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FACTORS IMPEDING EARLY DIAGNOSIS OF LEPROSY PATIENTS IN DAR ES SALAAM REGION

BY

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A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT FOR THE DEGREE OF MASTER OF SCIENCE IN TROPICAL DISEASE CONTROL (Msc.TDC) IN THE UNIVERSITY OF DAR ES SALAAM.

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ABSTRACT.

In its 1991 annual report, the Tanzania National Tuberculosis and Leprosy Programme (NTLP) expressed concern that about 15.0% of newly detected leprosy patients in the country were having disabilities of grade 2 or 3 (based on the 1970 WHO proposed disability grading scale) meaning delay in diagnosis of the disease. This figure remained more or less stable for the preceding five years. Such a situation was not only a surprise to NTLP in view of the efforts already made by the programme in increasing people's awareness about the disease and in training of health personnel specifically about diagnosis and management of leprosy; but also undesirable outcome as far as strategies for the control of leprosy are concerned.

To investigate factors responsible for the delay in leprosy diagnosis, an unmatched case-control study was performed to test the hypotheses that there is increased delay in leprosy diagnosis among people who have little or no knowledge about leprosy, negative attitudes towards modern health care for leprosy and those with foreboding anticipation of being socially isolated if known to have leprosy than among patients with high level of knowledge about the disease, positive attitudes and who do not anticipate isolation. Another hypothesis tested was taht delay in leprosy diagnosis was a result of hospital staff to recognize the disease early enough in patients who present to health care facilities for diagnosis and treatment.

The study was done in six health units within Dar es Salaam region. A total of 250 leprosy patients were recruited into the study, 46 being cases and 204 being controls. Patients without leprosy were also interviewed. A questionnaire was the main method of gathering information. It was designed to find out aspects of the leprosy patients'

clinical and personal history that might be related to delay in leprosy diagnosis, general knowledge about leprosy for both leprosy and non-leprosy patients and if prejudices and stigma about leprosy existed in the community where the patients lived. Treatment cards of the leprosy patients were also scrutinized for additional information.

Farming occupation and borderline tuberculoid leprosy were found to be significant risk factors for acquiring significant disability as a result of leprosy before leprosy is diagnosed in a patient (delay in diagnosis). Other findings of the study were that both leprosy and non-leprosy patients had deficient knowledge about leprosy and in general the family and the community were sympathetic and supportive to the leprosy patients. The study findings could not confirm any of the four hypotheses, suggesting that there could be other factors than those hypothesized, that impeded early diagnosis of leprosy in this study population.

The results of this study indicated the need for further studies on delay in diagnosis of leprosy addressing service and community related factors as well. A need for better education of leprosy patients and the public at large about leprosy was emphasized.

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DECLARATION

I declare solemnly that this dissertation is my own original work and it has never been submitted for a similar degree in any other University.

..... Date.....22/9/85

Candidate's signature

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LIST OF ABBREVIATIONS.

AMOs	Assistant Medical Officers.
CDC	Centres for Disease Control.
DTLC	District Tuberculosis and Leprosy Coordinator.
IARC	International Agency for Research on Cancer.
LEP	Leprosy.
LEPRA	Leprosy Relief Association.
MAs	Medical Assistants.
MDT	Multidrug Therapy.
MOH	Ministry of Health
MOs	Medical Officers.
NGO	Non-Governmental Organisation.
NTLP	National Tuberculosis and Leprosy Programme.
RDAs	Rural Dispensary Attendants.
RMAs	Rural Medical Aides.
RTLC	Regional Tuberculosis and Leprosy Coordinator.
TDR	Tropical Diseases Research.
TLCU	Tuberculosis and Leprosy Central Unit.
UNDP	United Nations Development Programme.
WHO	World Health Organisation.

1.0. INTRODUCTION.

1.1. Background information.

1.1.1. Geographical distribution of leprosy.

It is difficult to estimate the number of cases of leprosy in the world because case diagnosis and case definition are not always clear or consistent, and enumeration of cases in many regions of the world is either incomplete or irregular.

However, despite these difficulties, estimates are extrapolated from available data from time to time. For instance the WHO estimates of leprosy cases worldwide for 1966 and 1976 were 10.8 and 10.6 million respectively, and in the early 1980s it was estimated to be 10-12 million cases.[1] More recently, and particularly since 1985, the leprosy situation in many parts of the world has undergone major changes, following the widespread introduction of multidrug therapy (MDT) as recommended by the WHO study group on chemotherapy of leprosy for control programmes in 1981. Based on available information and its interpretation, the number of leprosy cases in the world for 1991 has been estimated at 5.5 million.[2] The number of individuals deformed by leprosy, including those cured of the disease, has been estimated at between 2-3 million.[3]

The distribution pattern of leprosy in the world has changed dramatically over the years. In the past the disease was remarkably cosmopolitan in its distribution, being endemic as far north as the Arctic Circle.[4] Today leprosy is of considerable importance in the developing countries of Asia, Africa, and Latin America. The global distribution based on the registered cases in 1990 is shown in Figure 1.[5]

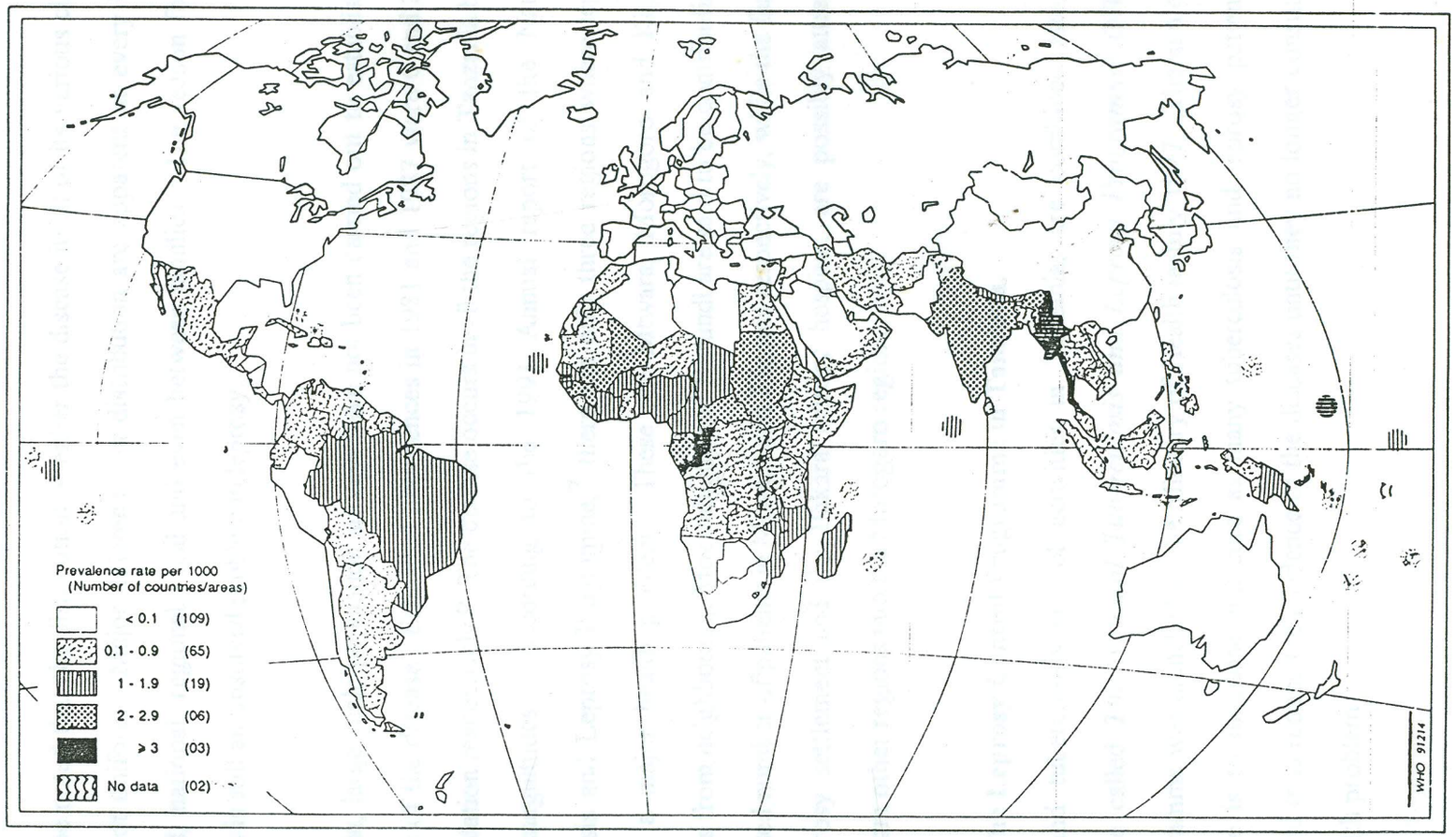


Figure 1. Prevalence of registered leprosy cases in the world October 1990.

It should be noted that the distribution of either the disease itself or its various clinical forms is not uniform. Major differences in distribution are apparent at every level: continental, national, regional, local and even between families. The reason for the differences is still an unsolved problem in leprosy.

In Tanzania, large scale population surveys have not been carried out to establish the prevalence of the disease. Estimated prevalences in 1981 and 1987 were 6 and 3 per 1000 population respectively.[6] The disease occurs in all the regions in Tanzania but at different magnitudes. According to the 1991 Annual report of the National Tuberculosis and Leprosy Programme,[7] there are only three regions where leprosy represents a major health problem. These are Mtwara, Morogoro and Kigoma. Immigrants from neighbouring Mozambique and Burundi are said to be contributing to the increased number of patients in Mtwara and Kigoma respectively, while the famous Chazi leprosy settlement and the Ifakara leprosy hospital, are possibly attracting patients from other regions into the Morogoro region.

1.1.2. The Leprosy Control Programme in Tanzania.

Leprosy and tuberculosis control activities in Tanzania, are combined into one programme called *The National Tuberculosis and Leprosy Programme* (NTLP). This programme was launched by the Ministry of Health in July 1977. The aim of the programme is to diagnose and cure as many tuberculosis and leprosy patients as possible and thus reduce the incidence of the diseases until they no longer constitute a public health problem.

1.1.2.1 Organization structure.

The National Tuberculosis and Leprosy Programme is one of the programmes in the vector-borne disease control section, which is under the directorate of preventive services in the ministry of health. Other programmes in this section are Malaria Control Programme, Diarrhoea Disease Control Programme, Acute Respiratory infection and Expanded Programme on Immunization to mention only a few (see Figure 2). The leprosy control activities are fully integrated into the primary health care structures. However the programme has its own managerial and supervisory staff dealing solely with tuberculosis and leprosy in their day-to-day activities, at the national, regional and district levels.

According to the 1991 annual report of the programme there are four doctors at the national level, one Regional TB/Leprosy coordinator (RTLC) in every region and at least one District TB/Leprosy coordinator (DTLC) in every district. They work in liaison with other health workers who provide general health services in the respective health care levels as far as case finding, treatment and case holding in leprosy and tuberculosis are concerned.

As far as primary health care is concerned the DTLC is a very important and crucial worker in the programme since he/she works full time at the peripheral level. His/her main task, is to guide and help peripheral health workers in the district so that they can initiate and sustain case finding and treatment. In addition, in collaboration with other district experts, the DTLC has the responsibility of creating awareness of tuberculosis and leprosy in the community with the aim of changing the attitudes towards these diseases so that the community can be involved in early case finding and regular and adequate treatment.

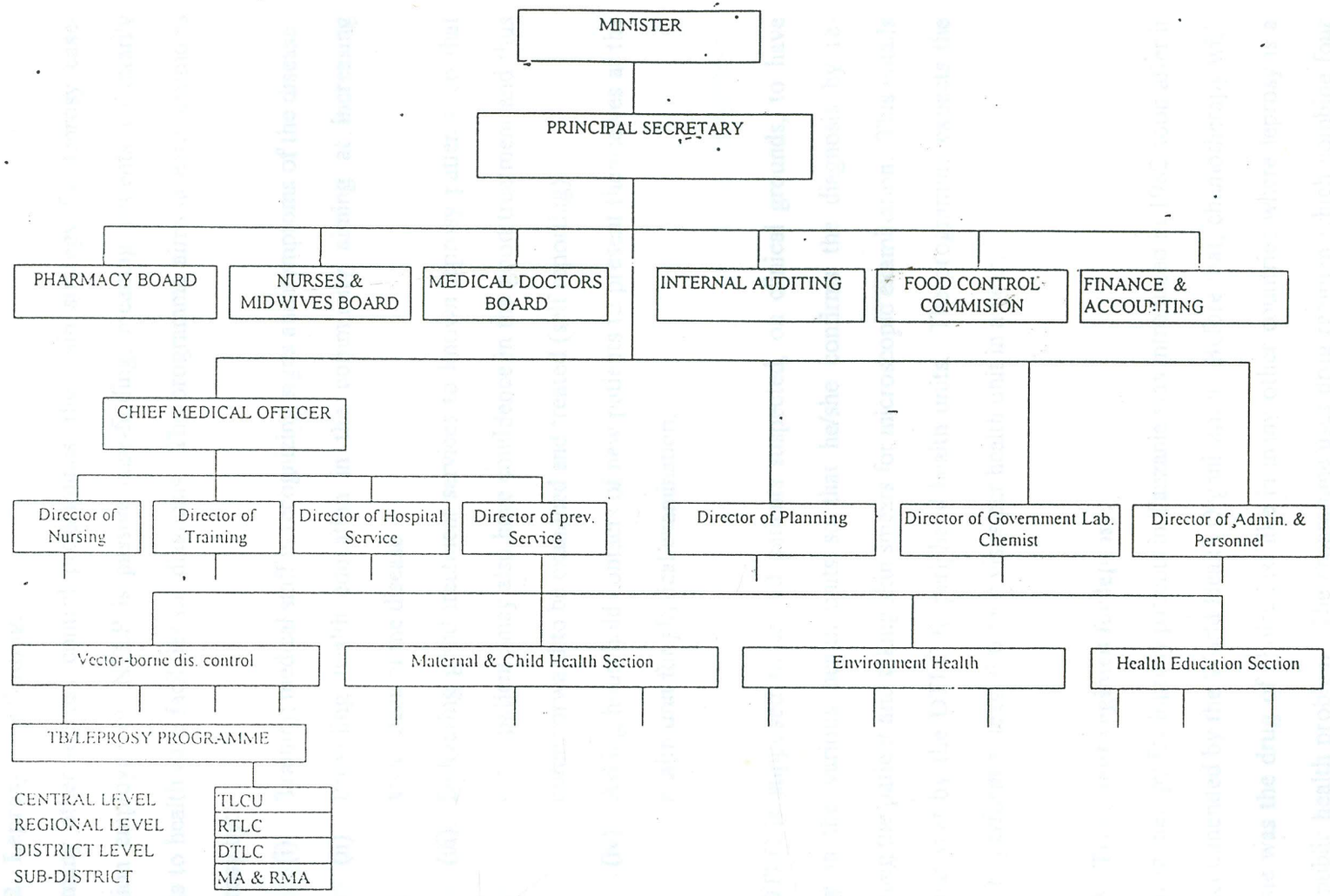


Figure 2: Part of MOH Organogram showing the position of NTLP (source: MOH Tanzania 1994)

1.1.2.2 Leprosy case finding.

Like many other leprosy control programmes, the main strategy for leprosy case-detection employed by NTLP is passive case-finding; meaning patients voluntarily reports to health care facilities for diagnosis. The programme aims at early diagnosis of leprosy by:

(i). Training medical staff in recognizing signs and symptoms of the disease.

(ii). Providing health education in the community aiming at increasing awareness of the disease.

(iii). Delivering good treatment services to known leprosy patients, so that other patients may also have confidence in the good treatment and thus come forward to be examined and treated (self reporting).

(iv). Asking household contacts of new patients to present themselves at the health unit for physical examination.

The DTLC is supposed to see all patients suspected, on clinical grounds, to have leprosy in the various health units so that he/she confirms the diagnosis by re-examining the patient and taking skin smears for microscopic examination. This entails a regular visit by the DTLC to peripheral health units. The programme expects the DTLC to perform at least 4-6 such visits per health unit in a year.

1.1.2.3 Treatment regimen for leprosy.

Multidrug therapy for leprosy patients in Tanzania was introduced in 1982 soon after it was recommended by the World Health Organization. Before that, chemotherapy with Dapsone was the drug of choice just like in many other countries where leprosy is a major public health problem. The programme uses drug regimen which combine four drugs; namely RIFAMPICIN, ISONIAZID, PROTHIONAMIDE and DAPSONE.

Isoniazid, Prothionamide and Dapsone are combined in one tablet called ISOPRODIAN. The proportion of each drug in the combined tablet is:- 175 mg Isoniazid, 175 mg Prothionamide and 50 mg Dapsone. This combination has been shown to have a synergistic lethal effect on the leprosy bacilli.[7]

The regimen adopted by the NTLP differs slightly from that recommended by World Health Organization.[8] Initially the NTLP had seven drug regimen depending on the category of leprosy but recently the number has been reduced to three in order to reduce confusion among health workers which in turn facilitates evaluation of treatment and training of staff. The recommended regimen are:

(a) For paucibacillary patients:-

(i). Isoprodian daily for six months.

(ii). Rifampicin monthly for six months (supervised).

(b) For multibacillary patients who can be supervised in the initial one month of treatment.

(i). Isoprodian daily for 24 months.

(ii). Rifampicin daily for one month followed by monthly Rifampicin for 23 months.

(c) For multibacillary patients who cannot be supervised in the initial one month of treatment.

(i). Isoprodian daily for 24 months.

ii). Monthly Rifampicin for 24 months.

It is important to note that;

- Dosages are adjusted according to age of the patient.
- For daily doses Rifampicin is given to patients while they are admitted in hospital.

- For monthly doses Rifampicin is given under supervision once every month in specific, strategically located health units on an outpatient basis.

1.1.2.4 Disability prevention and management.

The National Tuberculosis/Leprosy Programme aims at preventing disabilities through early detection and treatment of the patients. Thorough physical examination is done by the DTLC for all newly detected cases and any detected disability is graded and recorded on the patient's treatment card (The 1970 WHO proposed leprosy disability grading scale is used). In the course of treatment, periodic reviews of the patient's disability are made and progress recorded.

The DTLC is also responsible for teaching patients with disability on what to do in order to prevent further disability. Some of the important aspects being taught are:

(i). How to protect the feet in patients with foot sensory loss.

(ii). How to care for dry skin.

(iii).How to protect an eye with inefficient blinking.

(iv). How to care for wounds and eye infections at home.

Other services rendered by the programme include reconstructive surgery for patients with grade 2 disability and who are fit for operation. In addition every region has a workshop which deals with the manufacture of shoes and prosthesis for patients who need them.

1.1.2.5 Trends of leprosy in Tanzania.

Since multidrug therapy was introduced in Tanzania, the case detection rate of leprosy patients has been declining steadily as shown in Table I. This has been partly attributed to the success of the treatment regimen.

Table I Trends of leprosy in Tanzania.

Year	No. of pts. on register	No. of newly detected pts.	Case detection rate/100,000 population
1979	50740	5661	34.2
1980	49480	5423	30.0
1981	46150	3984	21.2
1982	42853	2880	14.9
1983	35092	3208	16.5
1984	30204	3124	15.5
1985	26630	3303	15.9
1986	20996	3183	14.9
1987	13928	3591	16.4
1988	9305	3610	16.0
1989	5840	3319	13.9
1990	4746	3202	13.4
1991	4360	3107	12.7

Source: NTLP Annual reports of 1985 & 1991.

1.1.3 Tanzania Leprosy Association.

Tanzania Leprosy Association (TLA) was established in 1978, in order to work in close co-operation with the National Tuberculosis and Leprosy Programme in its fight against leprosy. The head office is based in Dar es Salaam, but there are branches in Mwanza, Tabora and Mara regions. Currently the association have a total of 296 members. The major objectives of the association are:

i). To increase awareness of leprosy among the general population through health education campaigns, so that people with symptoms of leprosy come forward to the health care facilities for diagnosis and treatment.

ii). To ensure early and adequate treatment of all patients found with leprosy and rehabilitation of those disabled as a result of the disease.

In order to achieve its objectives, the association has established co-operation with the German Leprosy Relief Association and the Netherlands Leprosy Relief Association. These associations are the major donors of funds, drugs, equipments and vehicles required by NTLP. The donations are channelled through the Tanzania Leprosy Association, which has to ensure that the donations are utilised properly and give feedback to donor agencies. The contributions made by the Tanzania government to NTLP is provision of manpower and the infrastructure that are required.

1.2. Statement of the problem.

Disability in leprosy patients is largely a result of direct nerve damage leading to sensory, autonomic or motor loss of the affected body area or limb. Generally disability does not occur until some months or years after the onset of the clinical manifestation of the disease.

The extent and type of disability vary from one country to another. However, it is estimated that about one-third of all leprosy patients have significant disability[9] (grade 2 or 3 according to the 1970 WHO proposed disability grading scale; or grade 2 according to the 1987 WHO scale). In many parts of Africa, it is common to find up to 20% disability among leprosy patients.[7] The 1987 LEPRA report of the Malawi Leprosy Control Programme indicated that 21.9% of newly diagnosed patients had grade 1-3 disabilities.[10] This occurred in a programme that delivered treatment within three miles of patients' homes.

In Tanzania, disability due to leprosy has been unacceptably high for many years (see Table II). In this table it is seen that out of 2208 newly diagnosed leprosy patients in 1983, 63% had grade 0 disability; meaning they had no clinically detectable disability while 22% and 15% had, respectively, grade 1 and 2 disabilities, which represents an increasing severity of disabilities. This grading system was based on the 1987 WHO proposed leprosy disability grading scale (see Annex 9.4).

Table II. Disability in new cases of leprosy 1983-1991 Tanzania mainland.

Year	No.of new patients	% Disability grading of new patients		
		0	1	2
1983	3208	63	22	15
1984	3124	65	20	15
1985	3303	62	21	17
1986	3183	67	21	12
1987	3591	69	16	15
1988	3610	69	17	14
1989	3319	67	17	16
1990	3202	70	15	15
1991	3107	71	15	14

Source: NTLP Annual report of 1991.

The consequences of disability in leprosy patients are well known. Fear, abhorrence and stigma, are but few of the social consequences. Emphasizing on this point, Bechelli and his colleague wrote; "there is no other disease that causes such a reaction in the community and so much distress and unhappiness to patients and their families. This anxiety may follow leprosy patients and relatives throughout their lives and cast a permanent shadow over their families and professional and social activities".[11]

Disability also causes loss of productive labour which in turn has a negative impact on the economy of the country. Reconstructive surgery of the disabilities is expensive;

Tanzania, being among the poorest countries, cannot afford the costly reconstructive surgery of disabled patients on a large scale. Furthermore, in the absence of any other occupation, disabled patients become beggars. In the city of Dar es Salaam and other towns in the country, there is a large number of leprosy sufferers with disabilities who make their living by begging (personal observation).

It cannot be stressed strongly that disability is not an inevitable or necessary part of leprosy. Its occurrence indicates some defect in the strategy of leprosy diagnosis and treatment. The proportion of individuals with disabilities among newly detected patients is both an important epidemiological and operational indicator of leprosy case detection since it is directly related to the delay between onset of clinical signs and case detection. This indicator reflects the effectiveness of leprosy control programmes in terms of early case detection and the level of community awareness of the disease. In a well conducted leprosy control programme almost no leprosy patient on first diagnosis should be suffering from grade 2 disabilities[12] (1987 WHO disability grading scale).

The factors leading to this delay can be viewed in two perspectives: i.e. the patient reporting to a health facility already disabled (patient delay) or a diagnosis is made late inspite of the patient having reported early to the health facility (hospital delay). In the first instance, the patient as an individual and the community in which he/or she lives have parts to play. The patient's awareness of early symptoms and/or signs of the disease, percieved susceptibility, percieved severity, his or her attitudes towards modern health care, accessibility to a health care facility and prevailing socio-cultural forces are of utmost importance if early diagnosis is to be made, particularly where passive case-finding is used. The level of community awareness about early clinical features of the disease and its attitudes towards modern health care utilization *vis a vis*

traditional medicine are equally important factors in so far as early leprosy detection is concerned.

As for hospital delay, factors related to service provision have a role to play. Primary health care workers are frontliners of the leprosy control programme since they are the first level of contact by majority of patients. Therefore update knowledge and skills about leprosy diagnosis and treatment, among primary health care workers, is as important as it is for the availability of necessary diagnostic and treatment facilities at all times in the health units as well as a conducive environment for performing thorough physical examination of patients. Another important factor is the fact that health personnel need to have positive attitudes towards leprosy and the people affected by the disease.

Regular supervision of the primary health care workers by leprosy programme coordinators is crucial, since this enable timely confirmation of diagnosis in leprosy suspect patients detected in peripheral health units and consequently initiate treatment measures before the disease advances further.

Since its establishment in 1977, NTLP strategy for the control of leprosy has been passive case-finding, chemotherapy through MDT and health education. Health education campaigns by the NTLP staff put emphasis on correct ideas about the cause of leprosy, its early features, the importance of early reporting to health facilities for diagnosis after suspecting the disease and the need to attend treatment regularly in order to achieve complete cure. Furthermore, the training of health workers recruited into the programme, apart from imparting general knowledge about the disease, put special emphasis on the assessment and grading of disabilities. District leprosy

coordinators are expected to make an average of 4-6 regular supervisory visits to peripheral health units under their jurisdiction in a year. In view of these inputs, NTLP expected a decline in the disability rate in new cases of leprosy over the years.

However this has not been the case, particularly after 1987 when the proportion of newly diagnosed leprosy patients having grades 1 and 2 disabilities remained more or less static at around 30% (based on 1987 WHO proposed leprosy disability grading scale). This situation prevailed "despite increased health education to people and inspite of increased training for health workers".[7]

Hitherto, knowledge of which factors, among the aforesaid, that could possibly explain the observed high disability rate in Tanzania is deficient. It is against this background that this study was proposed.

1.2.1. Study hypotheses.

1.2.1.1 When knowledge about leprosy is inadequate, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.

1.2.1.2 When people have negative attitudes towards modern health care for leprosy, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.

1.2.1.3 When people have foreboding anticipation of being socially isolated if known to have leprosy, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.

1.2.1.4 Delay in hospital staff to recognize leprosy among patients who present to health care facilities for diagnosis is responsible for the delay in leprosy diagnosis.

The first two hypotheses were among the hypotheses proposed for testing by a meeting of WHO experts on social and economic aspect of leprosy in 1981,[13] but they have been slightly modified by the author. The third hypothesis was adopted from the study done by Muhondwa[14] while the fourth one was formulated by the author.

1.3. Review of the literature.

Published estimates of disability rates in leprosy patients vary widely. A field survey in south India in 1965 found that 33.5% of all detected leprosy patients had physical disabilities. The disability was associated with increasing age and duration of disease.[15] With regard to consequences of disability this study found that 72.7% of the disabled patients had worsened economically. In the same year, WHO conducted community surveys in Nigeria, Cameroon and Thailand.[16] It was found that 23.4%, 35.6% and 41.5% of patients found to have leprosy were respectively disabled. Also a higher rate of disability was found among lepromatous than tuberculoid patients and among males than females.

A survey of leprosy deformities among the patients of Hyderabad city found that neuropathic deformity was a major problem among the patients.[17] Nearly 44.3% of the patients had one or the other kind of deformity of the hand, foot or face. The patients with lepromatous leprosy showed greater tendency to deformity (66.4%). Patients with only anaesthesia in hands and feet formed the majority among the deformity cases.

A review of records of 809 cases of leprosy in a military hospital in India,[18] revealed that 9.13% were deformed; the rate increased with increasing age and only 1.5% cases developed deformity while on DDS treatment. Reaction precipitated deformity in 6.75% of the deformed. Another review of records of leprosy patients was done in an urban clinic of the university hospital, Varanasi.[19] It was found that gross deformity rate was 3.73%. The majority of cases of deformity were in borderline type of leprosy. The commonest deformity was a claw hand.

In a study done in French Polynesia,[20] the proportion of patients with disabilities of grade two and above at detection (based on 1970 WHO proposed leprosy disability grading scale) between 1967 and 1981 remained stable, ranging from 29.2% to 32.6%, with an average of 31.5%. In contrast, the average was 11.7% during 1982 to 1990. In Thailand, a steady trend of disability rate among new cases of about 10% nationwide, between 1981 - 1990 has been reported.[21]

Analysis of data in Karonga district, Malawi, between 1973 to 1987, revealed that 20.0% of new leprosy patients were disabled at the time of diagnosis before a control programme was launched and the figure dropped to 10% after the programme was initiated and evaluated.[22] The study also found that disability increased with age, was more frequent in males than females and was higher in borderline and lepromatous than in tuberculoid leprosy patients. Furthermore, the proportion of disabled patients was found to be higher for passively than actively detected patients.

In East Africa, the only published study on disability is that done in Kenya by Chum and Otsyula.[23] In this house to house survey, it was found that 41.3% of detected leprosy patients had disability; anaesthesia being by far the commonest type. This study also found that disability was more common in males than females.

A study recently done in Tanzania by Muhondwa aiming at identifying factors which impede leprosy case detection within the leprosy programme, revealed substantive findings with regard to leprosy disabilities.[14] Through the scrutiny of a sample of leprosy patient's registration and treatment cards, it was found that about 30.0% of the patients had disabilities of grades 1, 2 and 3, affecting the limbs or eyes (based on 1970 WHO proposed disability grading scale). Eye disabilities were however very rare.

In order to reduce the disability rate, it is necessary that diagnosis of the disease is made early before significant nerve damage has occurred. This depends, among other things, on the method used for case detection, patient and community awareness about early symptoms and signs of the disease and their attitudes towards modern health care, the extent of social prejudice against the disease and availability of efficient and reliable diagnostic and treatment services. Others include convenient clinic timings, efficient professional performance, good working morale and identification of the health workers with the community they serve. Needless to say, it must also be appreciated that the most convincing motivating factor for patients to come for treatment is the demonstration that leprosy can be cured and that treatment of patients is successful.

Several researchers have looked into how these factors influence leprosy control efforts. Van Etten and his colleague evaluated the health education component of a leprosy programme in three regions in Tanzania.[24] They interviewed local leaders, school children and a sample of adult population. It was found that the majority of school children had correct view of leprosy transmission. There was, however, a high proportion of adults who perceived leprosy as being caused by adultery, heredity and witchcraft. Almost all respondents believed leprosy could be cured. Between 80-85%

of adults stated they would use traditional medical treatment. The community leaders generally supported medical treatment.

In a study done in India involving 955 adult community members and 225 adult leprosy patients, it was found that the early signs/symptoms of leprosy were poorly understood by the community.[25] Majority of the community (81.0%) and the patients (75.0%) were unaware or held superstitious ideas about causation of leprosy. The spread of disease through close contact with patient(s) was better known to the community (65.0%) than the patients (45.0%); but the role of open cases in the spread of the disease was stressed by a higher proportion of the patients (17.0%) than the community adults (5.5%). As regard leprosy cure, 89.0% of the patients and 62.0% of the community adults believed in curability of leprosy with early and regular treatment. About 44.0% of the community members showed prejudice towards leprosy.

Another study, conducted in Mangalore, India,[26] found that very few people among the community know that leprosy is caused by a germ (8.0%). Knowledge regarding this was slightly better (22.0%) among patients. Only 15.0% of the community members and 42.0% of the patients were aware of the early signs of the disease. About 54.0% of the community members and 41.0% of the patients felt that leprosy is contagious. Sixty percent of the community and 86.0% of patients were of the opinion that leprosy is curable. Regarding prejudice towards leprosy, it was found that 60.0% of the community members and 56.0% of the patients felt that it is necessary to segregate leprosy patients.

Another study, conducted among 310 leprosy patients attending a clinic, observed that less than a fourth of the patients knew the causes of the disease while 40.0% feared

that their children were prone to get leprosy.[27] About 75.0% of the patients did not encounter any adverse reaction from the other family members, or neighbours even though most of them knew about the disease.

In the study done by Muhondwa, it was also found that the level of knowledge about symptoms/signs of leprosy was very low in the general population while it was generally high among health workers.[14] However the early features of the disease, namely numbness of hands/feet, hypopigmented lesions, red eyes and stuffy running nose were not widely recognised by both groups. The same study also found that stigma about leprosy existed in the two regions surveyed; but did not seem to impede people from seeking health care. As regards practice of leprosy patients, this study found that 75.8% of the patients reported to a health unit as soon as they realized that they might be suffering from leprosy whereas 35.0% took other actions first including consulting traditional healers. A similar phenomenon was found in Pakistan, where 52.0% of leprosy patients had initially consulted traditional healers, inadequately trained physicians and/or untrained medical practitioners for treatment of their symptoms, which resulted in lengthy delays (range from one month to 22 years) before they were correctly diagnosed.[28]

In Northern Nigeria an average delay of one-and-a-half years was found between onset of symptoms and seeking medical advice, among 129 patients.[29] However, 73 patients delayed for four years or more. Reasons for the delay were: taking native medicine (47.0%); lack of understanding of patches (31.0%); belief that patches would heal spontaneously (6.0%) and non-availabilty of diagnostic services (16.0%).

A survey of knowledge and attitudes of the general public towards leprosy and practice of leprosy patients carried out in India before a health programme was initiated showed that the general public had very little knowledge about leprosy compared with patients.[30] For instance as regard to the question "what is the first sign you can see?" only 16.0% of the public and 46.0% of the leprosy patients were able to recognize the sign of the patch. However many patients did not relate the patch to leprosy and therefore did not seek early treatment. As regard attitudes towards leprosy, measured by Likert scale, it was found to be negative (-12.3) for the general public and only slightly positive (+2.56) for the patients. Regarding practice, 26.0% of patients reported to have waited at least three months before seeking modern leprosy care, 22.0% showed up for the first time at leprosy clinic five years after the onset of symptoms. Reasons for not seeking treatment earlier were: patients thought it was only an insect bite (30.0%), or they hoped the patch would disappear (11.0%), or they did not know it was leprosy (14.0%) whereas 19.0% first tried native medicine. However, the evaluation which was done after a health education programme was introduced revealed an improvement in the three aspects:- knowledge; attitudes and practice.[31]

Another survey on knowledge, beliefs and attitudes was done in the Philippines.[32] The respondents were household heads and senior nurse students. It was found that 90.0% of the household heads and 45.0% of the nurses had inadequate knowledge of leprosy and both groups had negative attitudes towards leprosy patients. Similar results were found in Nigeria where the final year nurse students in ten schools were found to have a below average basic knowledge and largely negative attitudes towards leprosy.[33]

The general knowledge about the cause, symptoms, signs and curability of leprosy was also found to be deficient among outpatient population attending skin clinic in Trinidad for problems other than leprosy.[34] A study among leprosy patients with deformity in Bombay showed that few of them had the correct notion regarding the cause of leprosy and almost all said leprosy was curable. However, over 70.0% felt either worry, shame, embarrassment or their combination because of their illness.[35]

Distance to a health unit is often considered to have a deterrent effect on service utilization. In view of this, WHO recommended that distance travelled should be minimized in order to maximize leprosy case detection and have the patients under regular treatment.[36] However, two independent studies[37,38] have demonstrated that, distance of patient to nearest treatment centre does not significantly influence attendance. In fact some patients were found to be attending clinics which are far away from their own locality for fear of being stigmatized. Other studies have shown that, where strong social prejudices against leprosy prevail, some patients and families hesitated in seeking treatment until such a time that deformities and disabilities were obvious.[39,40]

Proper knowledge and skills about leprosy management among health workers, positive attitudes towards the disease, the patients and job commitment are a *sine qua non* conditions not only for early case finding but also for the success of the whole programme. Volinn found that some medical personnel had "negative reactions" towards patients with severe disabilities, terminal illness or diagnostic and therapeutic uncertainties. Such patients were characterized as being demanding, hostile and uncooperative.[41]

Delay in hospital staff to recognise patients' illnesses has been documented. For instance, a review of records for 8 leprosy patients admitted to a hospital in United Kingdom showed that there had been delays in diagnosis, ranging from a few months to many years.[42] The delays were as a result of misdiagnoses which included syringomyelia, allergy and mycosis. A detailed enquiry concerning the attendance of patients suspected to have Pulmonary tuberculosis at the peripheral health units and the investigations they had had was done in Kenya.[43] The study revealed that 70.0% of the respondents claimed attendance at more than one health unit, and an average of 5.3 visits had been paid. However, inspite of the large number of attendance with a chronic cough, nearly two thirds of the suspects claimed that they had never been examined radiographically or bacteriologically, meaning that a large proportion of persons with symptoms calling for investigation for tuberculosis were not being identified in the peripheral health units.

With regard to supervision of the primary health care workers, the study by Muhondwa[14] found that, out of 115 health units surveyed, 67.8% were visited by the DTLC over a period of one year while only 20.0% were visited by the RTLC. The respective average number of visits per health units were 2.5 and 1.4, which implies inadequate supervision.

2.0. RATIONALE OF THE STUDY.

Early diagnosis and treatment of leprosy and regular attendance of patients to health units providing treatment are very important for all leprosy patients if control of the disease is to be achieved. Attendance to health units depends, *inter-alia*, on the extent of disability which the patient has. For instance, patients with plantar ulcers are unlikely to be attending clinics as regularly as those with other types of ulcers because

of severe deformities which are associated with the former and therefore limiting their movements. The World Health Organisation advocates community rehabilitation or domiciliary care of disabled leprosy patients.[44] This strategy aims at enabling the patient to achieve social integration as opposed to formerly widely practised institution based care.

In order for the goal of early diagnosis and treatment of leprosy to succeed, the amount of stigma attached to leprosy has to be lessened. Since leprosy stigma is known to have a direct relationship with the grade of disability which a patient may have,[9] prevention of the occurrence or further worsening of disability before and after initiating therapy is therefore an important measure towards reduction of stigma. Hence, whenever a large proportion of leprosy patients is registered for treatment while already having significant disability, it becomes necessary that prompt measures are taken to determine factors underlying the problem and subsequently finding means and ways of reducing the disability.

In Tanzania, as previously mentioned, the proportion of patients who have significant disabilities at the time they are diagnosed to have leprosy, is currently high and seems not to have declined during the past five years. The National Tuberculosis and Leprosy Programme annual report of 1991 has voiced concern about this unexpected trend, in view of the effort the programme had put in; specifically, increased health education campaigns to population aimed at increasing awareness about leprosy, increased leprosy training for health workers and improved disability assessment. What is even more disturbing to the programme, is the fact that reasons underlying this problem are at the moment not apparent; as there has been no study performed in Tanzania or elsewhere in this direction.

As it was evident in the review of literature, most studies of leprosy disability have dealt mainly with its magnitude and how it relates to population denominators and knowledge and attitudes towards the disease in general. Thus more information is required to provide an answer to the question as to why there is still a big proportion of leprosy patients who are found with leprosy for the first time while already having significant disabilities. Is it due to inadequate level of knowledge about leprosy among patients and/or the community? Is it due to prejudices and stigma about leprosy prevailing in communities? Is it because of negative attitudes towards modern health care for leprosy held by the patients? Is it because of negative attitudes towards leprosy and/or those afflicted by the disease? Is it due to inability of the health workers to diagnose leprosy early enough in a patient who had presented to the health care facility while in early stages of leprosy? This study attempts to answer some of these questions particularly those which relate to the patient. It is envisaged that the results of the study, apart from being a basis for further large scale studies, will help the NTLP to plan and implement short term measures that will reduce the present rate of disability in leprosy patients in Tanzania.

3.0. OBJECTIVES.

3.1. Broad objective.

To identify factors that impede early diagnosis of leprosy patients in Dar es - Salaam region.

3.2. Specific objectives.

3.2.1. To determine the proportion of leprosy patients who are diagnosed late in the disease process.

3.2.2. To determine the delay in patient's self reporting to a health facility for diagnosis and treatment of leprosy.

3.2.3. To determine the delay in hospital staff recognition of leprosy suspects who present themselves to health facilities.

3.2.4. To determine the level of knowledge about leprosy among leprosy patients.

3.2.5. To determine the level of knowledge about leprosy among patients without leprosy.

3.2.6. To determine the attitudes and practices of leprosy patients as regards modern health care for leprosy patients.

3.2.7. To find out if prejudices and stigma about leprosy exist in communities where patients live.

4.0. METHODOLOGY.

4.1. Description of the study area.

The study was conducted in three leprosy clinics, three leprosy treatment centres and two eye clinics located in the three districts of Dar es Salaam region, namely Ilala, Kinondoni and Temeke. The leprosy clinics involved in this study were Temeke, Mwananyamala and Mnazi Mmoja; and the leprosy treatment centres were Magomeni, Tandale and Muhimbili. The eye clinics involved in the study were those at Temeke hospital and Mnazi Mmoja health centre.

The leprosy patients attend the clinics for clinical evaluation, administration of supervised drugs and to receive a regular supply of drugs for unsupervised use at home. The clinics also serve as referral centres for suspect leprosy patients from peripheral health units within the districts. Most of the referrals come from government health institutions and only a few are from NGOs or private clinics

(M.Masaki, personal communication). Referred patients are evaluated by the DTLC every Friday at the Mnazi Mmoja clinic and on daily basis for the Temeke and Mwananyamala clinics.

There are 12 government dispensaries, one health centre and one hospital in Ilala; 15 dispensaries, one health centre and one hospital in Kinondoni and 17 dispensaries, one health centre and one hospital in Temeke. Each dispensary has at least one Rural Medical Aide and each health centre has at least one Medical Assistant and two Rural Medical Aides who provide general health care for patients including diagnosis, treatment and referrals. Each of the three hospitals has a number of medical officers and medical assistants who perform clinical work. Apart from the government institutions, there are numerous dispensaries and a few hospitals which are owned by private individuals, parastatals or NGOs in all three districts. During 1991, there were a total of 149 newly diagnosed leprosy patients for the whole region; 82 being paucibacillary and 67 multibacillary. In 1992, new cases of leprosy were 157; 87 being paucibacillary and 70 multibacillary. New cases of leprosy patients registered in 1993 in the region were 179, 84 being paucibacillary and 95 multibacillary. Dar es Salaam region has an area of 1393 square kilometres. The population estimated in 1988 was 1,360,850 according to the preliminary census report.[45] The distribution of the population in the three districts was 333,708; 621,389; and 405,753 for Ilala, Kinondoni and Temeke respectively.

Dar es Salaam region was chosen as study area for convenience since the health units are relatively easily accessible because of good infrastructure and the swift communication system that is available in the region. Another reason is that by doing the study in Dar es Salaam cost of subsistence for the author was minimized since he

resides there. This was deemed necessary because of limitations of resources that were available for the study.

4.2. Study design.

An unmatched case-control study was performed in which the cases were leprosy patients who at the time of diagnosis had disability of grades greater than or equal to 2 (WHO 1970 classification) while the controls were leprosy patients with disability grades of less than 2. Comparisons were made of the extent to which the two groups were exposed to the four hypothesized factors:-

- When health knowledge about leprosy is inadequate, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.
- When people have negative attitudes towards modern health care for leprosy, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.
- When people have foreboding anticipation of being socially isolated if known to have leprosy, there is greater delay in a patient reporting at a clinic for diagnosis and treatment.
- Delay in hospital staff to recognize leprosy among patients who present to health care facilities for diagnosis is responsible for the delay in leprosy diagnosis.

A second control group composed of patients who had no leprosy was included in the study design in order to compare them with the leprosy patients in as far knowledge about leprosy was concerned.

4.3. Variables on which data was collected.

The following information was collected from the leprosy patients:

- Background information: name, age, sex, education status,occupation, date of registration, district in which the patient is registered, place where the patient lived and home to clinic distance.
- Type of leprosy and mode of detection.
- Disability grade and type at the time of diagnosis.
- Time lapse between the patient's recognition of features of leprosy and reporting to a health facility for diagnosis.
- Clinical features which made the patient seek medical attention.
- Type of health care facility first consulted by the patient for help.
- Time lapse between the patient's reporting to a health facility and the making of leprosy diagnosis.
- Place where the diagnosis of leprosy was arrived at.
- Number of visits made to the first consulted health facility by the patient before leprosy was diagnosed or before seeking treatment from elsewhere.
- Medication prescribed to the patient by the medical staff before he/she was told that he/she had leprosy.
- Diagnosis other than leprosy suggested by the medical staff who first saw the patient.
- Knowledge about leprosy with particular emphasis to its causation, its early manifestations and treatment.
- Attitudes and practices of patients with regard to modern health care as far as leprosy is concerned.
- Prejudices and stigma about leprosy which prevail in communities where the patients lived.

As regard patients without leprosy, information collected included the background variables mentioned above, knowledge about leprosy and existence of prejudices and stigma about leprosy in places where they lived. The information was meant to determine the level of awareness present in the general population regarding leprosy thus providing a base on which to measure the level of knowledge among leprosy patients.

4.4. Study population.

The study involved patients diagnosed to have leprosy for the first time between January 1989 and April 1994 who were attending leprosy clinics and treatment centres in the three districts within the region during the study period. Majority of these patients (86%) were those who were registered in 1992 and 1993. Also a sample of adult patients who were attending the Temeke and Mnazi Mmoja eye clinics for eye problems not related to leprosy were interviewed; particularly for the determination of their knowledge about leprosy and the existence of prejudices and stigma about leprosy in communities where they lived. The choice of eye patients as the second control group was based on an assumption that patients attending a specific clinic were much more likely to cooperate in interview than those attending general clinic. Besides the Tb/Leprosy clinics, the eye clinics were the only specific clinics which were operating in at least two different districts within the region.

4.5. Sample size for leprosy patients.

Information available before the study was conducted indicated that leprosy cases with a disability of grade 2 or above were very few,[7] thus it was necessary to recruit all available cases in the clinics and treatment centres with twice as many controls in order to increase the power of the study. This statistical technique is said to improve the

strength of the differences between the cases and controls, and has been used in several other circumstances.[46-49] The sample size for the leprosy patients in this study was calculated using version 5 of Epi info software package.[50] The calculation was based on the following predetermined information:

(i). Confidence level: i.e. Probability that if the two samples differ in exposure this reflects a true difference in the two populations.

(ii). Power: i.e. Probability that if the two populations differ in exposure the two samples will show a significant difference.

(iii). Control:Case ratio. i.e. The number of controls per each case.

(iv). Expected frequency of exposure in controls.

(v). Odds ratio (OR).

Following the lack of relevant information from available literature about tentative values for items (iv) and (v) the following assumptions were made:-

- The least possible proportion of exposure in the controls for any of the four exposures was taken to be 20.0%.
- Patients with exposures of interest were three times at risk of having disability of grades greater than or equal to 2; i.e OR = 3.

With this in mind, and choosing a 95% confidence level, power of 80% and control:case ratio = 2; the minimum sample size required was 53 cases and 106 controls; totalling to 159. However, the actual numbers obtained for cases and controls during the study period were 46 and 204 respectively.

4.6. Sampling procedure.

4.6.1. Leprosy patients.

Recruitment of the study sites and study units for the leprosy patients was purposeful. This was inevitable in view of the fact that the clinic records had indicated that

regularity of patient attendance to clinic could not be guaranteed. Moreover, records showed that almost all leprosy patients in Dar es Salaam region were being catered for by the six health care facilities which were involved in the study. In addition, the estimated sample size for leprosy patients, required to have 80% power to detect a difference in exposures between the cases and the first control group at 5% level of significance for leprosy patients was nearly as large as the expected study population. Thus, in order to obtain a large number of study subjects as possible, it was decided to include all patients who came to the clinics and treatment centres provided they satisfied the criteria and were willing to be interviewed. Subjects were recruited as they arrived at the clinic or treatment centres on first come first served basis.

4.6.2 Patients without leprosy (Eye patients).

During the study period there were only two eye clinics which were operating, the Temeke and Mnazi Mmoja clinics. Records from the clinics showed that on average 15 new patients of various age groups were being attended in each of the two clinics per day for eye problems. The author decided to interview only adult patients (18 years and above) who had resided in Dar es Salaam for at least one year. The decision to interview only adults was reached after realizing (when interviewing the leprosy patients) that most children were either shy to express themselves or were not conversant with the kind of information required. A minimum period of one year of residence was thought to be enough for the respondents to have observed or heard about problems being faced by leprosy patients in their communities.

In order to obtain as large a number as possible of respondents, the author decided to recruit patients from both clinics. The study subjects were interviewed as they arrived

into the consulting room after obtaining their consent. After one month of data collection, 207 respondents had been interviewed.

4.7 Data collection.

After obtaining a research clearance for the study from the academic staff of the institute of public health, Muhimbili university college of health sciences, permission to carry out the study was sought from the medical officer of health, Dar es Salaam city, and from the district medical officers of Temeke, Mwananyamala and Ilala respectively.

Two methods were employed in gathering the required data. These were;- the use of patients' records and interviews. Most of the background information about leprosy patients, type of leprosy and mode of detection and the grade of disability at the time of diagnosis was obtained from the patients' treatment cards (LEP 01). These cards are specially designed by the NTLP to collect information on type of leprosy, disability status and socio-demographic characteristics of the patients. Information missing on the records was obtained through interviews with the patients.

Interviews with leprosy patients were conducted to determine their knowledge about leprosy, attitudes and practices as regards modern health care for leprosy and the existence of prejudices and stigma about leprosy in communities where the patients lived. As for patients without leprosy, information regarding background variables, their knowledge about leprosy and the existence of prejudices and stigma about leprosy in places where they lived was obtained through interview.

Three research assistants, one in each leprosy clinic, assisted in collecting data pertaining to leprosy patients on days when the principal investigator was not available at the clinic or treatment centre. The use of assistants was necessitated by the fact that clinics for new patients operated on daily basis in the three districts. The data collected by the assistants was largely from patients who came for confirmation of their illnesses on days which did not coincide with the monthly follow-up. The research assistants were part of the staff working with the leprosy programme.

Questionnaires which had both closed and open ended questions were translated into Swahili, pretested and then employed in gathering the information (see Annex 9.3). Before data collection had begun the principal investigator trained the research assistants on how to administer the questionnaires. Furthermore the principal investigator was taking turns in visiting the leprosy clinics and treatment centres on alternate days to participate in data collection and to see to it that the process was going on smoothly.

Informed consent from each patient was sought before being included into the study. Each patient was interviewed privately. Leprosy patients who had come to the clinic for routine monthly follow up were interviewed either before they were attended by the staff running the clinic or after they had been attended but before they had collected their drugs stock from the clinic pharmacy. This was purposely done in order to increase the response rate as all patients had to collect their drugs from this pharmacy. Regarding patients who had come to the clinics for confirmation of leprosy, the interview was done after they had been attended by the clinic staff but before they had collected their drugs. For patients attending eye clinics, the interview was carried out

by the principal investigator himself. The interview was conducted before the patients were attended for their eye complaints.

In order to determine the level of knowledge about leprosy, respondents were asked a series of questions regarding leprosy with particular emphasis on the cause, early manifestations and cure of the disease (see questions 34, 35, and 37 in the questionnaire). The self reported statements were categorized into two levels of knowledge:- adequate knowledge and inadequate knowledge. The attitudes of leprosy patients towards modern health care for leprosy was determined by combining the responses in questions 22 and 50. Attitudes were categorized into two levels;- positive and negative. To determine whether prejudices and stigma about leprosy existed in communities where respondents lived seven questions were asked. These were questions 18 and 44-49.

There were 17 children suffering from leprosy who could not respond to most of the questions apparently either due to their young age or shyness. All were aged below 15 years. Consequently, no information was filled on sections of the questionnaire where they could not respond. Apart from this problem, data collection process went on smoothly with great cooperation from both the medical staff and the respondents. Indeed no patients refused to be interviewed among those whose consent was sought.

4.8. Data processing and analysis.

When data collection was completed serial numbers were assigned to the questionnaires to facilitate identification of the different categories of study subjects. Thereafter, responses for the open ended questions were reviewed, categorized and coded for computer data entry. The data were entered into the computer by the

principal investigator with the assistance of data processing technicians using the QUEST software package.[51] Data cleaning and validation was done by editing data entry errors and inconsistencies. Finally Odds ratios (ORs) with their 95% Confidence intervals (CIs) for suspected risk factors for acquiring significant disability as a result of leprosy before leprosy was diagnosed were calculated. Chi-square tests were done with P-value set at 0.05 level of significance.

4.9. Definitions.

4.9.1. Disability rate in leprosy.

The proportion of newly detected leprosy patient with disability in a given year.

4.9.2. Significant disability due to leprosy.

Disability of grade 2 or above (1970 WHO scale) or grade 2 (1987 WHO scale).

4.9.3. Early diagnosis of leprosy.

Diagnosis of leprosy made before the patient has developed disability of grade 2 (1970 & 1987 WHO scales).

4.9.4. Delay in diagnosis of leprosy.

Diagnosis of leprosy made after the patient has developed disability of grade 2 or above(1970 & 1987 WHO scales).

4.9.5. Patient delay.

Delay in patient's reporting to a health facility for diagnosis.

4.9.6. Hospital delay.

Delay in hospital staff recognition of leprosy suspects who presents themselves to health facilities.

4.9.7. Knowledge about leprosy.

This was categorized into two levels:

4.9.7.1 Adequate knowledge.

Respondents were regarded as having adequate knowledge when they correctly stated the cause of leprosy, or at least one early manifestation or the method of cure.

For the purpose of this study, correct responses were as follows:

Stated cause	-	germ
Early manifestations	-	numbness of hands and/feet, skin patch, skin nodule.
Method of cure	-	allopathic treatment.

4.9.7.2 Inadequate knowledge.

Respondents were regarded as not having adequate knowledge when they could not state the correct cause, the correct early manifestation(s) and method of cure.

4.9.8. Attitudes towards modern health care for leprosy.

Attitude was categorized into two levels as follows:

4.9.8.1. Positive attitudes.

The respondent's attitude was regarded as positive when any of the following conditions were satisfied (a reference to questions 22 and 50 in the questionnaire would be useful in order to understand the points):

- If the respondent sought treatment from a health institution and advised another person seeking advice from him/her with fear that he/she might have leprosy to do the same.
- If the respondent sought treatment from a health institution but would not have any advice for another person approaching him /her for advice with fear that he/she might have leprosy.
- If the respondent obtained drugs from shops and advised other persons to seek treatment from health institution.
- If the respondent took no action but advised other persons to seek treatment from a health institution.

4.9.8.2. Negative attitudes.

The respondent's attitude was regarded as negative if he/she used traditional medicine irrespective of the advice he/she would give to another person seeking advice from him/her with fear that he/she might have leprosy or if no answer was satisfied out of explanations in section 4.9.8.1.

4.9.9. Prejudices and stigma about leprosy.

For the purpose of this study, observation and/or exhibition of any of the following behaviour by the study subjects was regarded as indicative of the existence of prejudices and stigma about leprosy in his/her community.

- Use of euphemism in as far as leprosy is concerned.

- Not allowing other people to know about one's illness.
- Tendency to discriminate against patients such as isolation from social gathering or other social activities.

4.10. Limitations of the study.

4.10.1 Some of the leprosy patients on monthly follow-up could not turn up to the clinic regularly as expected. This necessitated prolongation of data collection period in order to obtain a large sample. Despite this, only 46 cases were obtained instead of 53, the originally desired number. However more than four times the number of controls per case was recruited and this is expected to increase the power of the study.

4.10.2. Some information could not be obtained from the 17 children in the study. Furthermore some adult respondents could not recall some of the information asked, particularly with regard to the duration of their illnesses. As for those who provided answers on this question, digit preference was noted implying some inaccuracy in their recall of the exact duration. This recall bias was however not significantly different between the cases and controls ($p > 0.05$). Thus the ORs obtained reflect the true differences in risk between the cases and controls.

4.10.3 Because of stigma attached to leprosy, information given by patients is at times distorted. The design of this study did not have a mechanism of cross-checking the validity of the volunteered information for most questions. Thus, it is possible that some of the information obtained from the leprosy patients might have been distorted.

5.0. RESULTS.

5.1. Characteristics of the study population.

A total of 457 subjects were included in the study. The study population consisted of males and females of various ages, education background and occupation. Out of the 457 subjects, 250 were patients suffering from leprosy while 207 were without features of leprosy and were seen and interviewed at eye clinics.

A review of the leprosy patients' treatment cards (LEP 01) revealed that 46 (18.4%) patients had leprosy disabilities of grade 2 or 3 at the time of diagnosis (measurement of disability was based on the 1970 WHO leprosy disability grading scale). When records of the remaining 204 (81.6%) leprosy patients were reviewed, it was found that 26 (10.4%) patients had grade 1 disability and 178 (71.2%) had no disability at all at the time leprosy was diagnosed (disability grade = 0). In this study the first category of 46 patients was referred to as the cases whereas the second category of 204 patients was referred to as the first control group (Control 1). The distinction between cases and the first control group was based on the patients' disability status at the time when leprosy was diagnosed. The group of patients who had no leprosy (207 patients) was referred to as the second control group (Control 2).

Table III summarizes the socio-demographic characteristics of the study population. It can be seen that 50% of cases, 20% of the first category of controls (Control 1) and 18.9% of the second category of controls (Control 2) were aged 45 years and above. The corresponding figures for subjects aged below 25 years were 8.7%, 35.8% and 32.2% respectively. This indicates that the cases were generally older than both categories of controls. There was a preponderance of males in all the three groups with the highest proportion among the cases (71.6%) followed by control 1 (65.2%)

Table III. Socio-demographic characteristics of the study population.

Characteristics	Cases (n=46)	First control (n=204)	Second control (n=207)	Total
Age (years)				
0-24	4(8.7)*	73(35.8)	46(22.2)	123(26.9)
25-34	11(23.9)	46(22.5)	76(36.7)	133(29.1)
35-44	8(17.4)	44(21.6)	46(22.2)	98(21.5)
45+	23(50.0)	41(20.1)	39(18.9)	103(22.5)
Sex				
Male	35(76.1)	133(65.2)	119(57.5)	287(62.8)
Female	11(23.9)	71(34.8)	88(42.5)	170(37.2)
Education				
Primary	28(60.9)	122(59.8)	148(71.5)	298(65.2)
Secondary	2(4.3)	20(9.8)	25(12.1)	47(10.3)
Post secondary	0(0.0)	3(1.5)	2(0.9)	5(1.1)
Adult education	5(10.9)	14(6.9)	13(6.3)	32(7.0)
Illiterate	11(23.9)	40(19.6)	18(8.7)	69(15.1)
Other	0(0.0)	5(2.4)	1(0.5)	6(1.3)
Occupation				
Civil servant	2(4.4)	20(9.8)	29(14.0)	51(11.2)
Business	14(30.4)	82(40.2)	97(46.9)	193(42.2)
Peasant	16(34.8)	21(10.3)	6(2.9)	43(9.4)
Student	2(4.4)	19(9.3)	8(3.9)	29(6.3)
Not working	6(13.0)	50(24.5)	58(28.0)	114(25.0)
Other	6(13.0)	12(5.9)	9(4.3)	27(5.9)

* Numbers in parentheses are column percentages.

and control 2 (57.55%) respectively. Majority (83.6%) of the study population had formal education of various levels mainly primary education (65.2%). However there was no patient among the cases who had more than secondary education. Six subjects(1.3%) had attained religious forms of education namely "Madrassa". Business enterprise of various kinds was the main occupation among the controls while majority(34.8%) of patients among cases were peasants.

The age and sex distribution of the study population is shown in Table IV. It can be seen that 76.3% of the males as well as 79.4% of the females were aged below 45 years. Even though there were fewer females the age-specific distribution was the same for both sexes.

Table IV. Distribution of study population by age and sex.

Age group	Male	Female	Total
0-24	79(27.5)	44(25.9)	123(26.9)
25-34	83(28.9)	50(29.4)	133(29.1)
35-44	57(19.9)	41(24.1)	98(21.5)
45+	68(23.7)	35(20.6)	103(22.5)
Total	287(100)	170(100)	457(100)

Table V shows the distribution of leprosy patients by case status and type of leprosy. It is seen that, overall borderline lepromatous leprosy was the most frequent (45.6%) type followed by borderline tuberculoid leprosy (22%). Tuberculoid and lepromatous leprosy each accounted for about 16% of the study population. However, of the cases, the majority (37.0%) had borderline tuberculoid leprosy whereas the majority (48.5%) of the controls (control 1) had borderline lepromatous leprosy. Tuberculoid leprosy was the least frequent type among the cases (6.5%), while among the controls the least frequent type was lepromatous leprosy (14.7%).

Table V. Distribution of leprosy patients by case status and type of leprosy.

Type of leprosy	Cases	Controls	Total
Tuberculoid	3(6.5)	37(18.2)	40(16.0)
Borderline tuberculoid	17(37.0)	38(18.6)	55(22.0)
Borderline lepromatous	15(32.6)	99(48.5)	114(45.6)
Lepromatous	11(23.9)	30(14.7)	41(16.4)
Total	46(100)	204(100)	250(100)

The distribution of leprosy patients by age and type of leprosy is shown in Table VI. It can be seen that 65.0% of Tuberculoid, 68.3% of Lepromatous, 45.5% of Borderline tuberculoid and 48.2% of Borderline lepromatous patients were aged below 35 years. The difference of the prevalences between age groups was statistically significant ($p < 0.05$). This implies that the extreme ends of the disease spectrum (tuberculoid and lepromatous leprosy) were more frequently observed among the young age groups.

Table VI. Distribution of leprosy patients by age and type of leprosy.

Age group	Type of leprosy. TT*	BT*	BL*	LL*	Over all
0-24	13(32.5)	14(25.5)	33(28.9)	17(41.5)	77(30.8)
25-34	13(32.5)	11(20.0)	22(19.3)	11(26.8)	57(22.8)
35-44	9(22.5)	9(16.3)	27(23.7)	7(17.1)	52(20.8)
45+	5(12.5)	21(38.2)	32(28.1)	6(14.6)	64(25.6)
All	40(100)	55(100)	114(100)	41(100)	250(100)

* TT = Tuberculoid leprosy. BT = Borderline tuberculoid

BL = Borderline lepromatous. LL = Lepromatous leprosy

The records of 72 out of the 250 leprosy patients (28.8%) indicated that they had disabilities of grade 1, 2 or 3 at the time they were diagnosed to have leprosy. The frequency of disability was higher among males (32.1%) than females (21.9%) and generally the proportion of patients with disability increased with age in both sexes (see Table VII).

Table VII. Prevalence of disabilities by age and sex.

Age group in yrs.	Male		Female		Total	
	Number exam.	% disabled	Number exam.	% disabled	Number exam.	% disabled
0-24	53	9.4	24	8.3	77	9.1
25-34	38	34.2	19	10.5	57	26.3
35-44	35	31.4	17	41.2	52	36.5
45+	42	59.5	22	31.8	64	48.3
Total	168	32.1	82	21.9	250	28.8

Table VIII shows the frequency of disabilities (grade 1-3) by type of leprosy. It can be seen that the highest proportion of disability (41.8%) was among patients with borderline tuberculoid leprosy while patients with tuberculoid leprosy had the lowest proportion of disabled patients (17.5%). In the lepromatous leprosy group, 36.6% had disabilities.

Table VIII. Frequency of disabilities by type of leprosy.

Type of leprosy	Leprosy patients		
	Total number	Number disabled	Percent disabled
Tuberculoid leprosy	40	7	17.5
Borderline tuberculoid	55	23	41.8
Borderline lepromatous	114	27	23.7
Lepromatous leprosy	41	15	36.6
Total	250	72	28.8

The proportions of grade 1, 2 and 3 disabilities among patients in the four types of leprosy is shown in Figure 3. It indicates that grade 2 disabilities were predominant in all types of leprosy with the exception of tuberculoid leprosy in which the majority of patients had grade 1 disabilities (57.1%) and none with disability of grade 3.

Proportion of disability by type of leprosy

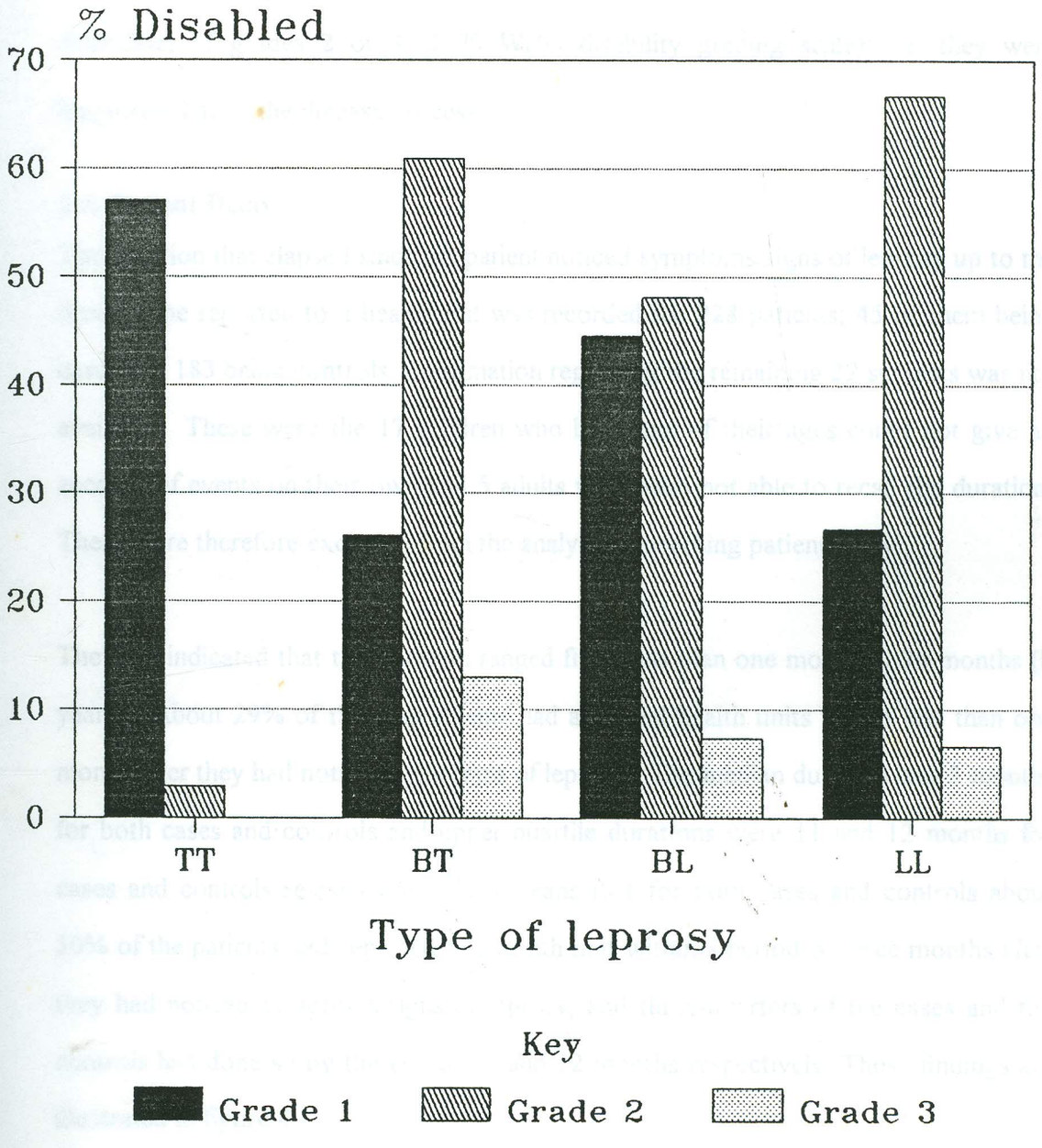


Figure 3.

5.2. Proportion of leprosy patients who were diagnosed late in the disease process.

Scrutiny of the leprosy patients' treatment cards revealed that 46 out of the 250 leprosy patients (18.4%) were diagnosed to have leprosy while already developed disabilities of grades 2 or 3 (1970 WHO disability grading scale); i.e. they were diagnosed late in the disease process.

5.3. Patient Delay.

The duration that elapsed since the patient noticed symptoms/signs of leprosy up to the time he/she reported to a health unit was recorded for 228 patients; 45 of them being cases and 183 being controls. Information regarding the remaining 22 subjects was not available. These were the 17 children who by virtue of their ages could not give an account of events on their own and 5 adults who were not able to recall the duration. These were therefore excluded from the analysis concerning patient delay.

The data indicated that the duration ranged from less than one month to 96 months (8 years). About 29% of the respondents had attended health units within less than one month after they had noticed symptoms of leprosy. The median duration was 3 months for both cases and controls and upper quartile durations were 11 and 12 months for cases and controls respectively. This means that for both cases and controls about 50% of the patients had reported to a health unit within a period of three months after they had noticed symptoms/signs of leprosy; and three-quarters of the cases and the controls had done so by the end of 11 and 12 months respectively. These findings are illustrated in figure 4.

Patient delay

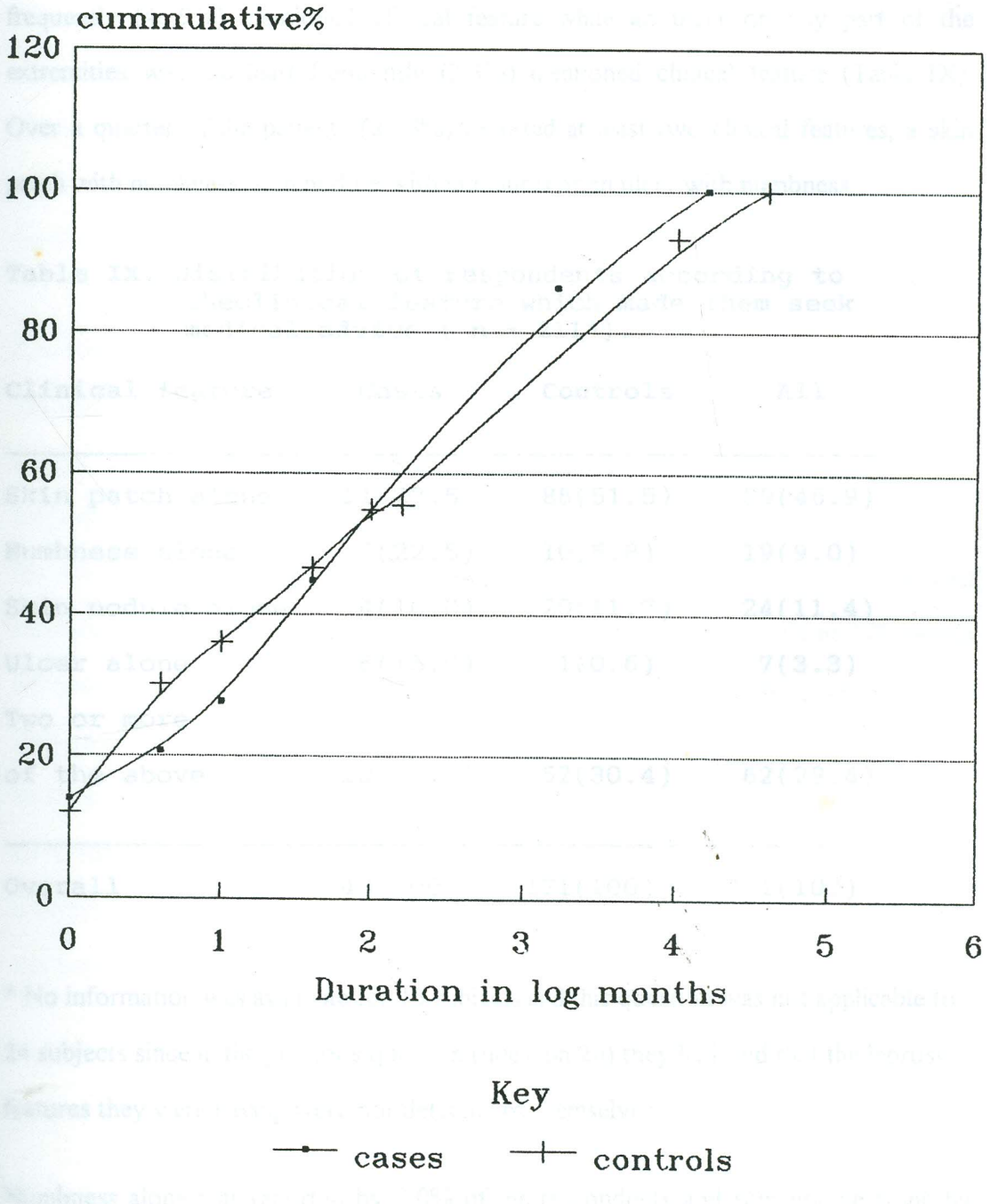


Figure 4.

When patients were asked to state the clinical features that had made them seek medical advice (question 21), it was found that, overall, skin patch alone was the most frequently (46.9%) mentioned clinical feature while an ulcer on any part of the extremities was the least frequently (3.3%) mentioned clinical feature (Table IX). Over a quarter of the patients (29.4%) reported at least two clinical features; a skin patch with numbness, skin nodule with numbness or an ulcer with numbness.

Table IX. Distribution of respondents according to theclinical feature which made them seek medical advice (n = 211*).

Clinical feature	Cases	Controls	All
Skin patch alone	11(27.5)	88(51.5)	99(46.9)
Numbness alone	9(22.5)	10(5.8)	19(9.0)
Skin nodule alone	4(10.0)	20(11.7)	24(11.4)
Ulcer alone	6(15.0)	1(0.6)	7(3.3)
Two or more of the above	10(25.0)	52(30.4)	62(29.4)
Overall	40(100)	171(100)	211(100)

* No information was available for 15 subjects and this question was not applicable to 24 subjects since in the previous question (question 20) they had said that the leprosy features they were having were not detected by themselves.

Numbness alone was reported by 9.0% of the respondents and skin nodule alone by 11.4%. About half (51.5%) of the controls reported skin patch alone and 30.4%

reported at least two features as described above. The corresponding figures for cases were 27.5% and 25.0% respectively. Numbness alone was less frequently reported by the controls (5.8%) compared to the cases (22.5%). Likewise, fewer controls (0.6%) than cases (15.0%) had reported an ulcer alone as the clinical feature that prompted them to seek medical advice. The difference in proportions between cases and controls with respect to the mentioned clinical features which made the respondents seek medical advice was statistically significant ($p < 0.05$) for all except skin nodules.

5.4. Hospital delay.

Information about the duration which elapsed between the patient's first visit to a health unit and the diagnosis of leprosy was available for 227 respondents. Information was missing for 23 respondents; one being a case and 22 being controls for similar reasons as explained under the section of patient delay above. The data indicated that the time which elapsed ranged from less than one month to 276 months (23 years). In 62% of the patients, leprosy diagnosis was made within a period of less than one month after the patient had reported to the health units. The median duration was less than one month for both cases and controls while the upper quartile duration for cases was 7 months and that for controls was 4 months. Thus, three-quarters of the controls had been diagnosed to have leprosy by the end of 4 months while for the cases this happened by the end of 7 months. These findings are further illustrated in figure 5.

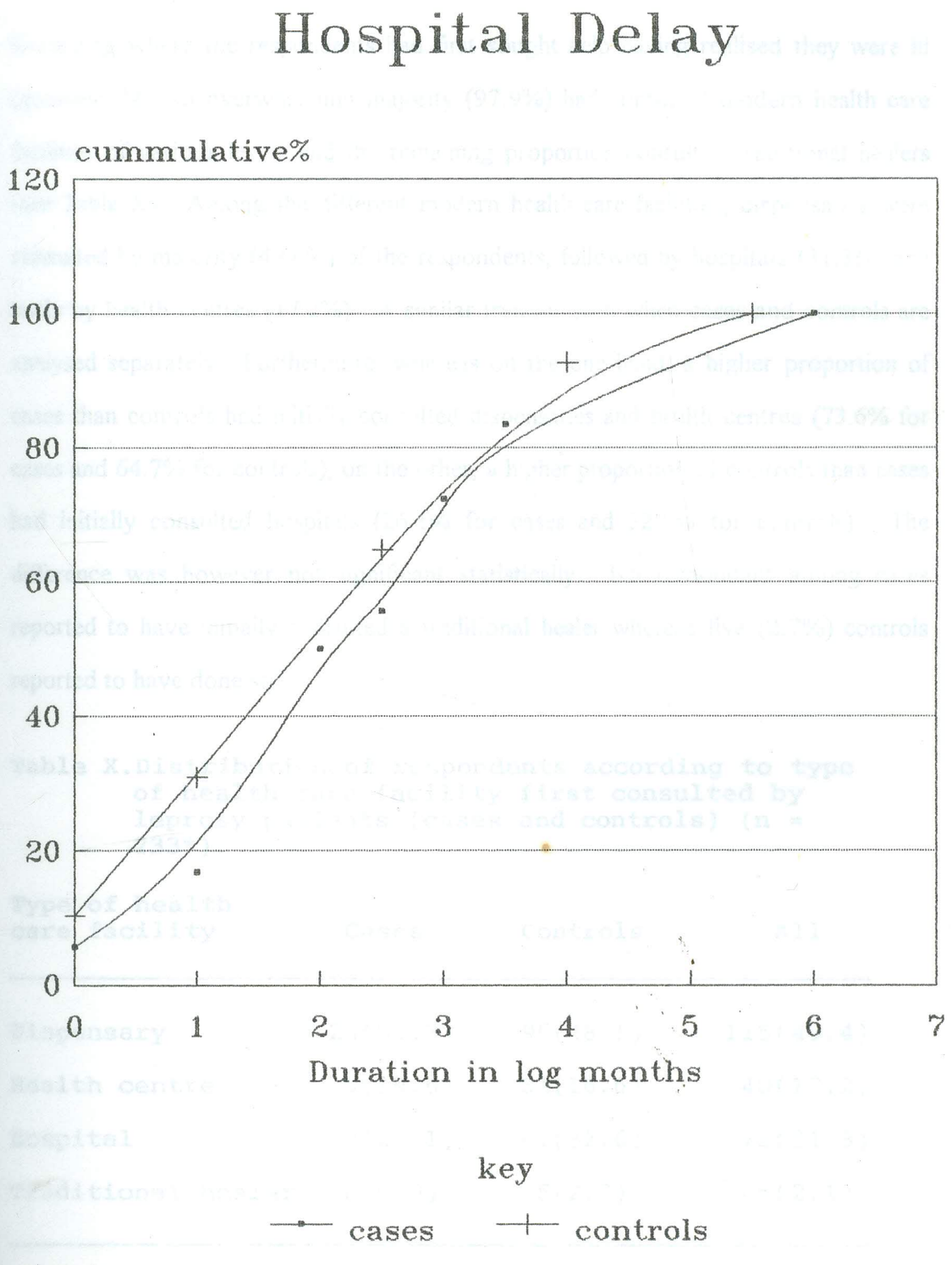

Hospital Delay
cummulative%
120
100
80
60
40
20
0
0
1
2
3
4
5
6
7
Duration in log months
key
cases
controls

Figure 5

Regarding where the respondents had first sought help having realised they were ill (question 24), an overwhelming majority (97.9%) had consulted modern health care facilities of various levels and the remaining proportion consulted traditional healers (see Table X). Among the different modern health care facilities, dispensaries were consulted by majority (49.4%) of the respondents, followed by hospitals (31.3%) and lastly by health centres (17.2%). A similar trend is seen when cases and controls are analysed separately. Furthermore, whereas on the one hand, a higher proportion of cases than controls had initially consulted dispensaries and health centres (73.6% for cases and 64.7% for controls), on the other, a higher proportion of controls than cases had initially consulted hospitals (26.1% for cases and 32.6% for controls). The difference was however not significant statistically. No respondent among cases reported to have initially consulted a traditional healer whereas five (2.7%) controls reported to have done so.

Table X. Distribution of respondents according to type of health care facility first consulted by leprosy patients (cases and controls) (n = 233*).

Type of health care facility	Cases	Controls	All
Dispensary	25(54.3)	90(48.1)	115(49.4)
Health centre	9(19.6)	31(16.6)	40(17.2)
Hospital	12(26.1)	61(32.6)	73(31.3)
Traditional healer	0(0.0)	5(2.7)	5(2.1)
Overall	46(100)	187(100)	233(100)

* No information was available for 17 subjects.

When respondents were requested to state whether the diagnosis of leprosy was made at the health care facility first consulted or at the referral facility (question 27), it was found that in 44.8% of the respondents the diagnosis was made at the unit first consulted and in 33.2% the diagnosis was made at the referral unit (Table XI). Thirty seven respondents (14.8%) said that the diagnosis was made in health facilities to which they had decided to refer themselves for better care. Eighteen respondents (7.2%) said they did not know the place where leprosy was diagnosed. There was no statistically significant difference between cases and controls, with respect to the various places where leprosy diagnosis was reached, even though in a slightly higher proportion of cases (41.3%) than controls (31.4%), leprosy diagnosis was made after the patients were referred to other health facilities by the medical staff.

Table XI. Distribution of respondents according to place where leprosy was diagnosed.

Place of diagnosis	Cases	Controls	All
Health unit first consulted	20(43.5)	92(45.1)	112(44.8)
Referral health unit through medical staff	19(41.3)	64(31.4)	83(33.2)
Another health unit after self referral	7(15.2)	30(14.7)	37(14.8)
Did not know place of diagnosis	0(0.0)	18(8.8)	18(7.2)
Total	46(100)	204(100)	250(100)

Table XII shows the distribution of the respondents according to the number of visits paid to the health care facility first consulted before the patient was told that he/she had leprosy or before consulting other units for better care (question 28). It can be seen that, by far, the majority (40.0%) of patients had paid two visits, while 10.0% had paid four or more visits to the health care facility first consulted. About 24.4% of the respondents could not remember the number of visits paid. Almost an equal proportion of respondents in cases and controls had paid four or more visits while a smaller proportion of cases (34.8%) than controls (41.2%) had paid two visits.

Table XII. Distribution of respondents according to number of visits paid to the health care facility first consulted before they were told they had leprosy or before they consulted other health care units.

Number of visits	Cases	Controls	All
1	7(15.2)	24(11.8)	31(12.4)
2	16(34.8)	84(41.2)	100(40.0)
3	5(10.9)	28(13.7)	33(13.2)
4+	5(10.9)	20(9.8)	25(10.0)
Did not remember	13(28.2)	48(23.5)	61(24.4)
Total	46(100)	204(100)	250(100)

When respondents were asked to state whether or not any medication was given to them by the medical staff before they were told they had leprosy, 20 (43.5%) respondents from the case group and 69 (33.8%) from the control group stated that they were given medications. The proportions of respondents per category of medication given were as follows:-

- 35% of the cases and 31.9% of the controls were given tablets only.
- 10.0% of the cases and 29.0% of the controls were given topical applications only.
- 55.0% of the cases and 37.7% of the controls were given combinations of tablets with topical applications or with injectables.
- 1.4% of the controls and none of the cases were given oral mixtures.

When the respondents were asked to state whether the medical personnel who first attended them had suggested diagnoses other than leprosy (question 30), eight cases (17.4%) and 32 controls (15.7%) had their suggested diagnoses being different from leprosy. These suggested diagnoses were; ordinary skin disease (56.4% of respondents), fungal disease (25.6%) and others (17.9%). Diagnoses under the "others" category included allergic phenomena, chronic malaria and vitamin deficiency.

5.5. Knowledge about leprosy.

The results about level of knowledge are shown in Table XIII. Of the 440 subjects for which information was available, 43.2% were regarded as having adequate knowledge while 56.8% were regarded as having inadequate knowledge. Among the three categories of respondents the case and the first control groups had higher proportions of subjects with adequate knowledge (71.7% for cases, 65.2% for the first control group) than the second control group (16.9%). The difference in levels of knowledge between leprosy and non-leprosy patients was statistically significant ($p < 0.05$).

5.5.1. Perception about cause of leprosy.

Perceptions about the causes of leprosy was recorded for 440 subjects. It was found that the majority of the respondents (87.9%) said they did not know of any cause of leprosy, 5.5% said a germ was responsible and only 2.5% said leprosy was acquired through inheritance and 4.1% mentioned other causes. The causes of leprosy mentioned under "others" category included "sharing of food or articles" and "poor environmental sanitation". The proportion of respondents from the three categories of patients separately (cases, first controls and second controls) did not differ significantly with respect to the given responses about cause of leprosy.

Table XIII. Distribution of respondents according to level of knowledge about leprosy (n = 440*).

Level of knowledge	Cases	First control	Second control	All
Adequate	33(71.7)	122(65.2)	35(16.9)	190(43.2)
Inadequate	13(28.3)	65(34.8)	172(83.1)	250(56.8)
Total	46(100)	187(100)	207(100)	440(100)

* No information was available for 17 subjects.

5.5.2. Perception about early manifestations of leprosy.

Information about early manifestations of leprosy was recorded for 440 subjects. It was found that 72.3% of all the respondents did not know any of the early manifestations of leprosy, 10.9% mentioned only one of the three features:- numbness of hands and or feet, patches on the skin, and nodular skin lesions. Thirty eight respondents (8.6%) mentioned a combination of two of the three early manifestations and eight (1.8%) mentioned all three. Twenty eight respondents (6.4%); one belonging to the first control group and 27 to the second control group mentioned other manifestations which were mainly the sequalae of the disease namely; ulcers and "missing" fingers and/or toes. Also mentioned were loss of weight, insufficient blood in the body, fever and itching of hands (no respondent from the cases group had mentioned these manifestations).

Among the three categories of respondents, the first control group had the highest (77.6%) proportion of subjects who did not know any of the early manifestations of leprosy, followed by the cases group (73.9%) and finally the second control group

(67.1%). Whereas a skin patch was more frequently mentioned by subjects in the second control group (10.1%) than either the cases (4.3%) or the first control group (5.3%), no subject in the second control group had mentioned numbness of feet or hands as one of the early manifestations of leprosy. About 8.7% of the respondents in each category mentioned two out of the three manifestations.

5.5.3. Perception about cure of leprosy.

There were 439 responses recorded about methods of leprosy cure. Information for 18 subjects (17 children and one adult) was not available. It was found that, overall, only 54.0% of the respondents stated that leprosy could be cured by allopathic treatment, herbs or prayers, 46.0% did not know of any method of cure. The majority of respondents among the cases (82.6%) and among the first control group (73.8%) mentioned allopathic treatment as a cure for leprosy compared to only 27.8% in the second control group. The second control group had the highest proportion of respondents who did not know of any method of leprosy cure (72.2%) while the cases group had the lowest (17.4%). The proportion of respondents among the first control group who did not know of any method of leprosy cure was 24.1%.

An attempt was made to find out the respondents' concepts of leprosy cure. The responses, in decreasing order of frequency were; "resolution of leprosy features" (77.8%), "death of germs" (7.3%), "being discharged from clinic by doctors" (6.4%), and "after completion of treatment" (6.0%). About 2.5% of the respondents could not understand the question as the responses given were out of context.

Whereas, on the one hand, the second control group compared to the other two groups had highest proportion of subjects who asserted that leprosy cure meant

"resolutions of leprosy features" (82.1%) and "after completion of treatment" (12.5%); on the other, the cases group had the highest proportion of subjects who thought leprosy cure meant "death of all germs" (10.5%) and "after being discharged from clinic by doctors" (10.5%). None of the subjects in the second control group shared the idea that leprosy cure meant "discharge from clinic".

5.6. Attitudes and practices of leprosy patients with regard to modern health care for leprosy.

5.6.1 Attitudes.

The results about attitudes are shown in Table XIV. It can be seen that majority of the respondents (88.7%) were found to have a positive attitudes towards modern health care for leprosy. The trend was similar in both cases and controls; 89.1% for the former and 88.7% for the latter.

Table XIV. Distribution of respondents according to their attitudes about modern health care for leprosy (n = 231).

Attitudes	Cases	First control	All
Positive	41(89.1)	164(88.7)	205(88.7)
Negative	5(10.9)	21(11.3)	26(11.3)
Total	46(100)	185(100)	231(100)

5.6.2. Practices.

Respondents were asked to state the immediate health care measures taken after they realised that they had a health problem which was later found to be leprosy (question 22). Information was obtained for 231 patients and the responses are shown in Table

XV. Of these, 50.6% had attended government health institutions for services, 11.7% attended privately owned health institutions, 8.2% bought drugs from shops, 11.3% resorted to traditional medicines and 18.2% took no action. There was no statistically significant difference between cases and first control group subjects in terms of the actions taken, even though proportionally more cases (69.6%) than controls (60.5%) had attended health institutions (government or private) and fewer cases (10.9%) than controls (11.4%) resorted to traditional medicine.

Table XV. Distribution of respondents according to type of health care sought immediately after realising that they had a health problem.

Type of health care sought	Cases	First control	All
Government health care	27(58.7)	90(48.6)	117(50.6)
Private health care	5(10.9)	22(11.9)	27(11.7)
Bought medicine from shops	2(4.3)	17(9.2)	19(8.2)
Traditional medicine	5(10.9)	21(11.4)	26(11.3)
None	7(15.2)	35(18.9)	42(18.2)
Total	46(100)	185(100)	231(100)

When patients who had not sought any type of health care were asked to give the reasons for not taking any action, it was found that 5 cases and 26 controls thought the condition would disappear on its own. Other reasons given were: "I thought it was a birth mark" and "health care facilities were too far". These were mentioned by two

control subjects. This question was misunderstood by five subjects; as their responses were out of context.

5.7. Prejudices and stigma about leprosy.

The findings about prejudices and stigma about leprosy in the communities where the patients lived are given in the following paragraphs.

Out of the 243 leprosy patients who responded to question 18 (which required the patient to mention the name of the disease he/she was suffering from), 221 (90.9%) said they were suffering from leprosy, 14 (5.8%) said were suffering from "maradhi ya ngozi" (skin disease) and 8 (3.3%) either did not know the name of their illness or said they were suffering from maradhi makuu" (great disease), "maradhi maalumu" (special disease) and "chronic malaria".

The responses to question 44 indicated that upon realisation by the family members that the respondents suffered from leprosy, 83.2% of the respondents were advised to continue with modern treatment of leprosy, 1.3% were advised to use traditional medicine and 9.1% were not given any advice. The rest of the respondents (6.5%) were yet to hear what their family members would say, at the time of interview, since the interview was done on the day leprosy was confirmed. Tendency to discriminate the patients such as shunning away or isolating them were not reported. Proportionally, the cases and controls did not significantly differ with respect to the given advice.

In question 45 patients were required to state whether or not their close friends knew about their (patients) diagnosis. Of the 228 subjects who responded to this question,

109 (47.8%) affirmed that their friends knew about it, 94 (41.2%) stated that their friends had not known of the diagnosis and 25 (11.0%) were uncertain. No significant difference was found between cases and controls with respect to their responses. Respondents who affirmed that their friends knew about their (respondents) diagnosis were further asked to mention what kind of advice, if any, was given to them by their friends (question 46). It was found that 67.6% of the respondents were advised to continue with modern therapy, 29.6% were not given any advice and the rest (2.8%) were either shunned away or advised not to eat pork, duck or rabbit meat. Respondents who were certain that their friends knew nothing about the diagnosis, as well as those who were uncertain, were further asked to state what they would anticipate to happen in case the diagnosis was known to their friends (question 47). It was found that 14.7% anticipated being discriminated in some way while 85.3% could not figure out possible reactions. Proportionally more cases (22.2%) than controls (13.1%) anticipated discrimination even though the difference was not statistically significant ($p = 0.29$).

In question 48 leprosy patients were requested to state which problems they encountered in the community which they thought might be linked to their illness. Likewise patients without leprosy were requested to state the problems they see or hear about which leprosy patients experience. It was found that 97.0% of leprosy patients and 97.6% of the non-leprosy patients had not experienced, seen or heard of any particular problem while the remaining proportions stated that discrimination against leprosy patients existed.

Regarding question 49, which required the respondents to state what aspects of leprosy were feared most in the communities they lived, 15% of the leprosy patients

said disability resulting from leprosy was the most feared outcome by the people. The proportion of non-leprosy patients sharing the same opinion was 8.2%. About 2.9% of the respondents from both groups (leprosy as well as non-leprosy patients) said people feared leprosy because they thought it was contagious and incurable. By far, the vast majority of respondents (84.8%) claimed that they did not know of any existing fear about leprosy in their communities.

5.8. Estimation of risk factors of acquiring significant disability as a result of leprosy before the disease was diagnosed.

Multivariate analysis of various exposure factors in relation to the occurence of disability in the cases and the first control group was perfomed using a multiple logistic regression while adjusting for age and sex. The age and sex adjusted odds ratio and the 95% confidence limits were obtained for each exposure considered relevant and the results are summarized in Table XVI.

Farming compared to other occupations and having borderline tuberculoid type of leprosy were significantly and independently associated with the development of significant disabilities as a result of leprosy before the disease was diagnosed. Factors for which no significant association with disability was found included having no formal education, living more than five kilometres from a leprosy treatment centre and having inadequate knowledge about leprosy. Others included having negative attitude towards modern health care and anticipation for isolation if known to have leprosy. Furthermore, neither patient delay in seeking medical help nor hospital delay in detecting leprosy in a patient presenting for a period exceeding one year were significantly associated with the development of disabilities. Borderline lepromatous leprosy was found to be protective of significant disability due to leprosy.

Table XVI. Exposure factors and the risk of significant disability as a result of leprosy before diagnosis.

Exposure	Population exposed (%)	Age and Sex adjusted Odds ratio*
Illiteracy	20.4	1.19(0.55, 2.57)
Occupation (Farmer)	14.8	2.23(1.14, 4.38)
Home-clinic distance > 5 Km	15.3	1.46(0.77, 3.00)
Tuberculoid leprosy	16.0	0.46(0.14, 1.51)
Borderline Tuberculoid leprosy	22.0	2.0(1.08, 3.70)
Borderline lepromatous leprosy	45.6	0.49(0.26, 0.91)
Lepromatous leprosy	16.4	0.67(0.33, 1.34)
Patient delay > 12 months	18.0	0.65(0.26, 1.65)
Hospital delay > 5 months	22.9	1.73(0.91, 3.29)
Hospital delay > 12 months	14.1	1.42(0.59, 3.42)
Anticipation for isolation	14.7	1.90(0.53, 6.75)

* Figures in parentheses are the 95% confidence limits for Odds ratio.

6.0. DISCUSSION.

The National Tuberculosis and Leprosy Programme (NTLP) annual report for 1991 observed that 29.0% of newly diagnosed leprosy patients in Tanzania were found to have disabilities of grade 1-3 in that year.[6] In this study it was found that 28.8% of the leprosy patients had disabilities, of grade 1-3 at the time they were found to have leprosy. The finding of this study agree well with the observations made by the National Tuberculosis and Leprosy Programme three years earlier. Furthermore, this study has found that 18.4% of the leprosy patients had significant disability (grade 2 or 3) at the time leprosy was detected. This figure is slightly higher than that reported by NTLP (14.0%). Probably this difference may mean that there has been an improvement in disability assessment and grading of patients by DTLCs compared to previous years.

However, the proportion of patients found with significant disability at diagnosis in this study, is lower than that found in China[52] two years ago (55.0%). Whereas, on the one hand, this difference may mean that Tanzania is better off than China with respect to early diagnosis of leprosy; on the other, the difference may be attributed to the differences in the ways the data was obtained. The study in China was community based unlike the present one which was hospital based. As a result of selection bias inherent in hospital based studies, it is possible that some patients who had significant disabilities in the present study were missed because they could not come to hospital, thus resulting in underestimation of the true proportion. Recent information regarding disabilities in newly diagnosed leprosy patients from nearby countries was not available for comparison.

Findings in connection with disability showed that the proportion of disabled patients increased with increasing age and was higher in males than females. This is in agreement with results of other studies.[15,18,19,22,23,52] The increase in the proportion of disabled with increasing age is thought to be due to longer duration of disease in older patients as most leprosy patients do not have disabilities when the disease first appears but tend to develop them later.

The finding of low prevalence of disabilities among females is not surprising, given the fact that involvement of nerve trunks is less frequent in females compared to males.[53] This may also have something to do with reduced opportunities for female patients to attend clinics in a male dominated economy such as that of Dar es Salaam. This means that even though there may be equal rates of disability among sexes it will be more frequently diagnosed among males.

The present study has also found that the proportion of patients with disability (all grades) was higher among patients with borderline and lepromatous leprosy than those with tuberculoid leprosy. This agrees with findings by previous studies.[16,17,19,22,52] This is understandable; because primary nerve damage (sensory, motor and autonomic), which is the underlying cause of disability in leprosy is restricted to only a few nerves in tuberculoid leprosy whereas it is widespread in borderline and lepromatous leprosy.

The fact that a moderately high proportion (18.4%) of the leprosy patients was found with significant disabilities at diagnosis in this study is of much concern, not only because it indicates that these patients were detected late but also because disability is the most important social aspect of leprosy; due to the amount of human suffering it

causes including stigmatization and family disruption. To the patient and the public it is disability that sets the leprosy patient apart. In addition the finding of significant disability among newly detected patients implies that the National Tuberculosis and Leprosy Programme has yet to attain its goal of early diagnosis of leprosy. In a successful control programme, no patient should have disability of grade 2 or above at diagnosis.[12]

Concern about delay in leprosy diagnosis has of late been voiced by the World Health Organization. In a foreword note in a book, the WHO chief of leprosy unit has written: "Leprosy continues to be a major concern in developing countries, not only because of the large numbers of the people affected by it and the potential for communicating the disease to others, but also because of the occurrence of deformities in a proportion of patients. While the introduction and widespread application of multiple drug therapy over the past decade has resulted in significant reduction in the incidence of the disease, the impact on the associated disabilities and deformities has been very limited."[54]

Delay in diagnosis of leprosy can be due to any of the two types; patient or hospital, although the two together often contribute. Whereas patient delay largely pertains to the individual and the community (in which he/she lives) level of awareness of the disease, their attitudes towards modern health care and other socio-cultural factors influencing health seeking behaviour; hospital delay pertain to factors governing health care provision. These, among others, include availability of adequate amount of easily accessible health care facilities, mode of leprosy detection, availability of medical and paramedical personnel with update knowledge about leprosy at all levels providing

health care as well as availability of necessary diagnostic and treatment facilities at all times in the health care units.

The present study was undertaken to discover the proportion of leprosy patients who are diagnosed in late stages of the disease and factors that may be impeding early diagnosis; mainly pertaining to the patient and to some extent to the community and the health care delivery system. In view of this, it was necessary to obtain information about what had taken place from the time the patient noticed features suspicious of leprosy to the time leprosy was confirmed in the patient. It was also imperative to find out the patients' awareness about leprosy, their attitudes towards modern health care, prejudices and stigma about leprosy prevailing in communities where the patients live; and relate the information to the delay in diagnosis of leprosy.

Regarding the duration which elapsed between the patients' recognition of symptoms of leprosy and his seeking of medical care, this study has found that 50.0% of both categories of the leprosy patients (those found with significant disability and those found without significant disability at diagnosis) had reported to a health care facility by end of three months after they realized they had symptoms of leprosy. Furthermore, it was found that 75.0% of the patients who were found with significant disability had reported to a health care facility by 11 months while 75.0% of those found without significant disability at diagnosis had done so by 12 months. These findings indicate that there was no significant difference in the duration that had elapsed before patients sought medical care in the two groups of patients.

Previous studies in Tanzania[55], Nigeria[29] and India[30] reported longer duration than found in the present study. For instance in Tanzania, it was found that 76.2% of

leprosy patients interviewed in Morogoro region had waited for 12-36 months before reporting to a health unit. Also 53.7% of the patients had waited for over 12 months and 68.2% for 24 months in Kinondoni and Temeke districts, Dar es Salaam region, respectively. In Nigeria, 57.0% of the leprosy patients delayed seeking medical help for 48 months (4 years) and average delay was 18 months. The study in India found that 26.0% of the patients delayed for at least 3 months and 22.0% delayed for 60 months (5 years). The differences in the proportions obtained by the studies in the three countries possibly represent varying levels of awareness about leprosy manifestations among the respondents rather than differences in health care delivery systems because, invariably, majority of the respondents who reported longer delays attributed the delays to inability to link the symptoms they were having with leprosy.

In the present study, it is interesting to note that, even though patients in the two categories (cases and controls) reported to have delayed seeking medical care for about equal time, yet patients belonging to the cases group were found having features consistent with late stage disease at the time of detection; connoting delay in diagnosis. Whereas on the one hand, it is possible for patients to ignore initial symptoms of leprosy until the disease advances to a stage of irreversible damage that finally prompt them to seek medical attention, on the other, it is also possible that the medical workers who come into first contact with patients may not be competent enough to diagnose leprosy in its early stage, thus tending to mismanage it until such a time that late features of the disease become obvious or the patient decides to consult other health care personnel who may then make the right diagnosis. Both these possibilities are implicated in the findings of this study.

Looking at the age distribution of cases and control 1 subjects, it was noted that, cases were generally older than controls. Indeed 50.0% of the cases were aged 45 years and above compared to only 20.0% of control 1 subjects. Records of patients also showed that subjects in the cases group were, at the time of detection, having disabilities of grade 2 or 3 as a result of leprosy while subjects in the control 1 group had either grade 1 or no disability at all. Since grade 2 and 3 disability appear after a long duration of illness, it is tempting to think that some patients in the cases group could have stayed with the disease longer than actually reported; thus acquiring significant disabilities before they were diagnosed to have leprosy (patient delay). This is further supported by finding in Table IX in which it can be seen that 15% of the cases reported to health units after they developed ulcers compared to only 0.6% of controls, the difference being statistically significant. However, there is no evidence to indicate that the patients in the cases group had stayed with the disease longer than those in the control group. Other factors not addressed in this study may be responsible.

The results of this study also indicate that hospital delay may have played some role in delaying leprosy diagnosis. Looking at the duration which elapsed from the time the patient reported to a health care facility for care, to the time leprosy was diagnosed, the data show that it took relatively longer time to diagnose leprosy among patients found with significant disability at detection (cases) than among those found without significant disabilities (controls). Whereas it took only 4 months for the health workers to diagnose leprosy in three-quarters of the controls after the patients had presented themselves to the health units, in the case group it took 7 months. In addition, the results of the study indicate that a higher proportion of the cases than the controls had their illness detected in places other than the ones initially consulted (Table XI).

Hospital delay in the diagnosis of leprosy or other diseases is not uncommon; previous studies have reported about this phenomenon.[28,42,43]

A plausible explanation for the relatively longer hospital delay among cases as revealed by this study, may be the fact expressed in Table X. In this table, it was apparent on the one hand, that a higher proportion of cases than controls had initially sought medical care from dispensaries and health centres, while on the other, a higher proportion of controls than cases had initially sought medical care directly from hospitals. Thus the process of referral from primary health care facilities may in itself have impeded early diagnosis of leprosy in these patients.

Furthermore, the difference in the level of training between health cadres serving at dispensaries and health centres and those at hospitals could also explain the relatively longer hospital delay among cases than controls as noted in this study. According to staff establishment in Tanzania, health cadres serving at dispensary and health centre levels are mainly Rural Medical Aides (RMAs), Medical Assistants (MAs) and a few Rural Dispensary Attendants (RDAs) while hospitals are served by Medical Officers (MOs) and Assistant Medical Officers (AMOs). The intensity of medical training for these different cadres obviously differ. Medical Officers and Assistant Medical Officers are expected to be more trained in the medical field than the rest of the cadres, and thus be more competent in diagnosing, not only leprosy, but also many other diseases. The study by Muhondwa[14] found that the health care providers interviewed (which included RDAs, RMAs, AMOs and Nurses) were less competent in diagnosing leprosy in its early stages, even though their general health knowledge of symptoms and signs of leprosy seemed to be high.

The issue of missed diagnoses is crucial in leprosy; not only because it allows the progression of disease into advanced stage hence increasing the cost of treatment and care of disabled patients while reducing chances of "cure", but also it may cause the person great social and personal distress by calling him a leper when he may not have leprosy at all. Moreover, when patients who were mistakenly thought to have leprosy do not get better with leprosy treatment, people think leprosy is incurable. In their series, Powell and Dougall[42] found that leprosy was mistaken for syringomyelia, allergy and mycosis. In the present study, it was found that in about 17% of the patients leprosy was initially mistaken for ordinary skin disease, allergy, mycosis, chronic malaria and avitaminosis.

It is interesting to note that no patient among those detected late (cases) reported to have first consulted a traditional healer after they realized they were ill, whereas five among those whose disease was detected early affirmed to have done so. This is contrary to common belief that seeking treatment from traditional healers is partly responsible for delay in leprosy diagnosis.

However, while the information obtained from the patients need to be regarded as representing what really took place; it may be dangerous sometimes to believe everything said by patients particularly where a blame is likely to be thrown in part to the patient as it may occur for patient detected already having features of advanced stage of any disease, including leprosy. In addition, the number of patients reporting to have sought care from traditional healers is too small to be relied upon. The above point is supported by the contradictory opinions expressed by patients in response to question number 22 and 24. In the former (question 22), the respondents were required to state the immediate action they had taken soon after realizing they were ill

while in the latter (question 24) they were asked to state where they had sought treatment from with regard to their illness. Whereas 5 subjects among the cases and 21 among the controls had earlier on (question 22) asserted that they first resorted to traditional medicine; in question 24 none of the patients in the cases group and only 5 in the controls said they consulted a traditional healer.

According to the organizational set up of the Tanzania National Tuberculosis and Leprosy Programme, diagnosis and classification of leprosy are the responsibilities of the District Tuberculosis and Leprosy coordinators (DTLCs). These are basically Medical Assistants by qualification but with additional specialized training in tuberculosis and leprosy control and are mainly based at district hospitals. The other medical personnel at district hospitals or other health care levels are only supportive in as far as the programme is concerned. These supportive staff are expected to identify patients with features suspicious of leprosy, in the course of performing general clinical work, and either refer them to the DTLC if that was possible or appoint them to return on the day the DTLC is expected to attend patients at the health unit according to the supervisory visit time table.

This set up adversely affects early diagnosis of leprosy, especially at the level of a dispensary and health centre. Patients suspected to have leprosy at these levels have either to go to the district where they can see the DTLC or wait and hope to meet him/her at the time of his/her next visit to that health unit. Economic constrains or the uncertainties of transport might delay or even hinder the leprosy suspect from seeing the DTLC. Worse still, even if such patients could manage to reach at the DTLC base, he/she (DTLC) may not necessarily be there on that day. By the same token logistic problems may interfere with the DTLC supervisory visits as scheduled. For instance in

his study Muhondwa[14] found that, invariably the DTLCs had not visited all the health care facilities under their jurisdiction, in all the districts covered by the study, and where visiting had been done the average number of visits made per health care unit per year was 2.5. This figure is far less than what is expected by the National Tuberculosis and Leprosy Programme (4-6 visits per year). The end result of these snags is delay in detection of leprosy, if not missing it altogether. At this juncture, it is tempting to suggest that there is need to review this set up, if the NTLP is to meet the target set up by the World Health Assembly[56] in 1991, of eliminating leprosy - meaning interrupting transmission and reducing prevalence rate down to less than 1 case per 10,000 population by the year 2000.

One of the issues which need to be considered is the need for adequate training of medical students in leprosy, irrespective of their calibres, so as to enable them to diagnose the disease without difficulty, in its earliest stage possible. From personal observation and experience as a medical student and later as a teacher of medical assistants, the author feels that the teaching of leprosy in Tanzania has not been given the seriousness it deserves. Invariably, medical schools have been teaching and continue to teach leprosy separate from other subjects, in a form of a crash programme employing DTLCs or RTLCs as teachers. Worse still, in most instances only a series of lectures are given by these experts without supplementing it with demonstration sessions because of time limit. Demonstration sessions are important as students can better appreciate the varied clinical manifestations of leprosy.

A number of previous studies have demonstrated an overall lack of knowledge in the basic areas of leprosy in both the leprosy patients as well as the general public.[24-27,30,32-35,55,57,58] This has been confirmed by the findings of this study, in which

it was found that only 43.2% of the study population could generally be graded as having adequate knowledge about the cause of leprosy, its early clinical manifestations and mode of treatment (Table XIII).

However, subjects in the three categories of patients differed, though not very markedly, in their levels of knowledge; the level being highest (71.7%) among cases and least in control 2 subjects (16.9%). The corresponding figure for control 1 subjects was 65.2%. The leprosy patients, when compared to patients without leprosy were found to be more knowledgeable about the disease. The difference in knowledge levels between leprosy and non-leprosy patients can be explained by the fact that leprosy patients being directly involved in leprosy programme could have had more exposures to health education talks about the disease than any other patients. However, it is also known that increased awareness about disease and its causes does not always result in positive action towards prevention or care. It depends on factors affecting motivation to act such as socio-cultural or economic factors.

The findings about the perceived causes of leprosy among patients in all three categories were not encouraging, especially with regard to modern views of leprosy control bearing in mind that the NTLP has been in operation for nearly two decades now. By far, the majority of the respondents said did not know of any cause of leprosy and only 6.5% of all respondents mentioned the correct response; which for the purpose of this study was simply - a germ. There was negligible difference in their responses regarding the causes of leprosy when patients with leprosy and those without it were compared. This is surprising as one would expect that leprosy patients, being participants in the programme, would be more conversant with the cause of leprosy than non-leprosy patients. It is tempting to think that, the health

education given to patients might be deficient in some facts. Regarding early manifestations of leprosy, the study results demonstrate poor knowledge by all three categories of patients. Only 21.3% of all the respondents knew the manifestations. Out of these majority knew only one of the manifestations.

Inadequate knowledge about early manifestations of leprosy has been reported in other studies.[25,26] But, in contrast to findings in those studies, in the present study leprosy patients scored poorer than patients without leprosy as far as knowledge of early manifestations of leprosy was concerned. However, non-leprosy patients appeared to know mainly the visible clinical features like a patch and nodule. There was no respondent from this group who knew that numbness of hands or feet could be an early manifestation of leprosy! Furthermore, respondents who had mentioned that ulcers and missing fingers/toes were early manifestations of leprosy, all except one belonged to this group. Such knowledge is likely to delay a patient from seeking health care until the disease has progressed to an advanced stage.

Unusual answers to this question, all mentioned by non-leprosy patients, were weight loss and insufficient blood in the body. These are not in line with scientific facts about leprosy. Another notable point is that, contrary to expectation, a slightly higher proportion of respondents among the group of leprosy patients who had less severe or no disability at all at the time of diagnosis (first control group), did not know the early manifestations of leprosy than those found having severe disabilities (cases).

Although on the one hand, chance variation may explain this difference, on the other there could be other factors responsible for the difference. One possible explanation is that the knowledge exhibited by patients represents differing emphasis in the various

aspects of leprosy when health workers give health education to individual patients at the time of diagnosis. Since patients in the cases group had features consistent with late stage disease, the stress in health education could have been mainly on early manifestations of leprosy. This could have been deemed as of less importance for patients belonging to the first control group as they did not have features of late stage disease at the time they were diagnosed to have leprosy.

During health education talks the patients and the public are informed that leprosy cannot be cured by traditional medicine, but by modern medicine. The results of this study indicate that about a half of the respondents believed leprosy could be cured and the remaining half did not know whether it could. Ignorance about cure were more pronounced among patients without leprosy; which represented a section of the general population as far as this study is concerned (72.0% for patients without leprosy and 22.7% for leprosy patients). This was in keeping with the results of Shetty and his colleagues,[26] who found that only 15.0% of the community believed that leprosy is curable. The finding that a higher proportion of leprosy patients than non-leprosy patients believed in the curability of leprosy is not surprising, given the fact that most leprosy patients had been undergoing treatment at the time of interview. Thus they could have already experienced some improvement in their symptoms as a result of the therapy given.

As for the concept of cure, the results of the present study do not differ much from those observed in the study by Masao and Ishengoma which found that leprosy cure, to the majority of patients, meant total recuperation.[55] This notion need to be corrected as it could create false confidence among some patients whom may think they are cured and no longer need treatment after symptoms have disappeared. By the same

token, if such notion prevails in the community, people might not believe that leprosy is curable if they see the insensitivity and deformity which the patients had before starting drug treatment do not disappear after the completion of therapy. The finding of poor score of leprosy knowledge among respondents in this study may probably be explained by the way health education is given at the clinics which has to be further studied.

From the data gathered, it was also shown that certain myths concerning the cause of leprosy continue to thrive. Various erroneous answers included sharing of food or articles, poor environmental sanitation and contaminated air. Interestingly, however, unlike findings of other studies,[24,30,32-34] in the present study leprosy was not attributed to witchcraft, divine punishment, sexual immorality and physical contact with a leprosy patient.

Regarding attitudes of leprosy patients towards modern health care for leprosy, the study results revealed a positive attitude in the majority of the patients. For many of them, they had sought treatment from modern health care institutions and they liked to advice people suspecting themselves to have leprosy, to seek care from similar institutions. This is encouraging and need to be reinforced through health education.

In health education campaigns it is often stressed that there is no need to isolate patients with leprosy. However prejudices and stigma about leprosy are deep rooted in cultures and as such take very long time to die out. Stigma about leprosy and the resulting discrimination of patients hinders successful leprosy control since besides causing anxiety to the patient, they hinder his/her early and willingness to resort to treatment.

The degree of stigmatization about leprosy vary from society to society. In Tanzania, previous studies[14,24,55] have found existence of stigma to some extent. This has been confirmed by finding of the present study. In the present study the use of euphemism was found in about 7.0% of the respondents; who when asked to mention the name of the disease they were suffering from, they responded by mentioning non-specific names like "skin disease", "special disease" and "great disease". It is important to stress here that some patients said did not know what they were suffering from, despite of them being on follow-up visits to a leprosy clinic. This is interesting, particularly because some of these had attained primary education and the treatment (follow-up) cards they were holding had the name of the disease written in Swahili! This could be a coping mechanism or denial in view of the stigma associated with leprosy.

The present study also found that about 94.0% of the leprosy patients had told their family members about their illness whereas only about 48.0% of all the patients had told their friends about the illness. This shows that majority of the patients would like to confine the news within family circles - a situation which in a way implies fear of stigmatization. Patients whose friends had not yet known of their (patients) illness when asked what they would anticipate in case the diagnosis was known to their friends, about 15.0% responded by saying they anticipated discrimination of some kind by their acquaintances. These findings indicate that prejudices against leprosy and stigma exist in some measure in the communities where the patients lived.

Prejudices and stigma about leprosy are some of the major obstacles to successful leprosy control. Thus there is need to combat these elements through health education and by demonstrating that leprosy can be cured. The population should be encouraged

to look at leprosy as one disease among others, requiring no special measures, and to accept patients in the community.

Other observations made by the author in connection to stigma about leprosy were that some patients at times were hesitant, evasive or indirect in responding to questions regarding their state. Other patients would lower the tone of the voice at the time of answering the questions. More interestingly, one patient had registered at one clinic using a name which was different from the real one! Above all, the use of euphemism was not uncommon even among medical personnel conducting the clinics. For instance, when they wanted to draw the attention of their clients, who normally mixed with other patients before the clinics commenced, the medical personnel would announce that "patients with skin disease should come this way" to be attended.

Many studies done elsewhere have reported stigmatization in leprosy.[25-28,32,59] Tekle-Haimanot and his colleagues found that stigma about leprosy existed to some extent in a rural community in Ethiopia.[59] In their study, when the respondents were asked if they could accept a successfully treated and cured case of leprosy back to the family, nearly 42.0% of the interviewees responded with "once a leper, always a leper". In the United States, there have been deliberate attempts to soften the stigmatizing blow on leprosy patients by using ameliorated designations such as "Hansen's disease and Mycobacterial neurodermatitis".[28]

Regarding adverse reaction suffered by patients following knowledge of the diagnosis by their families or friends, it is interesting to note that none of the patients reported to have been isolated or shunned away by family members. Only a few patients had said their friends shunned away. It appears that, to a great deal, both the family and friends

express sympathy, tolerance and support to the patients. Similar to the finding by Muhondwa, this study found that physical disability resulting from leprosy was attributed to the fear that some people express about leprosy. This was mentioned by 15% of the leprosy patients and 8.2% of patients without leprosy. Thus, by implication, the fear about leprosy is likely to diminish if leprosy is detected in its early stages and treatment initiated before the patients have developed obvious disabilities.

The study also provide some quantitative estimate of the risk factors associated with delay in the diagnosis of leprosy - that is acquiring grade 2 or 3 disability as a result of leprosy before the disease was diagnosed (Table XVI). The result suggest that farming as an occupation and having borderline tuberculoid leprosy were significant risk factors for acquiring significant disability. Plausible explanations for this observation could be as follows: Farming predisposes the patients to frequent trauma, producing small lesions which are secondarily infected by bacteria resulting into ulcers, osteomyelitis and finally deformity. Also because of insensitivity pressure sores easily form during the process of farming which involves holding farm implements firmly by the hands and standing in the farms for prolonged periods of time. Furthermore, because of being overloaded with work, farmers may not find enough time for them to seek medical attention in the early stages of leprosy, when there are few symptoms. Thus they wait until the disease has become "obvious", which means deformity.

The association of borderline tuberculoid leprosy with significant disability can be explained by the fact that nerve damage is more frequent and severe in this group and the group is also more prone to leprosy reactions especially type I (Reversal) reaction than other types of leprosy.[60] Disability sets in rapidly and tends to be severe when reactions occur. Another possible explanation for this type of leprosy being a risk

factor for delay in leprosy detection is the fact that while the patients may be having evidence of typical nerve damage, there may be no skin lesions. This causes difficulties in diagnosis, particularly in an inexperienced personnel; hence leading to misdiagnosis and therefore wrong treatment until such time that other "obvious" features appear - meaning delay in diagnosis.

The fact that having borderline lepromatous leprosy was found to be protective of acquiring significant disability prior to diagnosis is unexpected. This could possibly be explained by misclassification of the type of leprosy a patient was having. Since classification of the type of leprosy in the clinics surveyed is done on clinical grounds alone, it is possible that some of the patients who were classified as having borderline tuberculoid leprosy could actually be having other types of leprosy not associated with significant disability such as tuberculoid leprosy.

Factors which were not found to be significant risk factors for developing significant disabilty before leprosy is diagnosed included the four hypotheses behind this study namely; poor knowledge about leprosy, negative attitude towards modern health care, anticipation for isolation if known to have leprosy and hospital delay. These findings suggest that there were other factors which were impending early diagnosis of leprosy than those hypothesized. Further research is needed in this area to elucidate such factors.

7.0. CONCLUSION AND RECOMMENDATIONS

7.1. Conclusion

This study has found that 18.4% of the leprosy patients in Dar es Salaam region had been diagnosed to have leprosy late in the disease process. All four hypotheses behind this study were not verified by the study results, instead farming occupation and borderline tuberculoid leprosy were found to be statistically significant risk factors for late detection of leprosy in this study population.

The study has also found that there was not much difference between the two categories of leprosy patients (those who were diagnosed early and those diagnosed late) with respect to duration that had elapsed before the patients decided to seek medical care. About 50.0% of the respondents in both categories of the leprosy patients had reported to a health care unit within 3 months while 75.0% of the respondents in the cases and in the controls had done so within 11 and 12 months respectively.

It was also found that there was a tendency for the health workers to arrive at a conclusive diagnosis of leprosy rather late among patients belonging to the cases group category than among patients belonging to the control group category. It took 7 months for three-quarters of patients in the cases group category to have been correctly diagnosed whereas this process took only 4 months for patients in the control group category.

The study also found that generally, both leprosy and non-leprosy patients had inadequate knowledge about leprosy; specifically with regard to causation, its early manifestations and curability. Various misconceptions about these three aspects were

evident. Patients without leprosy were even worse off in terms of the level of knowledge about leprosy.

Another important observation seen in this study was that the majority of the leprosy patients had positive attitudes towards modern health care for leprosy. Such attitudes need to be reinforced at all times while we are fighting to eliminate leprosy.

The study also found that, although stigma about leprosy existed to some degree, majority of the patients generally do not in fact face outright segregation and ostracism. They seem to get sympathetic reaction from their families and community.

7.2. Recommendations.

In view of the findings of this study, the following recommendations are pertinent:-

7.2.1. Since this study mainly addressed patient related factors, there is need for more comprehensive studies on delay in diagnosis of leprosy, addressing service related factors such as competence of health workers at primary health care levels in diagnosis of leprosy in its early stage and their attitudes towards leprosy and the patients. In as far as leprosy diagnosis is concerned, particular attention should be paid to perceptions and interpretations of symptoms of the disease. Also, community related factors such as the community's awareness about leprosy and their attitudes towards modern health care for leprosy need to be studied in depth.

7.2.2. For the promotions of early diagnosis and control of leprosy, it is suggested that there must be greater health education thrust for the community and the patients in relevant clinics. Correct information of the cause, early manifestations, curability and outcome of leprosy need to be provided. Before this can be achieved there will be a need to assess and evaluate the kind of education given at the present time.

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