	Defaulter for 13 years Currently regular attendant

- question:- How did you know you had leprosy?
- answer:- My problem started in 1963. First I saw black and red patches and when I showed the patches to people they told me that it was a skin disease.
- question:- Did you know that it was leprosy?
- answer:- Yes, from the very beginning I knew that it was leprosy and for fear of other people's reactions I left my home town and came to Addis Ababa.
- question:- When did you start to take treatment?
- answer:- November, 1965
- Question:- Why did you stay for two years?
- Answer:- Because I preferred to see if my skin problem would disappear by itself.
- question:- To whom did you tell about your illness?
- Answer:- I never told anyone. When I knew it was leprosy I just left my wife and parents and came to Addis Ababa and remained here.
- question:- Did you return back to your home town?
- answers:- I only went once in the last 29 years
- question:- Why?
- answer:- Why should I go when I was rejected even by my wife, brothers and sisters
- question:- What were your feelings when you knew you had leprosy?
- answer:- I felt very much anger and I felt sorry for myself. I don't have words to tell what I felt. What can I

say? I don't have words to describe it. Once a person gets it he has no hope and I don't have any hope. I am hopeless. Let us continue to the next question.

question:- Were you married again?

answer:- Yes. After I got two children my second wife left me and the children behind and got a divorce.

question:- Why?

answer:- Because from other people she learned that I was a "Komata". I had no courage to tell her about my illness before our marriage. I never saw her eyes again.

question:- What kind of relationship do you have with your children?

answer:- They are ashamed of being the offspring of a leprosy patients. They don't help me and they don't know the feeling of being a father because they have no children.

question:- What kind of relationship do you have with the other priests?

answer:- I don't know what they feel inside but no one has insulted me. I am not allowed to lead a prayer or become a "Nefes Abate" (soul father). I always eat alone and have a separate dining place.

question:- Why?

- answer:- If somebody becomes 'below other human beings', how could he ask to be equal with others including your family.
- question:- What is the cause of leprosy?
- answer:- Some people might think it is hereditary, or caused by evil spirits, but it is due to Christ's judgment.
- question:- Is leprosy curable?
- answer:- Yes, if God wills.
- question:- Did you try traditional medicine?
- answer:- Never. Even Holy Water doesn't help for leprosy
- question:- How is leprosy transmitted?
- answer:- It is not a transmittable disease like Gonorrhoea or syphilis.
- question:- Is leprosy different from other disease?
- answer:- Yes. It is very disgusting and deprives the patient from any advantage in life .
- question:- Is leprosy worse than TB or AIDS?
- answer:- Leprosy is the worst disease. It makes a person a beggar and prevents from having marriage.

Sociological Characteristics

I.D. No LP6	Sex Male	Age 64
Birth Place	Jimma	
Present residence	Addis Ababa	
Marital Status	Married	
Number of Children	Six	
Ethnicity	Oromo	
Religion	Muslim	
Occupation	Teacher of the Koran	
Level of Education	Read and Write	

Medical Background

Year of Diagnosis	1981
Case finding	Self reporting
Type of leprosy	Borderline Tuberculoid
Treatment received	DDS (Dapsone), Rifampicin, clofazimine
Current status	On treatment
Handicaps present	No ulcer or deformity
Attendance at treatment session	Regular

- question:- How did you know you had leprosy?
- answer:- I had loss of sensation on my hands and feet and a traditional healer told me my illness was leprosy and advised me to go to Zenebwork Hospital.
- question:- Did he give you any treatment?
- answer:- No. He strongly advised me to go.
- question:- What was your reaction when you told about your illness?
- answer:- I asked him how I could have leprosy when I came from a clean family. He told me leprosy is not hereditary but is caused by evil spirits.
- question:- When did you go to Zenebwork Hospital?
- answer:- I was not convinced and went to Saudi Arabia seeking other treatment. I went to Zenebwork after 5 years when I exhausted all possible treatment
- question:- Did you find a solution when you went to ALERT?
- answer:- Yes. Yes. My health is returning.
- question:- To whom did you tell about your illness?
- answer:- I only told my wife. She advised me to take my medication and I took her to Zenebework for examination.
- question:- Why did you hide it from your children and other people?
- answer:- What good can one bring by just talking about ones disease. Once you have an illness you don't have to tell anybody.

- question:- Would you do the same if it were another disease?
- answer:- No, I wouldn't. But people hate leprosy and it is a bad disease.
- question:- What is the cause of leprosy?
- answer:- Evil spirits.
- question:- How did you get it?
- answer:- How can I know. My father and mother were clean.
- question:- Is leprosy curable?
- answer:- If one takes the drugs it is curable.
- question:- How is leprosy transmitted?
- answer:- Through flies.
- question:- what is the cause of deformity?
- answer:- Not taking treatment.
- question:- Is leprosy different from other diseases
- answer:- Yes. Other diseases cause pain in the stomach, bones or headache but leprosy only affects the hands and feet.
- question:- Is it worse than TB or AIDS?
- answer:- No, it is not.
- question:- What would you advise me if I want to marry a leprosy patient?
- answer:- You shouldn't have to. People will hate you.
- question:- What does the Holy Koran say about leprosy?
- answer:- I don't know.
- question:- What do you think about the future?
- answer:- I will pray not to be deformed.

Sociological Background

I.D. No Lp9	Sex male	Age 29
Birth place	Addis Ababa	
Present residence	Debre Zeite (refused to take treatment in Debre Zeite for fear of being known as a leprosy patient and was taking treatment in Addis Ababa).	
Marital status	Single	
Ethnicity	Amhara	
Religion	Orthodox Christian	
Occupation	Policeman	
Level of education	Completed grade 9 (discontinue education due to illness).	

Medical Background

Year of diagnosis	1980
Type of leprosy	Released from treatment (RFT) in 1991
Handicaps present	No ulcer or deformity.
Attendance at treatment sessions	Regular throughout.

question:- How did you go to Zenebework?

answer:- I had a patch on my right calf and my family thought that it was due to spider's urine and gave me many kinds of "Habesha Medhanit" (traditional Ethiopian Medicine)

question:- What kind?

answer:- I can't remember the name, but I was treated with different kinds of leaves. Day after day the patch got larger and another patch appeared on my ear. Then our neighbour advised my family to take me to Zenebework.

question:- When was that?

answer:- It was in 1980 I was advised to go to ALERT on that some year.

question:- When did you go to ALERT?

answer:- I spent no time, I went immediately. I was admitted for 8 months.

question:- Was there anyone who knew about your admission at ALERT

answer:- No one knew.

question:- Your family?

answer:- All of them know about my disease. No one knows outside my family and we hide it from everybody. At the time of my admission they told everyone that I had gone to Jimma.

- question:- Why did you do that?
- answer:- In our home we sat together and discussed the importance of keeping my illness a secret amongst us. Even today nobody knows.
- question:- What did you feel when you were told you had leprosy?
- answer:- I was seeing myself begging in the street with all my fingers torn away.
- question:- To whom did you first tell?
- answer:- My mother and my sisters took me to ALERT and they were told at ALERT.
- question:- What were their feelings?
- answer:- They were shocked and they were weeping throughout the day. It looked like a funeral of a close relative.
- question:- Why did they act like this?
- answer:- We had never expected to be told I had such kind of disease. In our culture you can not welcome leprosy as any other disease.
- question:- What do you mean when you say "in our culture"
- answer:- Because leprosy is believed to bring a disgrace to one's bloodline.
- question:- What was your relation with the other patients when you were in ALERT?
- answer:- I passed a very difficult time at ALERT. I was sleeping in the same room with many deformed

patients and I couldn't resist insisting that the workers let me go home.

question:- What is the cause of leprosy?

answer:- Many people say it is hereditary but I proved that it is not correct.

question:- Then how is it transmitted?

answer:- I don't know

question:- Is leprosy curable?

answer:- I am a living proof for its curability.

question:- What is the cause of deformity?

answer:- Not taking the medications regularly.

question:- Do you have the fear of transmitting your disease to your family?

answer:- No. I have no fear at all.

question:- Is leprosy different from other diseases?

answer:- Yes. It makes you weak and you lose your body parts.

question:- Is it worse than other diseases?

answer:- No. It is not.

question:- What about TB?

answer:- TB is worse than leprosy.

question:- What about leprosy?

answer:- Whatever stage it reaches it doesn't kill.

question:- What about AIDS?

answer:- How would you compare AIDS with leprosy? AIDS is a very bad disease.

- question:- Do you think that the other leprosy patients would give me the same answer like you?
- answer:- Yes. I don't think any leprosy patient prefers AIDS to leprosy.
- question:- Why?
- answer:- No one wants or prefers to die due to AIDS. Life with deformity is better than death.
- question:- Why do we usually see leprosy patients beg?
- answer:- They have no tools to work with their fingers.
- question:- You are cured and free from leprosy. Are you willing to teach other patients and the society?
- answer:- Yes.
- question:- Are you willing to encourage other patients to do the same?
- answer:- Yes. I will never turn my back on such type of activity.
- question:- What about your secret with your family?
- answer:- I was a patient. Now I am a normal healthy man and I am not ashamed to tell how and why I got my health back.
- question:- Are you willing to be interviewed through the radio or television?
- answer:- Yes. I will never be ashamed to telling my story.
- question:- What reaction would you expect from your family?
- answer:- There will certainly be an opposition. I don't know.

question:- What does the Bible say about leprosy?

answer:- I don't know.

question:- What would be your advice if I wanted to marry a leprosy patient?

answer:- Tell her to have her medications. You shouldn't have to miss her.

question:- is there anything you can tell me?

answer:- I only want to say one sentence. Please let us teach Ethiopians about leprosy.

Sociological Background

I.D.No Lp11	Sex Male	Age 22
Birth place	Wereillo (North Wello)	
Present Residence	Addis Ababa	
Marital status	Single	
Number of Children	No children	
Ethnicity	Amhara	
Religion	Muslim	
Level of education	Grade 2-8	
Occupation	Policeman	

Medical Background

Year of diagnosis	September 1991		
Type of leprosy	Borderline Tuberculoid		
Treatment received	Dapsone, Rifampicin, clofazimine		
Current status	On treatment		
Handicaps	No ulcer, deformity or contracture		
Attendance at treatment session	Regular		

question:- How did you know you had leprosy?

answer:- In 1989 I started to have a white patch above my left eyebrow and I was given different kinds of injections for two years. After two years I went to ALERT.

Question:- Did you try traditional medicine before going to ALERT?

answer:- NO.

question:- How did you go to ALERT?

answer:- I was referred from the Police Hospital.

question:- What were your feelings when told to go to ALERT?

answer:- I had no knowledge about ALERT and I didn't feel anything.

question:- What were your feelings when you were told of having leprosy?

answer:- I was shocked and very puzzled. I became hopeless.

question:- Why?

answer:- Because I knew that leprosy was hereditary and I couldn't explain how I got it. I was sure of being deformed like the ones I saw in the streets of Addis Ababa.

question:- To whom did you first tell?

answer:- I never disclosed it to anyone. How could I tell of having such a disgusting disease. Why should I invite fear and hate against me? I always take my drugs late at night after my friends go to bed.

- question:- What is the cause of leprosy?
- answer:- To laugh at a "komata".
- question:- Is this the cause of your illness?
- answer:- No I think mine is caused after i was shot on my thigh when we were fighting the "Derg" (previous government). I wish I had died then.
- question:- Why?
- answer:- Death is better than losing one's body and becoming a 'Komata'.
- question:- Is leprosy curable?
- answer:- I don't know. I am not sure.
- question:- What is the cause of deformity?
- answer:- It is the nature of the disease to cause deformity.
- question:- How is leprosy transmitted?
- answer:- It is not a contagious disease and I have no fear of transmitting the disease.
- question:- Is leprosy different from other diseases?
- answer:- Yes. It breaks off body parts.
- question:- Is leprosy worse than TB or AIDS?
- answer:- AIDS is the worst disease. Other than AIDS there is no disease worse than leprosy.
- question:- What would you advise me if I want to marry a leprosy patient?
- answer:- On my part I don't advise you to do such a thing.
- question:- What does the Holy Koran say about leprosy?

answer:- I don't know

question:- What do you think about the future?

answer:- I don't know. Only Allah knows what my future will be.

Sociological Background

I.D.No Lp 17	Sex Female	Age 49
Birth place	Asmara	
Present residence	Addis Ababa	
Marital Status	Married	
Number of Children	Three	
Ethnicity	Tigre	
Religion	Orthodox Christian	
Level of education	Read and Write	
Occupation	House Wife	

Medical Background

Year of Diagnosis	1991
Type of Leprosy	Borderline Tuberculoid
Treatment received	Dapsone, Rifampicin, Clofazimine
Current status	On treatment
Handicaps	No ulcer, deformity or contracture
Attendance at treatment session	Regular

- question:- How did you know you had leprosy?
- answer:- I don't know whether I had leprosy or not. No one told me about it.
- question:- Then why do you take the drugs?
- answer:- I didn't know what kind of illness I had but I suspected and had the fear it might be leprosy.
- question:- Why did you think like that?
- answer:- One day I asked one 'komata' to show me the drugs he was taking and it was the same type of drug like mine.
- question:- How did you react?
- answer:- I was surprised and very shocked. I called and told my daughter what I found. But my daughter couldn't be convinced like me.
- question:- Are you sick now?
- answer:- No. Let alone leprosy I have no headache.
- question:- Then why do you take the drugs?
- answer:- Because I have to do what doctors order me.
- question:- Did you tell this to anyone except your daughter?
- answer:- No.
- question:- What about to your husband?
- answer:- Should I tell him such kind of a thing. I don't mind whether he knows or not. Nothing will happen except divorce.
- question:- You are talking as if you know you have leprosy?
- answer:- I don't know

- question:- Is leprosy a disease that should be handled in secret?
- answer:- No one can hide it once God brings it.
- question:- Then why did you act otherwise?
- answer:- I don't know.
- question:- What is the cause of leprosy?
- answer:- It is a disease of 'lalibellas'; some times the cause is evil spirit.
- question:- Is it curable?
- answer:- Only God knows. But I am bathing with Holy Water.
- question:- How is leprosy transmitted?
- answer:- It is not transmitted.
- question:- Is leprosy different from other disease?
- answer:- It makes "Akale Godolo" (loss of eyes, limbs) and tears off human body it is also "Gabecha Kelkel" (prevents marriage)
- question:- Is leprosy worse than TB or AIDS?
- answer:- Yes. Once you have leprosy and lose your hands you cease to be a human being
- question:- What is the cause of your illness?
- answer:- My illness started after I washed clothes before sunrise
- question:- But you told me that you are feeling healthy?
- answer:- No one in this world can be healthy.
- question:- What would you advise me if I wanted to marry a leprosy patient?

answer:- I don't want to see them; let alone advise you to marry a "Komata"

question:- What does the Bible say about leprosy?

answer:- I don't know.

question:- What do you think about the future?

answer:- Please help me before I break into pieces. It is good if I know what my illness is.

Sociological Background

I.D. No	Lp20	Sex	Female	Age	52
Birth place	Wello				
Present residence	Addis Ababa (around ALERT)				
Marital status	Divorced				
Number of children	No children				
Ethnicity	Amhara				
Level of education	Daily labourer				

Medical background

Year of Diagnosis	1972
Current status	Released from treatment
handicaps	Lost 3 figures of the left hand

question:- How did you know you had leprosy?

answer:- I was told at Zenebework Hospital.

question:- How did you come to Zenebework Hospital?

answer:- Before I came to Zenebework I was married for 15 years and God didn't allow me to have a child. One day when I was going to the Borkena (Wello) river to fetch water I stumbled on a dead black hen which was thrown on the foot path. I was very shocked by the accident and returned back home without fetching the water.

question:- Why did you become shocked?

answer:- A black hen is always thrown by a person who wants to do evil to other people.

question:- Did you suspect some evil then?

answer:- Yes, that was why I returned back home. That night I told my husband about it and he was very angry with me why I couldn't see a big thing like a black hen. When I woke up early the next morning I started to have itching and burning sensation all over my body. After one week my husband took me to one "Awaki" (sort of wizard) and he gave us a lot of green liquid, which was very bitter, to drink before sunrise and before I eat anything and even before I swallow my saliva. I took the liquid for two months and saw no sign of change. Rather, I started to have red and white patches on my back

and right forearm. When the "Awaki's" treatment failed I took Holy Water for one year and got no improvement.

question:- After one year?

answer:- Finally my mother came and told me that my mother - in - law was the one who did this evil to me as a result of me being unable to give a child to my husband. My mother also warned me that unless I left my husband and returned to their (my parents) home my mother - in - law would never allow me to live with my husband.

question:- What did you say about for your mother's advice?

answer:- I agreed with my mother and went home leaving my husband behind. Soon I arrived at my parents home. They took me to another "Awaki" and to our dismay he told us that my illness was "Kumtena".

question:- What did your parents say?

answer:- My father begged the "Awaki" to give him anything if he agreed not to utter a word about my illness to anybody. My father gave the "Awaki" two big oxen and four sheep.

question:- Why did you believe the "Awaki's" interpretation?

answer:- He was a very popular man and there was no disease he couldn't cure.

question:- Did he give you a treatment?

answer:- No. He advised us to go to Dessie and to take

modern medicine.

question:- What were you and your parents' feelings?

answer:- All of us were shocked. My mother and I wept very much. My father, who was a very strong man, told us never to tell anybody about my illness, and he took me to Dessie.

question:- Why?

answer:- It is a very bad disease. If my disease was known none of my sisters, brothers or relatives could have been married. Leprosy is "Gabecha Kelkel".

question:- What about your husband?

answer:- He never heard. If he knew about it he would have considered it as a disgrace to be married with a "Komata Zer" and would go mad.

question:- What did the health workers in Dessie tell you?

answer:- They told me that it was leprosy. It was then that my father felt very bad and angry until he didn't know what he was doing.

question:- Why?

answer:- We had no leprosy in our family, before my mother's and my father's families were clean and he was saying that he should have to kill my mother-in-law who brought this shame to our family.

question:- Then what did you do next?

answer:- My father gave me 115 Birr, returned back home and told me he would come and see me after 10 days.

Three days after he left Dessie. I came to Addis Ababa once and for all. I never returned back to Wello and I don't know whether my parents, brothers, sisters or other relatives of mine are alive or not.

question:- Did you go to Zenebwork then?

answer:- No, I didn't. I just kept quiet and worked as a maid for five years. in the course of these five years the fire started to eat my hands gradually. One day the owner of the house asked me about the wound in my hands and took me to Ras Desta Hospital. The doctor in Ras Desta referred me to Zenebwork. Both the husband and the wife were very shocked when they heard that I was referred to Zenebework. At Zenebework the doctor told us that I was badly injured and had to sleep in the hospital. I was admitted at Zenebework for one year and have already lost 3 of my fingers.

question:- How did you start to live here (around ALERT)?

answer:- I had nowhere to go. No one would hire a "Komata" in those days.

question:- Do people hire a "Komata" these days?

answer:- No. Who likes a "Komata"? No one hires.

question:- Tell me how you started to live there?

- answer:- There was one "ferenji" (foreigner) who introduced me to another woman who was also a leprosy patient and, I started to live with her.
- question:- What is the cause of leprosy?
- answer:- It is hereditary.
- question:- But you told me you had it by "lekifete" (evil spirit)?
- answer:- I don't know.
- question:- Is it curable?
- answer:- The doctors say it is curable.
- question:- What is the cause of deformity?
- answer:- Fire and carrying heavy things.
- question:- How is leprosy transmitted?
- answer:- It is not a transmittable disease.
- question:- Do you have an "Eder", "Ekub" or "Maheber" in which leprosy patients are the only members?
- answer:- Yes, we have a "Maheber" on the day of Gebre Christos.
- question:- There are many saints, why only Gebre Christos?
- answer:- Because the Church is here and he is the one who always pray for us to God.
- question:- Why are only leprosy patients members of your "Mahaber"?
- answer:- Why do we ask people to come; only leprosy patients ask us to join.
- question:- Is leprosy different from other diseases?

answer:- Yes.

question:- Why?

answer:- Because it breaks and tears off our body.

question:- Which one is worse TB or leprosy?

answer:- Leprosy. TB kills you with no suffering. it doesn't cut off your fingers, nose and ears.

question:- What about AIDS?

answer:- AIDS is better.

question:- Why?

answer:- I heard that it kills very fast.

question:- What does the Bible say about leprosy?

answer:- I don't know.

question:- What would you advise me if I wanted to marry a leprosy patient?

answer:- Oh. "Yeseyetan joro Ayesmaw" (may this thing never reach to the ear of Satan!).

question:- Why?

answer:- Once upon a time I was a daughter of a rich man and now no one can recognize me even my mother or father if they are alive. Leprosy did this to me. Please don't do it.

Result

Part II Impact and disease on patient

For the main purpose of comparing the effect of Multiple Drug Therapy (MDT) on the perception of leprosy patients regarding their illness and to wards leprosy patients were divided into two groups: Those diagnosed before December 31, 1982 and those diagnosed after January 1, 1983 and the following findings are presented in such a way. The two groups included 10 (ten) respondents.

The ages of the leprosy patients ranged from 24 to 64. Eleven of the patients were below the age of 40 years which was almost similar between the two groups. Of the 20 leprosy patients interviewed, nine were females. There was a frequent refusal from the female patients to be interviewed and the disappearance of females at the date of the interview after accepting the request to participate in the study was more than the males.

The number of Orthodox Christians was much higher (17) among the leprosy patients and, among the dropouts, there were four Muslims and one Protestant. The ethnicity of the respondents was indicated by the respondents themselves and nine of the respondents were born and grew up in the Shoa administrative region and sixteen of the respondents came from Northern Ethiopia. All except one currently are residents of Addis Ababa.

Six of the respondents were government employees, out of whom two were patients who were diagnosed before 1983. Three were earning their living as daily labourer, two others were low income

business men and two were beggars. The other were one priest and one a Muslim who was teaching the Koran and four housewives (Table 1).

In both groups the first complaints of the patients were very similar except for the complaint of loss of sensation which was not mentioned by the first group.

Descriptions of the appearances of early problems were quite similar in both groups and in seven patients the disease had first been observed in the extremities, in six on the body, in five on the face and in two on the face and arms.

Ten patients, five from each group, associated the appearance of their first problem with circumstantial events like eating meat in the open, and being struck by robbers. Three patients associated their problem with "mitche" (evil sprits) and two patients spoke with certainty that their problems started due to the ill wish of a mother-in-law. One patient was treated by his family who believed his patches were caused by a spider's urine.

Only two patients admitted that they had recognized the disease from the time of its appearance. In one of the two cases, a female patient, the disease was recognized by her parents from the very beginning and she was forced to stay indoors for many years, in order to hide her illness from the neighbourhood, until the time she disappeared from her home. None of the patients in

the second group and the other patients in the first group had the slightest suspicion of leprosy. Almost all patients were answering with a loud voice and a strong "Never" when asked about their awareness of the disease.

Table 1
 General Characteristics of 10 Leprosy Patients Diagnosed Before 1983 and 10 Leprosy Patients Diagnosed after 1983

Characteristics	Diagnosed Before 1983		Diagnosed After 1983	
	NO.	No	Total No	
Age (Years)				
21-30	1	2	3	
31-40	5	3	8	
41-50	0	2	2	
51-60	3	2	5	
61-70	<u>1</u>	<u>1</u>	<u>2</u>	
TOTAL	10	10	20	
Sex				
Male	4	7	11	
Female	<u>6</u>	<u>3</u>	<u>9</u>	
TOTAL	10	10	20	
Religion				
Orthodox Christian	9	8	17	
Muslim	--	2	2	
Protestant	<u>1</u>	<u>--</u>	<u>1</u>	
TOTAL	10	10	20	
Ethnicity				
Amhara	6	3	9	
Oromo	1	3	4	
Tigre	--	3	3	
Gurage	3	--	3	
Dorze	<u>--</u>	<u>1</u>	<u>1</u>	
TOTAL	10	10	20	

Marital Status

	<u>No</u>	<u>No</u>	<u>Total</u>
Married	5	5	10
Divorced	4	--	4
Widowed	1	1	2
Single	<u>--</u>	<u>4</u>	<u>4</u>
TOTAL	10	10	20

Levels of Education

	<u>No</u>	<u>No</u>	<u>Total</u>
Illiterate	2	--	2
Read and Write	6	4	10
Grade 2-8	1	3	4
Grade 9-12	<u>1</u>	<u>3</u>	<u>4</u>
Total	10	10	20

Diagnosis:- As summarized in table 2 the year of diagnosis of leprosy patients in the study ranged from the year 1963 to September 1991 making the composition of the group extended over a 28 year period.

Half of the patients were diagnosed to have leprosy before they reached the age of 30 while one female patient was diagnosed at the age of 10 (Table 3).

The type of leprosy of the individual patients is the classification at the time of the study and doesn't show the initial or the first diagnosis made when the patient first came to treatment (Table 4). Out of the three released patients from treatment one male was released in 1991 and two female patients had been released for more than five years.

Table 2 Year of Diagnosis of 20 Leprosy Patients

Year of Diagnosis	Male No.	Female No.	Total No.
1955 - 1970	2	4	6
1971 - 1982	2	2	4
1983 - 1991	<u>7</u>	<u>3</u>	<u>10</u>
TOTAL	11	9	20

Table 3 Age at the time/year of Diagnosis of 11 male and 9 female Leprosy patients

Age (Yrs)	Male No.	Female No.	Total No.
10 - 20	2	2	4
21 - 30	3	3	6
31 - 40	3	2	5
41 - 50	1	2	3
51 - 60	<u>2</u>	<u>--</u>	<u>2</u>
TOTAL	11	9	20

Table 4 Classification of Twenty Leprosy Patients

Type of Leprosy	Male	Female	Total
Borderline Tuberculoid (BI)	3	3	6
Borderline Lepromatous (BL)	3	2	5
Lepromatous Leprosy (LL)	2	2	4
Released from Treatment (RFT)	1	2	3
Tuberculoid Leprosy (TT)	<u>2</u>	<u>--</u>	<u>2</u>
TOTAL	11	9	20

After the earliest appearance of the disease only two patients came seeking leprosy treatment by themselves, without being advised by another person. Six patients went to a leprosy clinic after being advised by friends, neighbours etc, four were advised by leprosy patients, two by traditional healers and three patients were advised by a doctor, a nurse or a laboratory technician. Only three patients were told by anyone that they had leprosy. Out of these three patients two patients were told of having leprosy by traditional healers.

Only four patients went to a leprosy clinic or to ALERT immediately after they were advised to go. None of the four patients had suspected leprosy, including the patient who was told about the disease by a physician who said that he just went to ALERT not giving a thought about the doctor's impression. Eleven patients who were advised to go stated that they were shocked and upset by the advice and six totally refused to go. Two patients refused to go for the only reason of not to bring a disgrace to their family by going to a "komata" Hospital and one patient quarrelled with the friend who had advised him to go and one patient remembered how he spent the night weeping. The father of one patient gave the traditional healer who suspected leprosy, a bribe not to disclose the secret to other people.

Five patients stated they didn't feel anything when advised to go the ALERT because they knew that leprosy was hereditary and never thought about leprosy.

Even though all patients eventually came by themselves (were self reporting), it took them a long time before starting treatment after they knew about the disease. The time lost in local or popular treatment which was ineffective ranged from 5 months to 8 years (Table 7). One patient was forced to stay indoors by her parents and started treatment only after 3 years. One patient started treatment 5 years after being told about her disease by a leprosy health worker by which time she had already lost 3 of her fingers. Another patient waited for 2 years even though he was certain that he had leprosy.

Almost all patients had very negative emotions when told about the diagnosis, ranging from shouting at the health worker who told them the 'bad' news to attempting suicide. Overall, there was no major difference in either group of patients regarding starting treatment early or experiencing negative emotions when told of the diagnosis.

Local or Popular Leprosy Treatment Attempted

Almost all patients had spent a considerable time before seeking treatment from a leprosy clinic. Half of the patients went to different hospitals and private clinics. Only one patient who went to a private clinic of a physician who was working at ALERT was told of having leprosy. One patient was told he had a skin disease and one was referred to ALERT. One patient went to Saudi Arabia and stayed there for one year going to different hospitals without being diagnosed as a leprosy patient.

All respondents defined traditional medicine as very different from "Holy Water" and the two categories are presented as such. Fourteen patients were bathing or drinking Holy Water by wandering from one church to another, and none of them admitted to seeing a significant change in their illness, before they came to a leprosy clinic. An Orthodox priest, a leprosy patient for the last 20 years, suggested that Holy Water couldn't help leprosy and he admitted not taking Holy Water for his leprosy even once for the last 29 years.

More than half of the patients who went to different hospitals were disappointed by the health workers' inability to diagnose their disease and blamed the health workers for not having adequate knowledge about leprosy. Only three patients didn't seek either traditional treatment or Holy water at all. Two of these patients contracted the disease when they were the age of 10 and 16 and were brought to Addis Ababa soon after they had the manifestations of the disease.

Table 6 What did you do before you went to a leprosy clinic?

Attempt Treatment	Period of Diagnosis		Attempted Treatment	No.
	Before 1983	After 1983		
Holy Water	6		Holy Water	8
Traditional Medicine	2		Traditional	1
Went to "Awaki"	1		went to local "Hakim"	1
Washed body with oil	1		Hot spring	1
Hospitals	1		Hospitals	9

* "Awaki (sort of wizard)

* Some gave multiple responses

* n= 10 N= 20

Table 7 When did you start Leprosy treatment at a leprosy clinic?

Duration (years)	period of Diagnosis		Duration (years)	No.	Total No.
	Before 1983	After 1983			
Less than 1 year	2		Less than 1 year	2	4
1 - 2 years	4		1 - 2	6	10
3 - 4	1		3 - 4	1	2
5 - 6	2		5 - 6	1	3
7 - 8	1		7 - 8	--	1
T o t a l	10			10	20

Nineteen of the twenty patients said that they saw no good future after they heard about their disease (Table 8). Only one patient spoke of telling herself that she wouldn't be deformed as long as she had faith in God. Twelve patients were certain of becoming deformed while eight stated that they become hopeless and thought they would no longer be equal with other people and one patient saw nothing except being a beggar.

Twelve patients never disclosed their illness to anyone and in two cases no one knew except their parents and siblings. Two of the patients disclosed their secret only to their wives. One patient only told her daughter; one patient kept her illness a secret for about 25 years, and, in the case of two patients their secret only became public when they started to have deformities.

All patients who never disclosed their illness declared they have no intention to reveal their illness in the future. More than half of the patients believed that if their illness was known their family members and relatives would not have a chance to get married and their children wouldn't have a friend to play with (Table 9).

Three patients said that they were not sure of having leprosy to tell other people while one patient said he was told to keep his disease a secret at ALERT.

Only one patient, who claimed to have a strong faith in the miracles of Jesus Christ, answered strongly that the disease should not be kept secret and she had informed about her disease to her children, relatives, neighbours and workmates.

Table 8

What were your reactions when you were told of the diagnosis?

Reactions	Period of Diagnosis	
	Before 1983 No.	After 1983 No.
"How? When I have no family history"	9	"How? when I have no family history" 10
Shocking news	5	shocking news 6
Saw the humiliation and the inferiority	3	very puzzled 5
Angry and sad	2	Angry and sad 2
Deep sorrow	2	Extremely bad feeling 2
Saw instant deformity	2	
Prefer Death	1	Prefer death 1
Decided to disappear	1	wanted to disappear 1
Don't know	<u>1</u>	Attempt suicide <u>2</u>
T O T A L	26	29

Many gave multiple answers

Table 9

Why were you afraid to tell?

Reasons	Time of Diagnosis		Total
	Before 1983 No.	After 1983 No.	
Cause disgrace to the family	8	Disgrace to the family 2	10
Fear of being called "Yekomata Zere"	4	Fear of being called "Yekomata Zere" 3	7
Cause divorce	3	Cause divorce 3	6
Prevent Marriage	3	Prevent Marriage 2	5
Why bother the children?	2	Why bother the children 1	3
Not Tellable	1	Not tellable 3	4
T O T A L	21	14	35

* Some gave multiple answers

Table 10

Did you take your family for contact examination?

	Time of Diagnosis		Total No.
	Before 1983 No.	After 1983 No.	
No, I didn't	5	No I didn't 9	14
Yes, I did	5	*Yes, I did 1	6
Total	10	10	20

* Only his wife

As summarized in Table ten patients who didn't take their family for contact examination stated various reasons. About half of the patients admitted doing it purposely in order not to disclose their own illness. Others suggested different reasons like, "I am not told to do so", "I didn't think of its importance" and one patient stated that his children would never agree to go to a leprosy hospital.

Two patients only took their wives to contact examination for fear of transmitting the disease through sexual intercourse. They never considered taking their children.

The three female respondents who took their children for examination were patients who had disappeared from their home town and their illness was known by their neighbourhood.

Only one young male patient, who was from Addis Ababa, took all his siblings and parents soon after being diagnosed to have leprosy. Even though the number of patients who took their family members seems higher in the first group of patients, the circumstances that forced the patients to take their children make the difference very minimal.

Except for the three patients whose illness is public knowledge, all the patients stated that they had no intention of taking their family or their children in the future.

Social Problems of Leprosy Patients:- The various social and personal problems described in Table eleven which showed the unchanged fear and social ostracism surrounding the disease. Three of the patients were forced to leave their birth place and never returned back, while two patients went only one time and one of the patients said he went for a few times. Two of the patients never saw the eyes of their families and relatives for more than 25 years. One patient went only once in 29 years, at the time of his fathers' death.

One of the patients was stranded by her father in order to keep the secret of her illness, so her father could marry another woman. This same man also forced the patient's mother, who

was also a leprosy patient, to leave home and go to Addis Ababa when the patient was a small child.

Two patients were divorced twice as a result of the disease (Table 11). The two patients who got married without telling about their illness to their new spouses were divorced after their spouses heard about them from other people.

None of the patients who had disclosed their illness to their spouses got divorced in either group. Those patients who stated their fear of divorce are patients who hid the disease from their spouses. One patient got married to a woman, whom he had known for seven years, soon after diagnosis without telling her. This man was expecting his first child at the time of the study and he was one of the two patients who admitted contemplating suicide.

All patients in both group who had told their illness to their spouse used very highly coloured expressions like "she is a gold to me" to describe the respect they had for their wives. None of the female patients had disclosed their illness to their husbands. One female patient said that her husband would go mad if he heard about her illness. One female patient who described her husband as "modern" (the patient's word) said that he would throw her away the moment he heard about her illness.

All the five female patients who complained of not being able to be members of "Ekub" or "Maheber" were actually members of 'eder' * with other healthy people. Their reason was stated as "no one will bury us unless we are members of "Eder". Four of the patients had never asked to be a member of an 'Ekub' or 'Maheber' and they themselves believed a social organization which is so small like 'ekub' or 'mahber' is only good when shared among 'equals'. The patients who live around ALERT had their own Mahber, on the day of St. Gebre christos (patron saint of leprosy patients) and the patients expressed their unwillingness to accept a non-leprosy person as a member. One of the five patients stated the same views which was expressed by nine patients, "I don't like and am not in the habit of having close social relations with neighbours or relatives."

One female leprosy patient blamed her fate and the disease which made her a wife of a leprosy patient when asked the impact of the disease on her life. After being divorced from her first husband due to her illness, this woman got married to a leprosy patient.

The two beggars strongly condemned the society's perceptions towards leprosy which caused them to be beggars. Both patients stated that no one wanted to hire them and they had no choice except begging.

The impact of the disease on both groups is quite similar. Patients in the second group were living with their secrets and no divorces were reported except the fear of being known which may cause divorce. In the first group all the four patients (one male, three females) had disappeared the moment they heard the disease. Two patients become beggars due to loss of their jobs, in the first group, while patients in the post MDT group were living with their fears of losing their job.

* "Eder" is a bigger social organization with a large number of members than either "Ekub" or "Mahber"

Table 11 What is the impact of the disease on your life?

Impact	Period of Diagnosis	
	Before 1983 No.	After 1983 No.
Forced to leave birth place and didn't want to return birth place	7	fear of being known & lack of peace mind 10
Rejected by family	5	Fear of divorce 4
couldn't be member of "Ekub" or "maheber" with other "healthy" people	5	Fear of loss of job 2
Divorce	4	Fear of loss of job 2
Fear of being known and lack of peace of mind	2	Contemplating suicide 1
Became beggar	2	Didn't want to return
Total	24	19

* Some gave multiple answers

Knowledge

Unlike the non-leprosy respondents, none of the leprosy patients implicated 'sexual misbehaviour or sin as causes of leprosy (Table 12). However several believed that leprosy was caused by evil spirits were associated with using water or food kept uncovered during the night, walking on 'Attela' (sediment of Tella' local beer) or ash at mid day, sleeping in the forest and falling on the ground and bleed. 'Gini' was mentioned by two Muslim patients in causing leprosy. Three patients who mentioned hereditary associated it with only "Lalibella" and one post 1983 patient said that all children of patients would certainly have leprosy after the age of twenty.

Contrary to what they had mentioned none of the patients had made any association with the causes they stated and cause of their illness (Table 13). Five associated their illness with evil wishes of other people, in two cases they blamed their mothers-in-law.

Even though many of the respondents expressed their suspicion in the diagnosis, complete denial of having leprosy was seen in three patients in the post 1983 group.

Seven patients said that leprosy could be transmissible directly from one person to another (Table 14) while eighteen stated that they had no fear of transmitting the disease to their family. "Never" was the immediate response of many respondents when asked "is leprosy contagious?". Two elderly women patients in the pre-1983 group admitted that in spite of believing it to be non-contagious the fear prevented them from breast feeding and sleeping together with their children.

Only three respondents, two pre-1983 and one of post 1983, patients believed leprosy to be cured by medical treatment and five expressed their desire to continue the treatment even if it would certainly bore them (Table 16). More than half the patients were taking Holy water along with their drugs during the time of the study. The perceptions of cause, and curability were related with a pessimistic expectation of the future in both groups.

Table 12 What is the cause of leprosy?

	Time of Diagnosis		Total
	Before 1983	After 1983	
<u>Causes of Leprosy</u>	No.	No.	No.
-Evil spirit	5	6	11
-Hereditary	3	5	8
- " Mitche"	2	1	3
- Showing contempt for a leprosy patient	2	1	3
- God's will	1	2	3
- Satan	1	--	1
- poverty	1	--	1
- "yesewe Afe" (when somebody talks about one's good deeds)	1	--	1
- If one is ill wisher	--	1	1
- Germ	--	1	1
Total	16	17	33

* Some gave multiple answers

Table 13 What do you think is the cause of your illness?

	No.		No.
I don't know	4	I don't know	5
'Mitche' due to birth	2	'Mitche'	1
washed with river water	1	when washing early in the morning	1
'Mitche' when I cook wot or red hen	1	Bullet wound	
walk on a black dead hen	1	may be a curse	1
After robbers struck	1	after a stone struck my ankle	1
Total	10	Total	10

Table 14 Is leprosy transmissible?

	Time of Diagnosis		Total No.
	Before 1983 No.	After 1983 No.	
No	7	6	13
Yes	3	4	7
Total	10	10	20

Table 15
How is leprosy transmitted?
n=7

	Time of Diagnosis		Total No.
	Before 1983 No.	After 1983 No.	
-Breast milk	1	1	2
-sweat	1	---	1
-contact with Ulcerated wound	1	---	1
-Through flies from ulcerated wound	--	2	2
-prolonged sexual contact	--	1	1
Total	3	4	7

Table 16 What are your feelings towards the prolonged treatment

	Time of diagnosis		
	Before 1983	After 1983	
	No.	No.	
Boring	8	Boring	1
praying is most important	2	no choice	2
I won't discontinue	2	Hope it will cure	3
Not cure all patient	1	Improvement very slowly	2
Only prevents deformity	1	Dislike very much	2
Total	14		10

* Some gave multiple answers

Table 17 What do you think about the future?

	No.	No.	Total No.
Fear of deformity	4	4	8
Fear of being known and "my children will not be married"	2	5	7
God will decide it	4	1	5
Have no hope of cure	--	3	3
Total	10	*13	23

* Some gave multiple answers

Eight patients in each group stated that they had no knowledge for how long should they take their treatment and no one had told them about the duration. They also denied having any health education session concerning leprosy.

Even though fourteen respondents identified cause of deformity to be related with loss of sensation and injury, only six said that treatment irregularity or lack of care to be the possible cause of deformity. A great deal of similarity was seen in the doubt regarding deformity, curability with future expectations and therapeutic outcome in both groups (Table 17).

All the respondents answered that they were unable to identify a leprosy patient even if they saw certain signs. None reported to have a family member who had contracted the disease after they had it.

The above findings suggested that even the patients who were taking their medications for more than two decades shared the same view as patients diagnosed in the last one year.

Seventeen patients stated leprosy is very different from any other disease for the sole reason of causing deformity. Sixteen patients also considered it worse than TB or AIDS (Table 18). "Leprosy prevents marriage", "It is a disgrace to family" and "It doesn't kill fast" were the frequently mentioned reasons for defending their views. Despite admitting that leprosy could cause less suffering than TB or AIDS, six respondents preferred death to their family's disgrace or to being called "yekomata zer".

All of the patients described the leprosy health workers as good, knowledgeable and kind, and about nine stated their preference to go to ALERT for any complaints and eleven said that they wouldn't go anywhere other than ALERT for their complaints. Most of them explained that going to other hospitals would expose their secret. One woman who has taken her treatment for about two decades said that, "unless Zenebe Work Hospital is destroyed we can't hide our secret" and refused to go to ALERT for any reason.

Table 18

Which one is worse? Leprosy, TB, AIDS?

	Time of Diagnosis		Total No.
	Before 1983 No.	After 1983 No.	
Leprosy is worse than TB or AIDS	4	5	9
Leprosy is worse than TB not AIDS	3	3	6
Both are worse than leprosy	2	2	4
Leprosy is worse than AIDS but not TB	1	--	1
Total	10	10	20

Table 19 What are your feeling towards general health workers?

	No.		No.	Total No.
Very good	4	Extremely good	2	6
"I heard that They are good"	2	Good	2	4
"Always tell us to go to ALERT"	1	Good for non deformed patients	2	3
Discriminate	1	Discriminate	--	1
Not good	1	Not good, have fear	1	2
Don't know about Leprosy	1	Don't know about leprosy	3	4
Total	10		10	20

Table 20 What is the cause of deformity?

	Period of Diagnosis		Total
	Before 1983	After 1983	
Irregularity of treatment	No. 3	No. 4	7
Loss of sensation	No. 3	Nature of disease 2	5
Fire	No. 2	0	2
God's will	No. 1	3	4
When the disease is hereditary	No. 1	1	2
Total	10	10	20

Table 21 Do all patients get deformed?

	No.	No.	Total No.
-Don't know	4	2	6
-Yes unless take treatment	2	0	2
-Yes unless take care	2	0	2
-God's will	1	5	6
-No	1	1	2
-Yes	0	2	2
Total	10	10	20

One woman stressed her wish of being treated in any place other than ALERT and a clinic near to her home (at the time of the study, for fear of being known, this woman who kept her secret for 20 years was taking her monthly drugs from a clinic about 15 Kms away from her home). Discrimination against leprosy patients and fear of leprosy by the general health workers was only stated by three patients while two commented on the general health workers lack of knowledge about leprosy (Table 19).

Almost all patients regarded leprosy as one of the important health problems in Ethiopia. Remarkable similarity of reason why leprosy was considered as important was seen in both groups that stated "hate" of people towards leprosy patients. Teaching of the society about leprosy was the most frequent response and recommendation for the question "what should be done?"

The respondents were asked what their advice would be if the interviewer wanted to marry a leprosy patient; sixteen opposed the idea and their main reasons were "leprosy will make you and your children unequal among "health people" and "you will be rejected by your family and society". One patient immediately responded by saying "yeseytan Joro Ayesma" meaning "may this thing never reach to the ears of satan" and strongly opposed the idea by claiming that leprosy was the cause that displaced her from her home town where she was a respected married woman and the daughter of a very rich man.

Leprosy and the Bible or the Koran were associated by none of the patients including the Orthodox priest and the patient who was teaching Koran at a mosque. All answers were stated either as "I don't know" or the Bible or the Koran says help the poor and the sick and those who have no hands or feet".

RESULTS -NON - LEPROSY RESPONDENTS**Part III**

A total of 34 non-leprosy respondents, consisting of 8 religious leaders, 6 General health workers, 6 health workers at ALERT, 5 High school Teachers, 5 High School Students and 4 non-leprosy patients were interviewed.

For the purpose of comparing the perception towards leprosy before and after the Multiple Drug Treatment (MDT) the respondents were grouped into two groups. The four religious leaders and the two non-leprosy patients aged fifty or above, three general health workers and three health workers at ALERT who graduated before December 31, 1982 and the five high school teachers were considered to represent the pre-MDT period. The post - MDT period was represented by the four religious leaders and the two non leprosy patients who were 40 years old or less, three general and three health workers at ALERT graduated after January 1, 1983 and the five high school students. Each group was arranged to have seventeen respondents with equal numbers of comparable respondents in each group.

Table 22

General Characteristics of 34 Non-leprosy respondents

Characteristics Age (years)	Pre-MDT No.	Post-MDT No.	Total No.
11 - 20	0	5	5
21 - 30	0	7	7
31 - 40	7	5	12
41 - 50	4	0	4
51 - 60	5	0	5
61 - 70	1	0	1
Total	17	17	34

Sex			
Male	14	11	25
Female	3	6	9
Total	17	17	34

Religion			
Muslim	7	7	14
Orthodox Christian	7	6	13
Catholic	1	3	4
Protestant	2	1	3
Total	17	17	34

Marital Status			
Married	14	8	22
Single	3	9	12
Total	17	17	34

Table 23

Ethnicity

Amhara	8	6	14
Oromo	2	4	6
Tigre	2	2	4
Hadere	2	0	2
Eritrean	1	0	1
Gurage	1	4	5
Konso	1	0	1
Kembata	0	1	1
	-----	-----	-----
Total	17	17	34

Level of Education

Above Grade 12	7	3	10
Grade 9 - 12	5	13	18
Grade 2 - 8	3	1	4
Read and Write	2	--	2
	-----	-----	-----
Total	17	17	34

Knowledge

Causation:- Among the thirty four respondents there were nine major categories explaining the etiology of leprosy (Table 24). Fourteen gave single answers and the remaining twenty gave two or more answers.

The most frequently mentioned causes of leprosy were related with infection in both groups. All Health workers at ALERT and four general health workers identified M. leprae as the cause of leprosy. All High School Teachers, three High School students and one non-leprosy patient related leprosy with bacteria, viruses and in one case with "Germ". One of the five health workers in the pre-MDT group believed leprosy to have unknown cause. All the high school students who stated bacteria as a cause related it only to be caused by the bacillus type of bacteria.

Four pre-MDTs and three post-MDTs mentioned sexual indiscretions as causes of leprosy. All the Orthodox Christian and Muslim religious leaders and three non-leprosy patients (who were Orthodox christian and Muslim) were the only respondents who associated leprosy with sexual 'mis-behaviour' particularly sexual intercourse with a menstruating woman which was stated to cause a child with leprosy.

Sexual indiscretions were highly associated with leprosy by the Orthodox Christian religious leaders who believed that sexual intercourse on days declared holy by the Orthodox Church like Easter and Christmas, Fridays, Saturdays and Sundays throughout the year could certainly cause leprosy. The pre-MDT Orthodox priest commented that there were very many days, which he said he couldn't remember all, on which it is forbidden to have sexual intercourse according to the Bible, but the rule was not accepted and usually broken by today's disobedient generation which resulted in the high number of patients in Ethiopia.

Evil spirits were mentioned by the same respondents who mentioned sexual 'misbehaviour' and one Orthodox non-leprosy patient. Other causes included evil spirits were frequently mentioned as "Likeft", "Gini" and "Aganent" and were believed to be

present in areas where ash 'Atlla' (sediment of Tella, local beer), "Ambula" (sediment of Tej) were splashed. Cemeteries, in the first 40 days after the dead was buried, and in water and food kept uncovered during the night. Walking, especially at noon, where evil spirits were supposed to be found and drinking or washing with water or eating the food kept uncovered during the night were causes implicated as the main means of contracting leprosy. One respondent only described the 'disease process' by stating that the 'Gini' which was made from fire caused burning of the blood and flesh and resulted in unclean blood that led to leprosy.

Heredity as a cause was implicated by five respondents with almost the same numbers in both groups. Categories of sin, God's will and Satan were mentioned only by Catholic and Protestant priests mainly by the Post-MDT group. Physical causes were mainly attributed by the post MDT group and the only "I don't know" answer came from a general health worker in the Post MDT group.

Transmission:- Thirty believed leprosy to be a contagious disease while four, all in the pre MDT group responded that it couldn't be contagious (Table 28). Two of those who disagreed with the contagious nature of leprosy were health workers at ALERT who stated that they and their work-mates could have been leprosy patients if leprosy was contagious. The other respondent stated that leprosy only occurs in those who committed sin like sexual misbehaviour.

More than half of the respondents used the expression 'prolonged skin contact' for which they couldn't define the time limit.

Belief in the transmission of leprosy was different among the two groups markedly in two views, breast milk and living together. six believed breast milk transmits leprosy to the child and this view was shared by two health workers. Breast milk was suggested by three high school teachers and living together by four students.

One health worker at ALERT stated that the sperm was one of the main ways of transmission of M. Leprae. Among those who mentioned hereditary two said that leprosy might be hereditary only

among the "Lalibellas". Two health workers in the Post-MDT group, one at ALERT and one General Health Worker, suggested transplacental transmission.

The Orthodox Christian religious leaders didn't mention any ways of transmission. They responded either as "not transmittable" or "don't know".

In general the beliefs expressed about transmission were about the same in the two groups and among categories of respondents except the Orthodox Christian religious leaders.

Table 24 What is the cause of leprosy?

Cause of Leprosy	Pre MDT No.	Post MDT No.	Total No.
1) Infection			
Bacterial/Virus/ Germ	6	3	9
M. Leprae	5	5	10
2) Sexual Indiscretions			
Intercourse			
- with a menstruating woman	3	3	6
- during Orthodox Christians fasting seasons	1	1	2
- during Fridays, Saturday Sunday, Christmas, Easter	1	--	1
On Saint's day	--	1	1
On the first 40 days after a male and 80 days of a female birth	1	--	1
Homosexuality	1	--	1
3) Evil spirits	3	4	7
4) Hereditary	2	3	5
5) Sin	1	1	2
6) God's Will	--	1	1
7) Physical causes in the environment			
- Strong "Bird" (cold weather)	1	--	1
- Air pollution	--	1	1
- poor sanitation	--	1	1
- Bad smell	--	1	1
8) Cause still unknown	1	--	1
9) I don't know	1	1	2
Total	27	27	54

* Some gave multiple answers

Table 25 How does leprosy transmit?

Ways of transmission	Pre MDT No	Post MDT No	Total No
- Skin contact	8	9	17
- Sexual intercourse	6	4	10
- Breast Milk	5	1	6
- Contact with blood of a leprosy patient	3	3	6
- Hereditary	3	3	6
- Through placement	3	1	4
- Through fomites	2	--	2
- Cough	1	2	3
- Living together	1	5	6
- Don't know	1	3	4
Total	33	31	64

* Some gave multiple answers

Only six suggested that leprosy couldn't be cured. This view was suggested by two of pre MDTs and four of Post - MDTs including one general health worker. Only one general health worker knew the current drugs for leprosy (excluding workers at ALERT) while one health worker at ALERT, a cured leprosy patient before 25 years, confessed his doubt about the curability of leprosy.

The pre-MDT Muslim religious leader explained that leprosy could be curable by Honey and 'butter'. If the patient came in the first six month of his illness and combination of Honey, butter and blood letting for a patient who came after six months.

Except for the health workers none of the other respondents had any idea as to what type (injection, tablets, etc) could be the treatment of leprosy and more than half the religious leaders believed faith in God or Allah the only treatment for leprosy. Holy Water was suggested by an Orthodox priest while a post - MDT Muslim religious leader stated the presence of the name of the drug for leprosy in the Holy Koran including for other 98 diseases, which he couldn't remember.

Only two respondents, one in each group, explained that they knew about the presence of traditional medicine for leprosy prepared from a leaf (not specifically mentioned) and honey and butter.

The cause of deformity was explained by loss of sensation by six respondents (other than the health workers at ALERT) and five explained it to be caused as a result of the bacteria which only attacked bone and flesh. Another five answered that to cause deformity is leprosy's unique nature.

One student said that leprosy only attacked and destroyed the tips of body parts while one respondent described it to be a disease which had the character of a sword, tearing of limbs, a stick, breaking off a part, and a spear.

One person stated that it could be caused by a dirty blood when Evil spirits entered ones body. Untreated infected wound was presented as the main cause by a general health worker. Six said they didn't know about the cause of deformity.

Deformity was associated with loss of sensation, irregularity of treatment and delay in taking treatment by five post - MDTS and three pre - MDTS.

Thirty one respondents answered "Yes" for the question "Do leprosy patients usually beg." and added that begging was higher among leprosy patients than any other segment of the population. Twenty implicated deformity as the reason for begging and fourteen blamed the society's fear for leprosy in preventing the patients from getting jobs.

Fourteen pointed out poverty as the main cause of begging in the non-leprosy beggars while only twenty pointed out poverty as a reason for leprosy patients begging. Four blamed leprosy patients by stating that patients considered themselves "useless", 'felt a inferiority complex', had fear of the society and usually keep away from the society after the diagnosis.

Lack of help and social rehabilitation was suggested by only two respondents. One pre-MDT health worker at ALERT believed in the absence of young beggars after the MDT programme started due to the reduction in the number of disabled patients .

The pre-MDTS believed deformity in causing begging more than the post MDTS; while eight post MDTS and six pre-MDTS believed the fear to hire a leprosy patient to be the main cause of begging.

Leprosy was perceived as a major health problem by twenty seven respondents including by the majority of respondents that had associated leprosy with evil spirits, sexual misbehaviour and sin (Table 26).

Four pre-MDTS and three post-MDTS believed leprosy to be a minor health problem and most of them justified their belief by the lesser attention given to leprosy by the mass media and in the absence of health education programmes in Schools and Churches mosques, and health institution where only AIDS was given emphasis.

Six respondents stressed the absence of consideration for leprosy and patients among the society and from the government despite being a major problem in Ethiopia.

More than half the respondents associated importance of leprosy as a public health problem with the disability and the subsequent increase of beggars. Five said that they could tell the problem from the number of beggars they saw in the street (Table 27).

One Muslim religious leader in the pre MDT group considered leprosy as a major problem because of the poor sanitation of the country that could result in very high numbers of evil spirits which would cause leprosy. One post MDT Orthodox priest strongly responded that it should be called a major 'curse' rather than a major problem.

overall, leprosy was perceived as an important health problem in both groups, mainly for its ability in causing deformities.

Table 26 Is Leprosy an Important Public Health Problem?

	Pre -MDT No.	post - MDT No.	Total No.
Yes	13	14	27
No	4	3	7
Total	17	17	34

Table 27 Why do you think it is important?

	Pre -MDT No.	Post - MDT No.	Total No.
Very deforming	7	9	16
Spoils body and name	3	2	5
High number of patients	4	5	9
Increases the number of beggars	3	2	5
Society has no knowledge about the disease	--	2	2
Evil spirits are increasing	--	1	1
Promiscuity is increasing	--	1	1
Total	17	22	39

* Some gave multiple answers

Table 27 What do you think should be done?

	Pre -MDT No.	Post - MDT No.	Total No.
To use mass media schools to teach society	7	8	15
In service training for health workers	4	3	7
To pray for the victims	4	4	8
Expand the services of ALERT	4	2	6
Separate children from leprosy patients	2	3	5
To segregate patients Apart from the population	2	3	5
Establish work places like factories for patients	1	1	2
Involve General Health workers in Leprosy control	1	1	2
Total	25	25	50

* Some gave multiple answers

ATTITUDE AND BEHAVIOUR

All but one responded that they had no relative who had leprosy. All students and three post - MDT respondents expressed their shock of being asked about leprosy in their family and one post - MDT Orthodox priest refused to answer the question. Almost no religious leaders were at ease at being asked whether they know a religious leader who had leprosy.

Three admitted of knowing old classmates who had the disease while only one respondent, a Moslem religious leader, admitted that he knew a religious leader and had an uncle who had leprosy. Even though this pre MDT respondent stated that leprosy was hereditary, in his uncle's case he believed it to be caused by evil spirit. He also mentioned that unlike Addis Ababa in his home town (welkite) people used to eat, sleep and live together with the leprosy patients.

Half of the health workers at ALERT explained that they always avoid to eat or drink tea with health workers at ALERT who had leprosy. Two of them revealed their wish not to have any social relation with these patients and added that they never attended any kind of ceremonies like wedding with them. One of them stated that she never drank anything without washing the cup or glass since she have been assigned at ALERT. No post - MDT health worker at ALERT suggested any negative remark.

Out of the seven respondents who claimed to have the same 'Eder' or 'Ekub' (Table 28) more than half are health workers at ALERT. The rest stated that the leprosy patients were known as rich people and lived in the neighbourhood for a long time. One high school teacher stated that " the leprosy patient couldn't have been a member if it were not for his money".

All respondents described that the support to leprosy patients was usually given only at time of death, otherwise twenty assumed that problems would occur if patients became member of "healthy" people's Eder (Table 29). One post - MDT woman answered by saying "Yalacha Gabecha" (marriage among unequal) and half of the

religious leaders commented that leprosy patients wouldn't be accepted in social organizations around churches.

About two third denied seeing any leprosy patients in health institution where the respondents are accustomed to go. Only one general health worker saw one patient for one time only and one Nurse spoke of not seeing any leprosy patient for 13 years in the health center where she was working.

The majority of the respondents thought that general health workers had no fear for leprosy and discrimination against leprosy patients, while thirteen believed that the fear and discrimination is recognized by the general health workers. Half of the general health workers and all of the health workers at ALERT stated this opinion shared by two non-leprosy patients and one teacher. Lack of knowledge about the disease and the fear of transmission were the main reasons implicated.

Unlike the comment on membership of 'Eder' more than half in both groups answered that they saw no problem if patients would go to any hospital.

All religious leaders said that there was no discrimination ceremonies like wedding and other church services, but they had never seen any leprosy patient come for such services eventhough all said that the church or mosque was the only place where leprosy patients could be treated with kindness. Except for one, none of them saw a leprosy patient who came for prayer. One post - MDT Orthodox priest commented that the disease spoiled their brain and moral and could prevent them from coming to such kinds of holy places and services.

Table 28

Is there a leprosy patient who is a member of your "Eder" or "Ekub"

	Pre -MDT No.	Post - MDT No.	Total No.
No	13	14	27
Yes	4	3	7
Total	17	17	34

* Student asked about their parents

Table 29

Would there be a problem if a leprosy patient became a member?

	Pre - MDT No.	Post - MDT No.	Total No.
Yes	9	11	20
No	3	6	9
Patients are not willing to be a member	5	--	5
Total	17	17	34

Table 30

What kind of problem do you think will happen?

N=20

	Pre - MDT No	Post - MDT No	Total No
Patient would feel inferior	4	2	6
No one wants to eat with them	3	4	7
Can't establish good social relation	2	5	7
Total	9	11	10

Fear of being known, asked about their illness and loss of courage to pray among 'healthy' people were the main reasons given by the religious leaders for the absence of leprosy patients in religious services.

Twenty four respondents blamed the leprosy patients for not utilizing health services and attending religious services. Only two post - MDT religious leaders stated the presence of religious rule which prevented a patient with ulcerated wound from entering a mosque and an orthodox rule which prevented a patient from being "Nefse Abat" (soul - father) and leading a prayer. One respondent commented that "Leprosy is the worst misfortune a priest can have."

All high school students and teachers answered that there would be a problem if a student with leprosy enrolled in their high school. All agreed that there would be a rejection of the patient for fear of contact and lack of adequate knowledge would cause the students to fear even a student who came from a leprosy patient's family.

Four of the five students stated they wouldn't be willing to sit beside and learn with a leprosy patient or a student who came from leprosy patients' family; all explained that, their fear started after they had known leprosy to be contagious.

Three high school teachers stated that they had no fear to teach leprosy patients. While three religious leaders disagreed to give services in the same church or mosque with a religious leader who had leprosy.

Including eight of the twelve health workers, twenty five respondents expressed that they had no wish of living together, eating, drinking, sharing latrine or travel by bus with a leprosy patient. Second to the frequently mentioned fear of contiguity the answer was given that leprosy patients were usually dirty and had bad smells. Only eight spoke of ever going by bus with leprosy patients and all of them said then tried to avoid contact with leprosy patient.

Comparable numbers of respondents in both groups described leprosy to be worse than TB or AIDS (Table 31). Every one of these respondents stressed the body appearance to be more of a concern than the fatality due to either TB or AIDS, which would be preferred to leprosy (Table 32).

Even though their reasons were not consistent with their previous views of cause and transmission, all respondents stated that they would never agree with marriage between a leprosy patient and a non leprosy person.

Table 31

Which one is worse: Leprosy, TB, AIDS?

	Pre - MDT No.	Post - MDT No.	Total No.
Leprosy	8	7	15
TB	6	2	8
AIDS	1	6	7
Leprosy and TB are the same	1	1	2
Leprosy and AIDS are the same	1	1	2
Total	17	17	34

Table 32

Why is Leprosy worse than TB or AIDS?
(N=15)

	No.	No.	Total No.
Causes deformity and rejection	3	2	5
Causes deformity	2	3	5
Doesn't kill but long standing suffering	2	2	4
Makes beggar and inferior to others	1	--	1
Total	8	7	15

All the general health workers and half of the health workers at ALERT admitted of never holding any health education session or seeing of health worker teaching about leprosy. All the rest twenty two responded that they never had or saw a health education session about leprosy. Two general health workers commented that "no one could remember about leprosy". Many respondents said that they were puzzled why health education about leprosy was not held in health institutions, schools (including in the curriculum) and churches like AIDS.

All religious leaders, except one, had never preached about leprosy. The only priest claimed leprosy to be one of the many diseases which he usually associate with evil. Except two all said they preached about AIDS after they were asked to do so by the Ministry of Health.

Table 33

What do you think is the cause of fear for Leprosy?

	RL'S N=8	HST N=5	HSS N=5	LHW N=6	GHW N=6	NLP N=4	Total (N=34)
Fear of Contiguity	6	5	5	6	6	4	32
Punishment for sin	6	1	1	--	2	2	12
Deformity	5	4	5	4	4	4	26
Disgrace to the family	3	--	2	3	3	3	14.
'Gabecha Kelekel' (preventer of marriage)	3	2	2	1	1	2	11
Inherited from parents	2	2	4	2	4	1	15
Lack of understanding about leprosy	--	2	4	3	5	1	15
Total	25	16	23	19	25	17	125

* All respondents gave multiple answers

RL'S = Religious Leaders
 HST = High School Teachers
 HSS = High School Students
 LHW = Health Workers at ALERT
 GHW = General Health Workers
 NLP = Non Leprosy Patients

Discussion

The findings of this study suggested the similarity in the patterns and trends of social stigma and prejudice regarding leprosy over the past 35 years. The trend of thought about leprosy was observed to be quite the same among the two groups of respondents who represented the pre-Multiple Drug Therapy period and the post- Multiple Drug Therapy (MDT) period. This observation has also been seen to be equally shared by the leprosy patients and the non-leprosy respondents. Leprosy was perceived as a unique, chronic, nonfatal but progressively deforming disease which usually causes a disgrace to the victim and family.

As shown in Tables 12 and 24 causes of leprosy identified by the majority of the respondents were equally shared by the pre-MDT and post MDT groups. The causes identified were found to be comparable, with previous studies done in Ethiopia in 1969 (67), 1973, (58) and 1986 (37).

The perceived cause of leprosy to be hereditary was observed to be associated with the patients and the other respondents negative reactions. As noted earlier, advice to go to ALERT, for treatment was taken as an insult for the very reason of "Kumtena" (being a "leper") to be a disease "given" for certain individuals and families. The negative emotions during diagnosis and advice were mainly due to the questions this caused: "How and why me?" "The question about having or knowing a relative or a friend with leprosy was observed to be very disturbing to most respondents. Most of the respondents were relating leprosy with heredity with the series of questions they were asked. In both groups the

perceived cause of leprosy as hereditary had an impact on the early self-reporting of patients as was stated by most of the patients.

The presence of strong association between sin and leprosy among the predominant religions of the country, Islam and Orthodox Christianity, and their role shouldn't be underestimated and needs a close look. At the present study other than the views of the respondents no striking role of religion in the perpetuation of the stigma was seen either by preaching about the disease negatively or discriminating against the leprosy patients. But, like the rule of Leviticus the Ethiopian Orthodox Church even today requires a cured leprosy patient to take the Holy Communion (51).

The association of leprosy with disgrace to the family was a very striking and frequent response. A majority of the respondents agreed that leprosy means a disease that would bring shame and dishonour to one's family as well as the victim. Interestingly half of the health workers interviewed believed it to be true. One thing observed throughout this study was the belief about the disease was not related with attitude and behaviour. In both groups of patients delay in seeking treatment was also found out to be for fear of bringing a disgrace to the family by just going to a leprosy clinic.

Among most respondents, including leprosy patients, the current Amharic Name for leprosy "Sega Dewe" (Disease of the flesh) was unknown. For most, it was known by a very stigmatizing name, and which describes the disgrace, "Gabecha Kelkel" (Preventer of Marriage) and less commonly by the name "Atente Sebara" (a person

with broken bone) which have an extreme negative impact on the patient as well as the family.

In this study for both groups of respondents disclosure of one's illness to a spouse or family meant divorce, meant rejection by family, friends or causing children to be unmarried for life. Concealing was a very common practice in Ethiopia for more than a century (37) and similar findings were seen in a study done in Princess Zeneb Work Hospital in 1969 (67).

The fear of disgrace to the family, and the name "Gabecha Kelkel" which was given strong emphasis, are points which couldn't be overlooked in a country like Ethiopia, where high priority for extended family is given.

These findings which were given strong attention indicated that patients must have family support and these problem areas must be assessed before integration of leprosy services into the general health service. Patients who disclosed their secrets to their family or spouses were better motivated and hopeful of the future at least at the time of the interview.

In both groups and in all categories of respondents the term leprosy was directly associated with an image of physical deformity. All respondents including the leprosy patients were describing leprosy only in terms of its deforming manifestations or stages. Even the leprosy respondents were answering by saying "they" whenever they were asked about other leprosy patients.

The majority of respondents considered deformity to be the inevitable consequences of leprosy. This unchanged view of

progressive deformity can be explained by the doubt most respondents have for its curability. Even a patient who was released from treatment as far back as 25 years was not certain what the future could bring. The persistence of this kind of fear needs further study in order to help people see cured patients as well as decrease the number of patients who prefer to conceal their previous illness after being cured.

Even though fear of contact was mentioned as the main cause of fear, social interaction with leprosy patients was not desired by the majority of respondents even in the absence of contact.

In both groups of respondents and among categories of leprosy patients and non-leprosy respondents social interaction among patients and "healthy" people was equally believed to be like "marriage among unequals". These perceptions would certainly have an impact in disclosing illness in an Ethiopian society where in most parts social organizations like "Eder" are regarded highly.

In the absence of restrictive laws 'which were not at least stated, at institutional level the very high response of not encountering leprosy patients at Churches and Mosques (attending services), Schools, or social organizations suggests the need for further study.

The health education about leprosy and the in-service training for General Health Workers seemed not to be given enough emphasis. This was observed from the almost similar attitude and behaviour of health workers with the other respondents. The effect of lack of adequate information about leprosy by the health worker and the

general public on the activities of the control programme should be given due consideration.

Learning from the failures and the mistakes of the past will help us in formulating appropriate policy for the present. The findings of this study suggest the care which should be taken in order not to repeat the failures of the policy of attempted integration in the 1960's.

Repeated studies must be made about the applicability of this study to the general population of leprosy patients and the public. The biases seen in this study were: the respondents were limited in number and were volunteers. The advance notice for interview made the respondents prepare to tell views and ideas they thought the investigator was after and there was an inclination to tell favourable answer about leprosy medicine since the interviewer was a physician.

Since the study was based on an individual interview, extensive probing was done to minimize these biases. Nevertheless, the study met its purpose by assessing the social perceptions of leprosy which might have practical implications in the control of leprosy and some insights on the acceptance or rejection of integrating leprosy control into the general health service.

CONCLUSIONS

The study revealed that:

1. Leprosy was considered by all respondents as a unique disease for its stigmatizing character.
2. Belief in the hereditary nature of leprosy was contributing to the absence of observable differences among the two groups.
3. Leprosy was perceived as a disease which meant a very severe disgrace to the victim and family.
4. Leprosy was seen as a disease with a chronic, nonfatal but progressively deforming nature.
5. Leprosy was seen as a disease which would cause breakage of social life in either modern, traditional or religious ways.
6. Health education for the public and inservice training to health workers about leprosy are lacking.
7. Integration of leprosy control into the general health services seemed unacceptable by the leprosy patients.

RECOMMENDATIONS

Hence, based on these findings the following recommendations are given:-

1. Leprosy Patients should be taught more intensively and specifically about the cause, and curability of leprosy at the time of diagnosis and in subsequent treatments.
2. In-service training for general health workers about leprosy should be given more extensively by ALERT and National Leprosy Control Program with particular attention to question of infectivity and genetic aspects.
3. Before implementing the policy of integration, further studies on the perceptions and social responses of leprosy patients, non-leprosy patients, and health workers should be done.
4. Further studies on the society's perceptions of leprosy should be made before integrating leprosy control program into the general health services.

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(Appendix A)

QUESTION FORMAT FOR LEPROSY PATIENTS

1. Please tell me about your family ? Your marriage and how you earn your living ?
2. Where do people in your neighbourhood go for medical care? FP? EPI? Deliver ?
3. Can you tell me why people become sick ?
4. Why do some people have some kind of disease and some do not?
5. Where? when did you first know you have leprosy ? Did you your self know it and self reported ? If yes after how many days/months did you go ? why waited that long ? where did you go ? why that place ?
6. When you knew you have leprosy what did you feel? Why ? whom did you first tell ? Why ? what was the reaction of your family ? Was there any problem in your marriage?
7. Did the people in you work place, friends, neighbours know you have leprosy ? Who told them ?
Was there any problem you and your family faced? What kind ?
Why ? did your children face a problem in school ? From whom? why? what did you do?
8. Did you take your family for medical examination? Did you go by yourself ? If not who advised you ? Did you take your medication regularly ? If not Why?
9. Were you in leprosarium before ? What did you feel about the leprosarium ? Why did you leave it ?

If not what did you hear about it ? ALERT ? can you tell me about leprosy health workers?

10. Where did you and your family go for medical care and advise? Why ? and now where do you prefer to go ? why?
11. What do you think is the cause of leprosy ? Is it curable? How ? When did you know this ?
12. What did you remember what people think and say about leprosy at the time you have leprosy? Do you think there is a change now ? Why? How? If not why?
13. Was there a social organization like 'Eder' 'Maheber' or Ekub where only leprosy patients are members? Why only leprosy patients? are you a member? when did you join? Why?
14. Did you ever have a faith in law? Did it discriminate? what about now?
15. What is the cause of deformity ? How did you get it? was it preventable ? What did you feel when unwelcomed due to deformity? Why? Now?
16. Did you feel health workers discriminate you in health institutions? and other patients to sit in a waiting room? Other people to go in the same bus? What about now? Do you like to go to the clinics where other non leprosy patients are treated? Why and why not?
17. Is leprosy different from other diseases? Why?
18. When did you marry? Before you know you have leprosy or after? Did you remarry?
19. What does the Bible/Koran say about leprosy ?

QUESTION FORMAT FOR RELIGIOUS LEADERS

1. What does health mean?
What are the causes of ill health?
Why do some people have some disease and others do not?
2. What kind of patients usually come to churches/mosques? Why?
Why do we usually see leprosy patients around churches/
mosques?
3. What did your church/mosque do to help leprosy patients ?
Many religious people and organizations were concerned on
building a leprosarium why?
4. Do you think many leprosy patients are beggars? Why?
5. What do you think is the cause of leprosy ? Is it curable?
How?
Is leprosy different from other diseases? How?
What is the cause of deformity ? Is it preventable?
6. Why do many people fear and have anxiety about leprosy? Why
do they isolate patients?
Is this the reason why leprosy patients usually come to
churches/ mosques?
7. Was there a difference for a leprosy patient for ceremonies
like funereal? christening? marriage?
Can you tell me about these things how they are done now? I
will appreciate it if you can tell me based on your
experience.
8. Did leprosy patients usually come for confession? Did you

ever meet such encounter?

Did you see it different from other people's confession? why? were leprosy patients allowed to pray inside the church/mosque? what were religious leaders' reaction ? Other people ? What about now?

9. In the old days what was preached about leprosy? Now? Did you ever preach about leprosy? Can you tell me more?

10. Are leprosy patients very religious people ? why?

Did you ever know a religious leader who is a leprosy patient? What was his relation with other religious people? Was he ever involved in preaching? How do you know he is a leprosy patient?

11. Did other people know? Who told them? What were their reaction?

- Did religious leader fear or have anxiety about leprosy? Why? Now? Why?

12. Is there a place you know where only leprosy patients are treated?

- Do you usually see leprosy patients in other health institutions?

- Did you see any discrimination? By whom? Why?

13. Is leprosy a major public health problem in our country? why? What should be done? What will be your role?

14. What does the Bible/Koran say about leprosy? can you tell me more?

- What do other religions say about leprosy?

15. Is there any other specifically named disease in the Bible/Koran? What does it say?
16. Do you think there is a difference between your generation and the previous generation in your perception of leprosy?how?
17. Is leprosy one means of punishing the human race for their sins?
18. Did the previous religious leaders accept the medical professionals idea on the cause of leprosy? What about you?
19. Did you ever think or worry that you can have leprosy? Why?

QUESTION FORMAT FOR THE LEPROSY HEALTH WORKERS

1. When did you graduate? Where? How did you become a leprosy health worker? Self choice? Why? Did you learn in school about social perception of leprosy?
2. Before you became a health worker what was your idea of the causes of disease ? Leprosy?
3. Did other health workers (general) discriminate against leprosy patients from others? why? what about now? Is there a change? How? Why?
4. Why do general health workers have deep rooted fear about leprosy?
5. Where did leprosy patients go for medical care? FP? Anc? delivery? EPI? Why? Now? where do patients who were released from treatment (RFT) go for medical advice? for rehabilitation?
6. Why do patients default ? What kind of patients usually default? Do they return back? Why? Do they give reasons why they default? can you tell me some of the reasons they give?
7. Can you tell me the reason why they usually become beggars? What did you do for rehabilitation? In the past? Now?
8. Do you have a friend, relative or a health worker you know who is a leprosy patient? Is there a change in your relation after diagnosis ? Why?

9. Do you know of a marriage between a leprosy patient and a non leprosy person? can you tell me more about the marriage?
10. Can you tell me about the people who came to ALERT? Over the years what did you observe about the number and type of people coming to ALERT?
11. What did your family, friends, health workers think of you being a leprosy health worker? Why? What about now? Is there a change? Which group?
12. Can you tell me your relation with leprosy patients other than medical aspect? What did they think about you? Now? Is there a change overtime?
13. What is the cause of deformity?
14. Is leprosy curable? How? Why?
15. Can you tell me about your feelings since you have started to function as a leprosy health worker? Is leprosy a public health problem? what should be done?
16. What does the Bible or Koran say abut leprosy?
 - Do you think this belief perpetuates the fear?
17. Are you satisfied with your job ?
18. Did you ever worry that you could get leprosy as long as you work with them?

QUESTION FORMAT FOR THE GENERAL HEALTH WORKER

1. When did you graduate? Where? When did you come to this health institution?
2. Before you become a health worker what was your belief in causation of disease?
3. Did you learn about leprosy during your training? Can you tell me what you were taught?
4. Did you ever participate in leprosy training programme like EPI? CDD? If not why? Do you know others who participated?
5. Did you ever see a leprosy patient in the health center? Health post? How were they treated? Why?

If they came to the health center where did they wait? At what time of the day or week do they come? Why?

Did they come for FP, EPI, ANC and delivery?
6. Did you ever assist leprosy patient in delivery? If yes what were your feelings? the patients ?
7. Do you have a relative, a friend, a health worker who is a leprosy patient? How do you know he is a leprosy patient? Was there a change in your relationship after you now? Why?
8. Is there a leprosy patient who is a member of your "Eder", "Maheber", Ekub? when did he become a member ? before or after diagnosis? Do people know he is a leprosy patient?
9. Do you know a marriage between a leprosy patient and non leprosy person? When ? Can you tell me more if you know about this marriage?
10. Is there a difference between leprosy and TB? How? Why?

11. What is the cause of leprosy? Is it curable? How?
12. Can you tell me the current drugs for treatment of leprosy?
13. Is leprosy preventable? Can you tell me some signs and symptoms of leprosy?
14. What is the cause of deformity ? Is it preventable?
15. How is leprosy transmitted? Why did children become leprosy patients?

Did you think a leprosarium is the best place to treat leprosy? why?

Can you tell me what multiple drug therapy is? For what disease are we using it? What is its effect?

16. Do you think health workers in ALERT are at risk? Why?
17. Did health workers show discriminatory behaviour towards leprosy patients? Why? Now? Why did health workers have deep-rooted fear and anxiety on leprosy? Now?
18. Did you ever give health education about leprosy? When? Where?what did you teach?
19. Is there a leprosy clinic in this health institution? When did it start to work ? Did you ever attend the clinic session? Why?
20. Did you ever worry that you can have leprosy? Why?
21. Is leprosy an important public health problem? Why? What should you think must be done ?
22. What does the Bible or Koran say about leprosy ?
is it the root cause of fear and anxiety?

QUESTION FORMAT FOR HIGH SCHOOL TEACHERS

1. When did you start to teach? Did you work in any other place before?
2. What is health? Causes of ill health? Why do some people have disease and some don not?
3. Did you know teachers, students who are leprosy patients? How did the teachers and the students approach them? How did you and others know they are leprosy patients? Do you have friends or relatives who are leprosy patients? Is there a change in your relationship after diagnosis? Why? Are leprosy patients a member of your Eder?
4. Did you ever meet a leprosy patient in a health institution? What did you feel? Why? Did you see any discrimination by the health workers? Other patients? Where were the leprosy patients waiting?
5. Where did you think leprosy patients go for FP? EPI? Delivery? Why? Do you know any institution which is giving medical service for leprosy patients? where is it?
6. Did you ever go to ALERT? If yes what were you feelings? Why? If not why?
7. Do you know the bus number which goes to ALERT? Did you ever go on that bus? What did you feel? Why?
8. Why do people beg? Do you usually give money for beggars? Why do leprosy patients beg? Do you see any difference between the leprosy and the non leprosy beggars? Why?

9. Why did people fear leprosy? Now? Why did people isolate leprosy patients? Do they isolate them now?
10. How do adults get leprosy? How does a child get leprosy?
Do people who work in ALERT are at a higher risk of getting leprosy? Why?
11. What is the cause of leprosy? Is it curable? How?
What is the cause of deformity? Is it preventable?
12. Did you ever get health education about leprosy? Where? What did you learn? Who gave the education?
13. Is leprosy a major public health problem? If yes what should be done?
14. What does the Bible? Koran say about leprosy?
Do you think it is the root cause for the fear people have on leprosy?

**QUESTION FORMAT FOR NON LEPROSY PATIENTS ATTENDING
OPD OF TEKLE HAIMANOT HEALTH CENTER**

Before we start our conversation I want you not to misunderstand me as if I consider you as a leprosy patient. I am interested on the views of non leprosy patients, who come to this health institution, regarding leprosy.

1. To day why do you come to T/Haimanot Health Center?
2. What do you think the cause of your illness?
3. Did you ever meet a leprosy patient in a health institution? What did you feel? Why? Did you see any discrimination by the health workers? Other patients? Where were the leprosy patients waiting?
4. Where did you think leprosy patients go for FP? EPI? Delivery? Why? Do you know any institution which is giving medical service for leprosy patients? where is it?
5. Did you ever go to ALERT? If yes what were your feelings? Why? If not why?
6. Do you know the bus number which goes to ALERT? Did you ever go in that bus? What did you feel? Why?
7. Why do people beg? Do you usually give money for beggars? Why do leprosy patients beg? Do you see any difference between the leprosy and the non leprosy beggars? Why?
8. Why did people fear leprosy? Now? Why did people isolate leprosy patients? Do they isolate them now?

9. How do adults get leprosy? How does a child get leprosy?
Do people who work in ALERT are at a higher risk of getting leprosy? Why?
10. What is the cause of leprosy? Is it curable? How?
What is the cause of deformity? Is it preventable ?
11. Did you ever get health education about leprosy? Where? What did you learn? Who gave the education?
12. Is leprosy a major public health problem? If yes what should be done?
13. What does the Bible? Koran say about leprosy?
Do you think it is the root cause for the fear people have on leprosy?

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QUESTION FORMAT FOR HIGH SCHOOL STUDENTS

1. What does health mean? causes of ill health?
Why do some people have some kind of disease and some do not?
2. Would you be willing to go to a health institutions where leprosy patients are treated? Why? Is there a discrimination? If yes by whom?
3. Do you have a friend or relative who is a leprosy patient? How did you know he/she is a leprosy patient? Can you tell me the relationship you have with the leprosy patient?
4. Do you think there is a problem for the leprosy patient if students know he/she or his/her family member is a leprosy patient? How? Why?
5. Do people fear to travel with leprosy patient in the same bus? Why?

Did you ever eat with a leprosy patient? What did you feel? What did other people say about it? Did you ever travel by bus with leprosy patents? What is the bus number leprosy patients usually use?
6. Do you know a health institution where only leprosy patients are treated? Do you think it is good for the leprosy patients? Why? What does leprosarium mean?
7. Why do you see many leprosy patents who are beggars? What is your feeling towards the leprosy beggars?

8. What is the cause of leprosy? Is it curable? How?

Cause of deformity? Is it preventable?

Why did people get leprosy? What do you do not to be a leprosy patient?

How do little children get leprosy ?

9. Is leprosy a major public health problem? Why? What should be done?

Did you ever get health education about leprosy? Where?

What did you learn? Who gave the education?

10. Did you ever think you could have leprosy?

11. What does the Bible or Koran say about leprosy?

Do you think a religious leader can have leprosy? Did you see one? What do people say about him?

(Appendix B)

INTRODUCTION - To all respondents

Hello, My name is Dr. Mesfin Adissie and I came from the department of community health at A.A. university. I am doing research on leprosy sponsored by the department of community health. My plan is, to help the leprosy control programme in improving its services for the leprosy patients and I strongly believe your participation increases the success of my plan as well as the leprosy control programme.

In order for me to do well, I need to know what people think, talk, feel and do concerning leprosy. I am interested in all your ideas, comments and suggestions. I understand that the questions might be very personal and some might be very sensitive. But from the practical importance of your views for the total programme planning I truly need to ask you such questions. To help me analyze yours and other peoples' views I will taperecord our conversation.

I assure you that all your comments are confidential and will be used for research purpose only. You should know that I will not use your name or address when I write your comments and the recorded tapes will be destroyed thereafter.

We will conduct the interview in the place you think convenient. Before starting our conversation I need to have your agreement. If you agree, as is done in such kind of research, I want you to say your agreement, without mentioning your name, and I will taperecord it. Thank you very much.

1. ለባዘገገን በሰ ቤብብያ ሊነገሩኝ ? በበተኛት ? ለምን ለንደሜቱዳደሩ?
2. የሚቻሩበት ለባባቢ የግሩሩ በገኙ ወይም ሌላው የሚሄዱት ?
ለወሊዱ መብባዎሪያ ? ህጻናትን ለማስቀመጥ ? ነፍሰወርጅ ለመውሰድ ?
3. በገኙ ለምን ለንደሜታው ሊነገሩኝ ይችላሉ ?
4. ለምንደር ነው ለንደሜታ በገኙ በሽታ በይዘተው ሌሊት በገኙ ደግሞ የማይዘገቡ ?
5. የኋላ መጻ ነው ለመጀመሪያ ጊዜ የሥጋደዌ በሽታ ለንደሜታ ያወቁት ?
6. ራስዎ በሽታው ለንደሜታ ለውጥ ነው ወይ ሆኖ ተጋም የሄዱት ? ለርስዎ ለውጥወራ ስህተት ሥን ያህል ተናት ወይም ወራት የይተው ሄዱ ? ለምን ያን ያህል ጊዜ ቆዩ ? የት ነው የሄዱት ? ለምን ያን የሄዱበትን ቦታ መረዱ ?
6. የሥጋ ደዌ በሽታ ለንደሜታ ያወቁ ጊዜ ሥን ተሰማኙት ? ለምን ? በሽታው ለንደሜታ በመጀመሪያ ለማን ተናገሩ ? ለምን ? ቤብብያ ለበሽታው ቢያሁቁ ሥን ተሰማተው ? በተኛት ላይ የተፈጠረ ገገር ነበርን ?
- 7 ለርስዎ የሥጋ ደዌ በሽታ ለንደሜታ ገረቤቶቹ በሚመሩበት ቦታ በገኙ ያሁቁ ነበር ? ማን ነገሩ ቤብብያ ያጋጠማችሁ ገገር ነበር ? ሥን ዓይነት ? ለምን ? ልጅዎ በት/ቤት ያጋጠማተው ገገር ነበር ? ስነማን ? ለምን ? ሥን አደረጉ ?
8. ቤብብያን የሥጋደዌ በሽታ ለንደሜታው ለማወቅ ለህክምና ዳርመራ ወሰዱት ነበር ? ራስዎ አሰበው ነው ይዘተው የሄዱት ? ስልጣን ማን መዘርት ? የሚ ወዘተን መድኃኒት ባያደርጉ ሁለጊዜ ይወሰዳሉ ? ስልጣን ለምን ?
9. ስሁን በፊት የሥጋደዌ በሽታች ሆስፒታል ወይም መኖሪያው ውስጥ ኖረው ያውነሱ ? ስብረት ሥን ተሰማኙት ነበር ? ለምን ስዚያ ወሱ ? ስዚያ ኖረው ስብረት ስብረት ሥን የሰውት ነገር አለ ? ስለ አሰርት የሰውት ነገር አለ ? ስለ ሥጋ ደዌ የሆኖ ወራት ሊነገሩኝ ይችላሉ ?
20. ለርስዎና ቤብብያ ለህክምና ሥጋደዌ ለመወየቅ የት ነበር የሚሄዱት ? ለምን ? አሁን የት ነው መሄድ የሚኖርዎት ? ለምን ?
11. የሥጋ ደዌ በሽታ መንስህ ገለጽታል ? በሽታው የሚሄዱ ነው ? ለንደሜታ መጽ ነው ይህን ያወቁት ?
12. ለርስዎ የሥጋደዌ በሽታ በያዙት ጊዜ በገኙ ለሥጋ ደዌ በሽታ ሥን ያሰቡና ይናገሩ ለንደሜታ ያሰቡት ? አሁን የአስተሳሰብ ለውጥ አለ ተሰው ያሰቡት ? ለምን ? ለንደሜታ ? ለውጥ ስሌት ለምን ?
13. ስዚህ በፊት የሥጋ ደዌ በሽታች ቦታ አባል የሆነበት ማህበራዊ ገንጌነት ለንደሜታ

ለርቦቻ አባል ናት ? መጽ ነው አባል የሆነች ? ለምን ?

14 . በህግ ላይ አምነት ናጂት ያውያል ? ህጉ ለዳኑ ወይም አጭሪ ያደርግ ነበር ?
አሁን ?

15 . በሥነ ደዌ በሽታ ምክንያት የሰውነት ቀርጽ ለምንጭ ነው የሚበላሸው ? በሰውነት
አንድ አንድዚህ ሊገጽ ነለ ? መሰላሰል ይህ ነበር ? ሰውነት ቀርጽ
መበላሸት ምክንያት በቻጅ በጥሩ ሁኔታ ሲያቀርቡ ሲቀሩ ምን ይበጣታል ነበር ?
ለምን ? አሁን ?

16 . በጤና ተቋማት የጤና ሠራተኞች ለምሳሌ በሽታዎች በሌሎች በሽታዎች መከሰል
ለዳኑ ያደርጋሉ ብለው ሃሰቡ ነበር ? ወረፋ መመበቲያ ክፍል ነሎ ሌሎች በሽ
ታዎች ስህተት በሽታዎች ጋር አብረው ለመጥጥ ?

17 . በአንድ አውቶብስ ተሳፋሪው የጊዜው በጊዜው ? አሁን አንድ ነው ? የሥነ ደዌ
በሽታ ያላያዘው ሰዎች በሚታዩበት የጤና ተቋም ሄደው ለመመርመር ፍላጎት አሉት?
ለምን ? ከሌሎች ለምን ?

17 . የሥነ ደዌ በሽታ ከሌሎች በሽታዎች የተለየ ነው ? ለምን ?

18 . መጽ ነው ላይ የመሠረተ ? በሽታው አንዲያዘው ከወቅ በኋላ ነው ወይስ
ከዚህ በፊት ? በድጋሚ ላይ ይህ ነው ?

19 . መጽሐፍ ተጻፎ ወይም ቀደስ ቅርጽ ስለሥነ ደዌ በሽታ ምን ይላል ?

የገብ መደቁ ፍርድ ለሀይማኖት መረጃ

1. ጤና ግለሰብ ምን ግለሰብ ነው ? የጤና መታወቅ ምክንያቶች ምንድን ናቸው ለምንድን ነው አንዳንድ ሰዎችን በሽታ ሲይዙ የሚከተሉ ሌሎችን የማይዘገዙ ?
2. ምን አይነት በሽታ የያዘው ሰዎች ናቸው አጠቃላይ ጊዜ ወደ ቤቱ ድርሰት ወይም መሰጠት የሚችሉት ? ለምን ? ለምንድን ነው አጠቃላይ ጊዜ የሥጋ ድቁ በሽታዎችን በቤቱ ድርሰት ወይም በመሰጠት ማናገሻው ?
3. አርባ ያለበት ቤቱ ድርሰት ወይም መሰጠት የሥጋ ድቁ በሽታዎችን ለመርዳት ምን ዓይነት ርገው ያውቃሉ ? ለምንድን ነው ብዙ ህይወት ያደገው ሰዎች ወይም ድርጅቶች የሥጋ ድቁ በሽታዎች ወይም ሆስፒታል ለመሥራት ተከራካሪ ያደርጉ የነበረው ?
4. ብዙ የሥጋ ድቁ በሽታዎች በሌሎች ሥራ ላይ የተሰማሩ ይመስሉታል ? ለምን ?
5. የሥጋ ድቁ በሽታዎች መንገድ ምን ይመስሉታል ? በሽታው የሚደብደብ ? አንድ ? የሥጋ ድቁ በሽታ ከሌሎች በሽታዎች የተለየ ነው ? የሚሰማው ? መከላከል ይቻላል ?
6. ለምንድን ነው ብዙ ሰዎች በሥጋ ድቁ በሽታ ላይ ፍርሃት ሥጋ ያለባቸው ለምን የሥጋ ድቁ በሽታዎችን ያገቧቸዋል ? በዚህ ምክንያት ይህን ብዙ የሥጋ ድቁ በሽታዎች ወደ ቤቱ ድርሰት ወይም ወደ መሥጫው የሚመጡት ?
7. በአንዳንድ ወይም ሌሎች ሥነ ሥርዓቶች ላይ ለማሳሰብ ድርሰት ለመሰጠት ? ለገንዘብ ወይም ተባብሮ ላይ ለሥጋ ድቁ በሽታዎች ልዩ ነበር ? አንዳንድ ሰዎች ለሌሎች ስራ ላይ ለምን ተከራካሪ ይሆናሉ ? ይህን ድንገት ለርባ ሰዎች ስራ ላይ ተከራካሪ ቢሆን በጣም ይጠቅማል::
8. የሥጋ ድቁ በሽታዎችን ገንዘብ ለመገባት ወይም ጥፋታቸውን ለማወቅ ይጠቅማል ነበር ? አንዳንድ አይነት ሁኔታ አገጥሞች ያውቃሉ ? ሁኔታው ከሌሎች ሰዎች የተለየ ነበር ? ለምን ? የሥጋ ድቁ በሽታዎች በቤቱ ድርሰት ወይም በመሰጠት ጠቅላላ ለመጠየቅ ይረዳል የሚባለው ነበር ? ሌሎች የሀይማኖት መረጃዎች በሌሊት ጊዜ ምን ይሉ ነበር ? ሌሎች ምዕመናንን ? አሁን አንድ ነው ?
9. በተጨማሪ ጊዜ ስለሥጋ ድቁ በሽታ ምን ተብሎ ነበር የሚመዘኑ ? አሁን ? ስለሥጋ ድቁ በሽታ ስብከት ስጥታው ያውቃሉ ? ብዙ ሌሎች ይገባሉ ?
10. የሥጋ ድቁ በሽታዎች በጣም ህይወት ያደገውን ናቸው ? ለምን ? ግን ወደ ሆስፒታል የሆነ የሥጋ ድቁ በሽታ ያለው አገጥሞች ያውቃሉ ? ብዙ ከሌሎች የሀይማኖት መረጃዎች ጋር ያለው ገንኙነት አንድ ነበር ? ድቁ በሽታ መሆናቸውን በምን አወቁ ?
11. ሌሎች ምዕመናንን ያውቁ ነበር ? ገራቸው ? ምን አይነት የሀይማኖት መረጃዎች በሥጋ ድቁ በሽታ ፍርሃት ሥጋ ያለባቸው ያውቃሉ ? ለምን አሁን ? ለምን ?

- 12 . የሥጋ ደዌ በሽቶች ብቻ የሚታወቁት የጤና ተጋም አሰን ? የሥጋ ደዌ በሽቶችን በሌሎች የጤና ተጋም አጠቃቀም ጊዜ ያያሉ ? ለዳኑ ወይም አዳሉ ያያሉ ? በግግን ? ለምን ?
- 13 . የሥጋ ደዌ በሽታ ጠባቂዎችን ገፍቶ የጤና ፕገር ነው ? ለምን ? ምን መደረግ አለበት ? የናንተ የሀይማኖት መረጃች ሜና ምን ይሆናል
- 14 . መፅሕፍ ቀዳሳ ወይም ቀዳሳ ቁርካርታ ስለ ሥጋ ደዌ በሽታ ምን ይላል ? ስፍራ አድርገው ሲነገሩኝ ይቻላል ? ሌሎች ሀይማኖቶች ስለሥጋ ደዌ በሽታ ምን ይላሉ?
- 15 . ስሥጋ ደዌ በሽታ ሌላ በመፅሕፍ ቀዳሳ ወይም በቁርካርታ ስሙ ተጠርቶ የተጠየቀ በሽታ አለ ? ምን ይላል ?
- 16 . በአርብ ያ ተወለደና በቀዳም ተወለደ መካከል የሥጋ ደዌን በሽታን በመለከት የአስተማሪ ልዩነት አሰን ? አንዲት ?
- 17 . የሥጋ ደዌ በሽታ የሰው ልጅ ለጊዜ ለሚያገኘው ምክንያት ገጭተኛነት መንገዶች አንዲ ነው ?
- 18 . የቀዳም የሀይማኖት መረጃች የሀይማኖት ሰጪ ስለ ሥጋ ደዌ መንበህ የሚናገሩትን ይተባብሩ ነበር ? አርብ ያ ወይም የሀይማኖት ጋዶችን ?
- 19 . የሥጋ ደዌ በሽታ ይይዘኛል ብለው አሰበው የይም ተጋምተው ያውታሉ ? ለምን ?

- 15 . ሥጋ ደዩ አገዳሥ ነው የሚታወቀው ለምንድር ነው ህባድ ላይ የሥጋ ደዩ በሽታ ተገኝቶ የሚኖሩት ? የሥጋ ደዩ ሆስፒታል ወይም የበሽታውን ጠቅላይ ሥጋ ደዩን ለማስወገድ በዘጠኝ ጥረት ስራ ነው የሰጠው ያምናል ? ለምን ?
በሰ / / አም ዲ . ፡ ሲነገሩን ይገባሉ ? ለምን በሽታ ነው የሚገጠው የሥጋ ደዩ ሁኔታ ምንድን ነው ?
- 16 . በአጠቃላይ የሚገኙ ጤና ሠራተኞች ሥጋ ደዩ በሽታ በተገባሉ ለመገንባት በአገር ላይ ነው ያሉት ? ለምን ?
- 17 . ጤና ሠራተኞች ለሥጋ ደዩ በሽታ ላይ ለዳኑ ወይም አድልዎ ያሳዩ ነበር ? ለምን ? አሁን ? ለምንድን ነው ጤና ሠራተኞች ለዚህ የሰጠው ፍርድ ሥጋ ደዩን በሥጋዎቹ በሽታ ላይ የነበራቸው ? አሁን ?
- 18 . ሥጋዎቹን በተመለከተ የጤና ማህበረሰብ አስተማሪው ያውቃል ? የሌላ ? ለምን ? ምን አሰጣጥ ተገኝቶ ?
- 19 . በዚህ ጤና ተቋም ውስጥ የሥጋ ደዩ በሽታ የሚገጠው ስለሆነ ሌላ ? ለምን ነው ሥራ የሚቀርቀው ? በስራ ላይ ሥራ ላይ ለመገባት ያውቃል ? ለምን ?
- 20 . ሥጋ ደዩ ለደዘን ይገባል የሰጠው ተጠቃሚው ያውቃል ? ለምን ?
- 21 . የሥጋ ደዩ በሽታ በአገራችን ዘርፍ የጤና ጥገና ነው ? ለምን ? ለምን ለምን ስራ በሌላ የሰጠው ያውቃል ?
- 22 . ጠቅላይ ጥቅም ወይም ጥቅም ለሥጋ ደዩ በሽታ ሥጋ ደዩ ላይ ?
ይህ ስራን በበሽታ ላይ ለምን ፍርድ ሥጋ ደዩን ለማስወገድ ነው የሰጠው ያምናል ?

DECLARATION

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

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This thesis has been submitted for examination with our approval as university Advisers.

Advisor

Prof. Dennis Carlson 