Immigrant leprosy patients' views of their illness and its influence on their position in Dutch Society; an emic view

Thesis for the Degree of Master in Medical Anthropology
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Preface

Leprosy caught my attention for the first time when I was about six years old. Not because of my own physical experience, but because a biblical story told by my teacher at primary school struck me psychologically. I was intrigued by the fact that lepers were socially isolated (1). The idea of becoming isolated from society, mutilated, walking with a rattle to announce one’s approach, frightened me. During a period of some weeks I was very worried and even asked my parents every night at bedtime: “I won’t become a leper, will I?” (Ik word toch geen melaatse pappa/mamma?)

About thirty-four years later, leprosy caught my attention again. This time I worked as a medical doctor in Nigeria (Western Africa). For three and a half years I was control officer for Tuberculosis and Leprosy in Bauchi State. On my supervision tours to the leprosy clinics I met many leprosy patients. What moved me was the impact the disease had on their physical, psychological and social life. I became very interested in finding out more about the ideas and experiences of patients in relationship to their cultural background. With this in mind, in September 2000 I started The Amsterdam Master’s in Medical Anthropology (AMMA) at the University of Amsterdam, and learned to look at leprosy from the human perspective, the so-called ‘insider’s view’. In this context, anthropologists use the terminology emic view (2), a term which is referred to in the title of my thesis.

In December 2000, I followed the module ‘Culture, Care, Chronic Illness and Disability’ as part of the AMMA-programme. The article ‘Leprosy among the Limba’ (see references) brought this intriguing disease again to my mind, but now in a way that differed from the biomedical approach. A person’s worldview influences the way in which (s)he expresses and experiences illness and healing. The text of the article challenged me to contemplate leprosy in that context.

I was informed by a colleague that a small group of leprosy patients exists, who are under medical management in different Academical Medical Hospitals in the Netherlands. This group of patients consisted of immigrants. Because there is so little information available about the ideas and experiences of these immigrants, it appeared valuable to take this emic view as a subject of my research.

Clarifying in this context is the poem which one of the fourteen interviewed patients has sent me. He wrote it himself, under a pseudonym. The original Dutch text is typed on the next page and translated into English at the end of the thesis (Annex 9). In his letter to me, the writer of the poem quoted another poet in stating that: “A poem is the uttermost individualistic expression of the uttermost individualistic thought”. And he added himself: “And in my view, this is the reason why poems are actually not transferable”.

In this thesis I have tried to find words to transfer thoughts, experiences and emotions of people who are dealing with* leprosy. I struggled to get track of connections and comparisons. I realise that the interviews, like poems, can actually not be totally transmitted. Hopefully my efforts on this point have succeeded in contributing to a better understanding of the ideas and experiences of immigrant leprosy patients in the Netherlands.

* ‘dealing with’ can be perceived in two ways: to be patient; or to be near to the patient as a relative, friend or medical staff
Poem by Pieter Baars

eenzaamheid

de lans van het verlangen
het zwaard van mijn kruis
de hunker naar volmaaktheid
de heimwee naar mijn thuis
doorsteekt en wondt gestadig
vertraagt verteert mijn lot
mijn rondwandelen op aarde
mijn wachten op mijn God

heet dat messiaans verlangen
begrijpt iemand dat dan
is er ergens een mens hier
die hetzelfde voelen kan
of zijn jullie allemaal gekken
verslaafden van je baan
verdoofd in de tredmolen
van het dagelijks bestaan

hoort iemand mij

hoort iemand mij

is daar iemand

is daar iemand

Lay-out according to the original.

Anthropology, like good poetry, makes the strange familiar and the familiar strange (Spiro 1995 in Nanda and Warms 1998); addition of the author of the thesis.
Acknowledgements

Herewith I would like to thank all the interviewees for their co-operation and their confidence in me.

This research would not have been possible without the assistance of Prof. Dr. W.R. Faber, Dermatologist in the AMC and Dr. Ben Naafs, Dermatologist in the LUMC. They introduced me to the immigrant leprosy patients and acted as mediators in obtaining their permission to be interviewed. I am very grateful for the opportunity to visit their policlinics. In this way, I met both leprosy patients and medical staff.

The facilitators of the AMMA inspired me to write this thesis. Special acknowledgements go to Prof. Dr. Sjaak van der Geest, Ria Reis (PhD) and Prof. Dr. Pieter Streefland, Prof. Dr. Corlien Varkevisser and Trudy Gerrits for their guidance during the course. Els van Dongen (PhD), who facilitated the module ‘Culture, Care, Chronic Illness and Disability’ twisted my medical mind with anthropological viewpoints on this subject. She acted as my main inspirator for this thesis, together with Dr. Erik Post (MD, MSc). Dr. Post was the first one to inform me about the existence of medical care for leprosy patients in certain hospitals in the Netherlands. Piet Feenstra (MD, PhD) Medical Consultant at the Royal Tropical Institute (KIT), assisted in contacting Prof. Dr Faber and Dr. Ben Naafs, both Dermatologists.

Annette Noordzij, working at INFOLEP of the Netherlands Leprosy Relief (NLR) in Amsterdam, assisted me in locating literature in a very professional way. Bas van Leeuwen, who works at the NLR Fundraising Department was so kind to supply me with the images presented in this thesis. Leonie McCann corrected my English and Sonja Verbeek-de Ruiter (MA, B.Sc.) motivated me with her ever lasting enthusiasm for anthropological research.

The Q.M. Gastmann-Wichers-Stichting, a foundation which stimulates leprosy research in the Netherlands, financially supported part of the research (3).

Last but not least, I would like to thank all the acquaintances, family and friends who have supported me during the period in which I conducted this research. From time to time they took care of my two daughters and, in this way, were also looking after me. I especially want to thank my dear mother, my sister Anja and my friend Maria, alias ‘Roos’.
Summary

Immigrant leprosy patients’ views of their illness and how it influences their position in Dutch society

Statement of the problem

Leprosy is an endemic disease in many countries of the developing world. It is well-known for one of its complications: frightening visible deformities. Leprosy was endemic in the Netherlands for many centuries and was most prominent in the 14th century. It subsequently disappeared during the seventeenth century. Since that period, leprosy has only been diagnosed in the Netherlands as an imported disease from the Dutch colonial areas. The group of leprosy patients, who are currently being treated in the Netherlands, are immigrants from countries where leprosy still prevails. The patients can be divided into two subgroups; immigrants from the former Dutch colonial areas (Indonesia and Surinam) and immigrants from other countries where leprosy still prevails (refugees and economic immigrants). There is no contemporary literature about the experiences of the immigrants who are affected by leprosy while living in the Netherlands. In this study I will attempt to contribute to knowledge about leprosy patients’ experiences in the Netherlands, by seeking answers to questions and assumptions about these experiences.

Objectives

The main objective of the study is to identify the ‘emic’ view (2) of immigrant (mostly Surinamese and Indonesian) leprosy patients on the influence of their illness on their position in Dutch society. At the same time, their perception of treatment in the Netherlands will be explored.

Specific objectives:

1. To describe the views of immigrant leprosy patients concerning:
   a. The etiology of their ailment.
   b. The consequences of their ailment for their position in Dutch society, particularly among their close relatives, their friends and neighbours, and their colleagues.
2. To investigate if the symptoms create special problems for the patients and, if so, how they cope with these problems.
3. To assess patients’ views of their medical treatment.

Study type, researcher, supervisor and research period

The study is an exploratory, descriptive study.

Marion Steentjes, MD is the researcher. Prof. Dr. Pieter Streefland is the supervisor. Prof. Dr. Corlien Varkevisser is the co-reader.

The research and writing of this thesis was carried out in the period 14 May to 13 August 2001.
**Sampling and data collection**

**Data collection techniques**

1. Information from three key-informants. An interview with two medical doctors in Amsterdam and Leiden (Annex 4). The third key-informant is a researcher, who has extensive experience with anthropological research in the field of leprosy in developing countries. I obtained very much and very useful information from this researcher by means of personal communication and guidance during the development of the project proposal, as well as the reading of the draft thesis.

2. Interviews with three general practitioners (GPs) (Annex 5):
   a. A GP who has experience with the management of immigrant leprosy patients.
   b. A GP who has no experience with the management of immigrant leprosy patients.
   c. An interview with another GP in Maassluis.

3. In-depth interviews with leprosy patients (14 persons) under management in the AMC or LUMC (Annex 6).


5. An interview with a nurse from the AMC and one nurse from the LUMC, both directly involved in leprosy care (Annex 8).

6. Participant-observation during consultation of immigrant leprosy patients who visit the dermatological out-patients’ department of the AMC (Amsterdam) and LUMC (Leiden).

The population to be studied is the group of immigrant leprosy patients, who are under treatment/management in the Netherlands. The group consists of approximately 150 patients. The sample is taken from the leprosy patients under management in Leiden (LUMC) and Amsterdam (AMC).

Further, the technique of *snowball sampling* is used. (Patton, 1990, p 176). The medical key-informants acted as the intermediaries between leprosy patients and the researcher.
Discussion of results and conclusions

In-depth interviews with fourteen leprosy patients have been conducted at the LUMC and AMC. Two interviews could take place in patients' homes. Analysis of the information resulting from these fourteen interviews show that the immigrant leprosy patients seem to live normal lives in Dutch society. But during the interviews it became clear that all patients keep their ailment hidden from their surroundings. Only very close relatives and the spouse were informed and sometimes the secrecy is complete. The Surinamese perceive their own community as stigmatising. However, such stigma is in actual fact not really experienced. In reality, the patients are only fearful of stigma, and therefore it can be called 'expected' stigma. But for the lives of leprosy patients, expected stigma seems to be a problem and can lead to self-stigmatisation. Most patients mention more than one cause for their leprosy; the multicausality concept (9). The patients appreciate the medical treatment in the management centres. They have more problems with medical doctors who work in other medical fields, such as GPs and neurologists. The greatest problem appears to be lack of specific knowledge regarding the complications of leprosy.

'Once you have come across leprosy, it will never let you go'. This statement from one of the key-informants seems to apply to both patients and medical staff.
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Introduction

1.1. Background information

Leprosy is an intriguing infectious disease, known to mankind since ancient times. For a long time there was no cure for it. Repellent visible deformities can result from the infection. Such deformities are striking for everyone who is confronted by them. A germ called ‘Mycobacterium leprae’ causes the infection. Armauer Hansen, who was a Norwegian medical officer, discovered the ‘Mycobacterium leprae’ in 1872. In medical literature, leprosy is sometimes named after this medical doctor: Hansen’s Disease.

It is a contagious disease, airborne and transmitted from person to person by sneezing and coughing. The nose is an important carrier of the germ. It is known that in endemic areas the development of immunity, without any clinical signs, is the normal response to exposure. If somebody belongs to the five percent of the infected people who develop the disease leprosy, (s)he can nowadays be treated with Multiple Drug Therapy (MDT) (5). The first sign of leprosy is usually a hypo-pigmented skin lesion, without sensation. This skin patch is physically similar to many other skin diseases that are harmless, such as some fungal skin diseases.

Genetic factors play an important role in the susceptibility of the person. However, living near a person suffering from ‘active’ leprosy during an extended period increases the chance of transmission. The time between the actual infection and the onset of the clinical symptoms of the disease is estimated between two and ten years. A person, who has not yet been identified as suffering from leprosy, can transmit leprosy in the neighbourhood over a long period. The disease is more prominent among the lower social classes in developing countries, and is associated with poor socio-economic circumstances (crowded houses, poor food). Children below six years old do not normally suffer from leprosy, because of the long incubation period of the disease (Hastings, 1985).

When patients delay reporting for treatment, they can develop mutilations. The germ affects the peripheral nervous system, which causes paralyses of the extremities and insensibility of the skin. Because of this, patients do not feel any pain on the insensitive parts of the skin. Those insensitive places are especially dangerous at the extremities (the hands and the feet), because a patient may develop wounds without noticing it. If the infection of the wounds is not treated well, this can lead to further infection of the bones and, ultimately to the mutilation of the hands, feet and face that we are all familiar with from paintings, photographs and films. Leprosy can also affect the eyes and lead to blindness.

It is assumed that leprosy originates from Asia. Leprosy is already mentioned in old Indian and Chinese manuscripts that were written hundreds of years B.C. Via the Middle East and Northern Africa, the disease reached Greece and Italy. During the Roman Empire it spread through Europe and was most prominent in Northern Europe during the Middle Ages.

Today, the disease is still endemic in many developing countries. However, over 85% of all leprosy cases in the world are concentrated in only six countries in the following order of magnitude: India, Brazil, Bangladesh, Indonesia, Myanmar and Nigeria (Revised Workers’ Manual Nigeria, 1998).
Stigmatisation of persons affected with leprosy is a common factor in all endemic countries, as far back as memory reaches. The stigma can manifest itself in different ways in different cultures. Stigma has been defined by Goffman (1963) as ‘an attribute, an undesirable differentness that discredits or disqualifies the individual from full social acceptance. The person is reduced in our minds from a whole and usual person to a tainted, discounted one’. Stigmatisation would then be the process in which group values are affirmed, and the ‘normal’ are separated from the ‘deviant’. The stigma may be caused by a discrediting mental or physical disease (leprosy), or by social characteristics such as race, gender or religion. Leprosy, especially when frightening outer signs appear, disqualifies patients from full social acceptance in many parts of the world. Another aspect of stigmatisation is the fact that someone who feels (s)he is not fully socially accepted will avoid social contact and restrict him/herself in certain activities, all of which is not actually required from the outside world (self-stigma).

In the Book of Leviticus in the Old Testament, leprosy was associated with uncleanness (tsara‘ath). “Unclean” sufferers were isolated, requiring them to cleanse themselves and their clothes, and were kept isolated from others until inspection determined that they had again become “clean” (Green, 1999, p 239). The idea of ‘uncleanness’ was also dominant during the Middle Ages in Western Europe. Annet Mooij (2001) tells us that a committee of three professionals (medical and religious) had to judge the condition of leprosy suspects in Amsterdam (the Netherlands). If leprosy was confirmed, the sufferer got a certificate (‘vuylbrief’). This certificate gave him/her the right to beg. Apart from rights, there were also many obligations and prohibitions for the persons suffering from leprosy: they had to wear special clothes, they were not allowed in the city, they should not come into the neighbourhood of healthy people and they had to announce their arrival with a wooden instrument (a rattle). The disease was seen as a punishment from God. The attitude against persons affected by leprosy in that time had two sides. On the one hand those people were unclean and had to live separately, on the other hand they were ‘the chosen’, cared for (in leprosy-houses) because of Christian charity. But in general the sufferers of leprosy had a bad reputation. They were suspected of sexual exorbitances and were known as drunkards and good-for-nothings.

In the Netherlands, leprosy disappeared during the seventeenth century, probably due to better standards of living (food, sanitation, housing). The introduction of the use of a handkerchief for sneezing and coughing could also have been of importance, taking into account that leprosy is spread by droplets in the air (personal communication by Prof. W.M. Faber). After the seventeenth century, Dutch people were only infected through contact with leprosy patients in the colonial areas.

1.2 Statement of the problem

Since the seventeenth century, leprosy has been a rare condition in the Netherlands, but there are still leprosy patients under treatment today. People from Dutch origin, who worked within leprosy-projects in endemic areas, such as medical doctors, their family, Christian priests and nuns, have seldom been infected with leprosy. The leprosy patients who are under treatment nowadays are immigrants. They originate from countries where leprosy still prevails. The group of immigrant leprosy patients consists of two subgroups; the immigrants from former Dutch colonial areas (Indonesia and Surinam) and the immigrants from other countries (refugees and economic immigrants). These patients bring the disease with them from their country of origin. They are treated as ambulatory patients.
by the dermatological departments of three different academic hospitals in the Netherlands. Those centres are situated in Groningen, Amsterdam and Leiden. Most of the patients under treatment do not have an active leprosy infection anymore. They have finished their MDT and they visit the treatment centres because of (neurological) symptoms that remained from the leprosy infection and/or for research purposes, actually for management of their disease (4).

The present immigrant leprosy patients come originally from another culture and live with their condition in Dutch society, where leprosy seems ‘far from our bed’ which means that it is not thought close enough to be a problem. Because of the long incubation time, leprosy can also be detected after arrival in the Netherlands. To autochthonous Dutch people it seems that the immigrants who are affected by leprosy have a rare disease, only existing in developing countries and all the different ways it might affect the patients are poorly understood. However, because of their backgrounds one has to keep in mind that the experience of leprosy is, apart from being an individual experience, also a social experience which is embedded in the cultural beliefs of the country of origin. These immigrant leprosy patients are an exclusive group of people, who will have interesting experiences with their rare condition.

We are not aware as to what immigrants with leprosy know and believe about their disease and their condition. There is no insight into how they perceive their medical treatment in the Netherlands. We do not know how they experience the reactions of their family, the group of fellow-immigrants and, in a broader context, how Dutch society (school, work, environment) reacts. It will be interesting to know if (and why) immigrant leprosy patients keep their disease secret from their surroundings and if this fact causes problems. It is not known if immigrant leprosy patients gain any advantages from their condition (financial assistance, easier working situation). These experiences will be influenced by different circumstances. Influential factors will involve how long an immigrant leprosy patient lives in the Netherlands, how much (s)he is integrated in Dutch society. Other important aspects will be the (in)visibility of frightening aspects of the symptoms of leprosy. Also the cultural background of immigrant patients will be very important for their perceptions. In this study I hope to shed some light on the experiences of immigrant leprosy patients in Dutch society.

1.3 Literature review

There is much literature available on all kinds of aspects of leprosy. Most of the literature about leprosy originates (unsurprisingly) from research in developing countries. Because leprosy patients in the Netherlands are originally from non-Western cultures, it would seem important to know more about leprosy in their cultures of origin. Literature that provides information on non-Western cultures could contribute to understanding the immigrant leprosy patients in Dutch society.

For my research I have chosen literature about different themes, which originate from the diagram I made around the core theme ‘How immigrant leprosy patients cope with their illness in Dutch society’. In the field of perception, the themes knowledge and beliefs about leprosy, stigma and self-stigma came into view. Further themes were the reaction of the spouses and blood-relatives and the surroundings (neighbours, fellow-immigrants, work, school). As regards to the health system, the perceptions of the medical treatment and the attitudes of health care providers seemed to be relevant. Another theme is the way in which
patients cope with the chronic symptoms (visible and invisible) of leprosy, in actual fact how they cope with a chronic illness or disability. Literature about coping with chronic illness or disability originates more from research in Western society.

For further reading it is important to define the difference between disease and illness, terms that will be used alternately in the following text. As defined by Kleinmann (1983), 'illness' is the culturally constituted, socially learned response to symptoms, that includes the way we perceive, think about, express and cope with sickness, while 'disease' is the technical reconstruction of sickness into terms of the theoretical system used by health practitioners. In other words, illness is the disease as experienced by a person; disease is the 'scientific' point of view.

People can have more than one perspective on their illness. This is expressed in the way they talk about it. Knowledge* and beliefs can both be intermingled in these perspectives.

In the following literature review I will describe what I have found by theme.

* knowledge: indigenous and gained from outside

1.3.1. Knowledge and beliefs about leprosy

It is known, that persons in different parts of the world have a different explanation for the same disease. This explanation is connected to peoples' worldview. Disease etiology is an aspect of the worldview a person has. G.M. Foster (1998) describes two identified systems of disease etiology in his article ‘Disease Etiologies in Non-Western Medical Systems’: the naturalistic and the personalistic disease etiology.

In the naturalistic system the causation of the illness is equilibrium loss. Disease is thought to stem from natural forces or conditions such as cold, heat, winds, dampness, and, above all, by an upset in the balance of the basic body elements. The illness is seen as unrelated to other misfortune. Religion and magic are largely unrelated to illness and the causality is defined as being on a single level. Prevention can be achieved by avoidance and the responsibility of the illness resides with the person suffering from the illness. Ayurvedic and traditional Chinese medicine are for example based on the naturalistic disease etiology.

The viewpoint of people from many different cultures can also be classified as personalistic, which is different from the naturalistic system. In the personalistic system the causation of the illness is an active agent. The illness is seen as a special case of misfortune. Religion and magic are in this case intimately tied to illness. The causality is defined on multiple levels. Prevention can be reached by positive action and the responsibility is beyond the control of the person suffering from the illness. Witchcraft is an example of the personalistic disease etiology.

According to Opala and Boillot (1996), this personalistic system is part of the worldview of the Limbas, who live in Sierra Leone (West Africa). The Limbas see the town (mehti) as civilised, linked with the color white. It is the place where the ancestors live together with the living. In contrast to the town, the Limbas see the bush (feli) as uncivilised, a zone of chaos, inhabited by powerful and destructive spirits, or devils and linked with the color red. The hypo-pigmented skin patches of leprosy patients with a dark skin, are reddish of color. In this way, leprosy is seen as connected with the destructive powers. The Limbas attribute
minor illness to natural causes but life-threatening diseases and chronic debilitating illness are attributed to witchcraft, destructive power.

Green (1999: 236) thinks that there is too much emphasis on witchcraft as an explanatory model for leprosy among the Limba. He gives examples of other explanations of leprosy, such as; God’s will; the role of maggots, gnats, flies and leaches; stepping in excrement; sexual intercourse; bad water; poor working conditions; or breezes. According to him those other explanations, some of which fit into his Indigenous Contagion Theory (ICT), are neglected (6). From the examples of Green (1999), it appears that in daily life the worldview of the Limbas consists of both personalistic and naturalistic disease etiologies, which indicates that the two systems are not so strictly divided as described by Foster (1998).

Van de Weg (et al., 1998) carried out research in Adamawa state (Northern Nigeria) and determined that many (of the 60 interviewed) patients held a variety of causes responsible for leprosy. Most patients explained the disease in traditional terms (58%), while only a minority used ‘modern’ concepts: contagion (20%). According to Van de Weg, food was a frequently mentioned cause in northern Nigeria. The same was true for Pakistan and Bombay, but not in Thailand. Whereas in Pakistan, patients explained the cause of leprosy as an imbalance between ‘hot’ and ‘cold’, this did not seem to be the case in northern Nigeria, nor did sorcery or a taboo seem to be the underlying reason. The high number of respondents attributing the disease to God ‘Ciwon Allah’ was specifically the case in northern Nigeria. In the Muslim view, all events, including disease, are caused by the will of God, irrespective of causes. However, they are not considered as punishment by God for sins or wrong-doings, as we know from Christian tradition.

In a discussion with Prof. Dr. C.M. Varkevisser, she queries the fact that most authors deal with the concept of ‘the cause of leprosy’. Her extensive experience with anthropological leprosy research in many parts of the world has shown that people have more than one explanation about the cause of leprosy. Therefore, it is important that the researchers, who interview people about knowledge and beliefs about leprosy, are attentive to this phenomenon and to the fact that there are changes in perceived cause over time.

‘The Hausa in Northern Nigeria, for example, may submit to the will of Allah, but at the same time they believe a person can get leprosy by breaking social rules. In that case, the leprosy patient is blameworthy. At the same time, they can have the idea that the person affected by leprosy has disturbed the djinns (ghosts). In that case, the leprosy patient should try to make restitution for his/her mistake’ (information from a written comment by Prof. Dr. C.M. Varkevisser).

People think in terms of causes of a disease and not about ‘the’cause. I would like to call the fact, that one person can have several explanations for ‘the’cause of a disease, as mentioned by Prof. Varkevisser, the ‘multicausality concept’. Green (1999) also seems to support this way of perception. On page 236 of his book about ICT(6), he mentions that the Limba (as a community) have several explanations for the cause of leprosy. However, it is not completely clear whether he also means that one single person will have several explanations at the same time about the cause of a disease. In this thesis the ‘multicausality concept’ will be used in relation to one single person.
From my own experience, having worked in the Tuberculosis and Leprosy control Programme in Bauchi State, Northern Nigeria (1997 – 2000), I have observed that people deal with both modern and traditional concepts at the same time. A recent interview with a female refugee from Sierra Leone, who was a student nurse in the Netherlands, leads to the same conclusion; she knew about the germ-theory and believed in taking modern drugs, but at the same time she saw witchcraft as a cause of leprosy.

I think that the immigrant leprosy patients in the Netherlands will have different ideas and perceptions about the cause of leprosy depending on their different cultures, but also depending on the mixture of thoughts and beliefs they will have about leprosy originating from their position as immigrant from a non-Western society within a Western society. It will be instructive to explore their ideas and perceptions.

1.3.2. Stigma and self-stigmatisation

Much literature deals with (leprosy) stigma. I will repeat again the description Goffmann (1963) gave of stigma. Stigma is ‘an attribute, an undesirable differentness that discredits or disqualifies the individual from full social acceptance. The person is reduced in our minds from a whole and usual person to a tainted, discounted one’. Stigmatisation would then be the process in which group values are affirmed, and the ‘normal’ are separated from the ‘deviant’. The stigma may be caused by a discrediting mental or physical disease (leprosy), or by social characteristics such as race, gender or religion. Another aspect of stigmatisation is the fact that someone who feels (s)he is not fully socially accepted will avoid social contact and restrict him/herself in certain activities, all of which is not actually required from the outside world (self-stigma).

I have tried to choose literature that enables one to look at stigmatisation from different perspectives.

Bainson and van den Borne (1998) state that diseases are feared, but it is people who are stigmatised. They quote Katz, who noted that the reaction of the majority observer group to the stigmatised individual would seem to have two basic components: first, the perception of a negative attribute, and second, the global devaluation of the possessor. This would suggest that stigmatisation of the leprosy patient has two basic components: perception of a negative attribute(s) to leprosy and devaluation of the leprosy patient, which corresponds with the definition Goffmann gave about stigma.

‘Ignorance, fear and superstition surround the problems of hanseniasis (7). In almost all cultures the predominant attitude is emotion, disgust and rejection towards persons suffering from this disease’ writes M. Dogliotti (1979). Visible signs of leprosy, in particular deformities, appear to be the major indicator for stigmatisation (Brazil, Varkevisser and Moreira, 2000: 33; Nepal, Goodfield, 1985: 147; Indonesia, Idawani et al.,2001: 44), which is comparable to the experiences mentioned by disabled deformed persons in Western society (Murphy, 1995). With regard to Aceh (Indonesia), all informants reported that visible signs of leprosy will drastically reduce the chances of cure and will have a severe impact on the lives of patients. For young men and women, the chances of a respectable marriage is reduced; for couples, the risk of divorce increases, and for all, there would be the risk of a less respectful burial (Idawani et al., 2001). As regards Nigeria (Plateau State), it is reported that female leprosy patients suffer more stigmatisation than males. Such stigmatisation may lead to divorce, expulsion from the community and,
equally importantly, economic catastrophe. The latter is due to the fact that most economic activities carried out by women involve farming, food processing and vending, all of which is rendered impossible by the fear of association with a “leprosy carrier”. Most of the stigmatisation derives from perceptions about causes of leprosy, and how the disease is transmitted. It is generally believed that any form of physical contact, sharing plates, clothes or even the sweat from an infected person, can be contagious. Based on this belief, community members keep leprosy patients at a physical and social distance, both during and after treatment. This constitutes an expression of stigmatisation (Varkevisser et al., 1998)

Aya Brandsma (1980, page 17) described the experience of a female acquaintance, who came to the Netherlands in 1950. In 1954, she was diagnosed with leprosy and was placed under treatment in the Netherlands. In the beginning her illness was kept hidden by her and her family. In the country of origin (Indonesia), leprosy patients were marginalised and isolated. When she developed complications of her disease and amputations were necessary, she pretended to the outside world that she had had an accident. She found it difficult to be forced to keep silent about her disease. Later on, she stopped her medication for some time, because her skin became more dark, due to the side effects of a particular drug (8). She thought that this effect would attract the attention of her surroundings, and could stigmatise her even more. She also indicated that she experienced programmes on television, which showed leprosy patients with deformities, as strengthening the stigmatisation. She expressed her fear that leprosy would be associated with severe deformities and dirty, putrid open wounds.

The experiences of this female immigrant leprosy patient in the Netherlands shows elements of stigmatisation and self-stigmatisation which, in the context of the culture of origin, can be understood very well.

Varkevisser and Moreira (2000) looked at stigma experienced by 54 leprosy patients at community level, through partners and blood-relatives in Rio de Janeiro State (Brazil). At community level, they found self-stigmatisation in a mild form (restricting social contacts) with 3 out of 54 interviewees, and a severe form (self-isolation/suicide attempt) with 2 out of 54 interviewees. Towards partners (and in-laws) there was no self-stigmatisation found and in relation to the family only one patient was reported who did not want to share food/drink/bed with relatives, or visit them.

I would like to end this section on stigma and self-stigma with the important concept of the difference between expected and experienced stigma. The negative attitude from the environment that the leprosy patient expects does not have to become reality. Varkevisser and Moreira (2000, p 72) write that it should be noted that the fear of being deserted by spouse, relatives and community members was far higher among female and male patients than they experienced in reality.

1.3.3. Reaction of the spouses, blood-relatives and the surroundings

The reaction of the environment towards the leprosy patient is dependent on many factors. According to Bainson and van den Borne (1998), individuals and societies make attributions to phenomena in order to make sense of their world. Attributions describe the processes of explaining events and the behavioural and emotional consequences of those explanations. To be stigmatised is in many ways similar to being a ‘failure’. As ‘failures’, leprosy patients elicit causal search and attributions from others and themselves.
to the Attribution Theory, the perceived cause of a stigma should determine affective
reactions towards the stigmatised person (e.g. anger, pity, and fear), future expectations
regarding that individual (e.g. the likelihood of recovery), and a variety of behavioural
responses. Thus, the attributions a given society, group or individuals make on leprosy
influence significantly the emotions they develop towards the disease and, consequently,
their behaviour towards leprosy patients.

Weiner (1986) described three major dimensions of attributions: locus of causality,
controllability and stability. Locus of causality is the perception that the location of the
source is either due to factors internal or external to the person. Controllability is the extent
to which causes are believed to be under volitional control. Stability is a person’s location
of cause(s) on a continuum according to how stable or unstable that cause is perceived.
According to the theory, if society, groups or individuals perceive the cause of leprosy as
controllable by the leprosy patient, it is likely that anger will be directed towards the
leprosy patient and, as a consequence, the patient will suffer social rejection. On the other
hand, where the cause is perceived to be uncontrollable, this is likely to generate pity and
help-giving. For example, if the cause of leprosy is attributable to uncontrollable factors,
such as physical causes in the environment, then this is likely to generate sympathy or pity
for the person suffering from the disease. On the other hand, where the disease is
attributable to controllable (external) factors such as religious transgression or sexual
indiscretion or eating the wrong food, this elicits anger, revulsion, and social rejection.
In leprosy, the locus of causality may be perceived as internal where it is believed that the
source of the disease is infectious or contagious. This attribution is likely to generate fear.

It is interesting to analyse why some societies adopt different affective responses towards
leprosy. Bainson and van den Borne (1998) write that they identify three main reasons.
First, it may be that in some societies, physical abnormality is associated with moral
bankruptcy. This is probably likely to hold true in societies that explain diseases as
resulting from a transgression against a divinity. Second, among certain cultures and
religions, ethical norms do not demand explanations of the type that are called for in the
majority of societies. For example, Muslims believe that every outcome (success or failure)
is ordained by God. Consequently, it is not surprising that Shiloh (1965) observed little
stigma against leprosy among the Hausa in Northern Nigeria, who are predominantly
Muslim. Third, social psychologists have proposed that the affective response derives from
the norm of social responsibility, which requires that we help those who are dependent
(charity). Communication with Prof. Dr. C.M Varkevisser showed that she feels that the
conclusion of Shiloh, as mentioned above, is a source for discussion. From her experiences
in Northern Nigeria as an anthropological researcher specialised in leprosy research,
stigmatisation is definitely present in Hausa society. This corresponds with my own
experiences working in the Leprosy and Tuberculosis Programme in Bauchi, Nigeria. The
reason why Shiloh observed little stigma among the Hausa in Northern Nigeria can perhaps
be explained because he did not take the ‘multicausality’ concept (9) into account.

Out of a group of leprosy patients in Adamawa State (Northern Nigeria), Awofeso (1995)
describes that more males are ejected from their communities than females, partly because
the males are more exposed and partly because of the ‘inconsequential’ role generally
ascribed to women in African societies. It is in the area of family life that female leprosy
patients are worse hit. Divorce is a common problem amongst leprosy patients, but a man is
more likely to divorce his wife should she contract leprosy, than vice-versa. While in some
parts of the world, long periods of hospitalisation has been identified as the single most
important cause of divorce, in Nigeria it is the presence of stigmatising deformities that usually rocks such marriages (like in all societies, note researcher).

From the previous review it is clear that different cultures will exhibit different reactions to the disease leprosy. I have not (yet) found specific literature (e.g. from the United States) on how immigrant leprosy patients experience the reaction of spouses, blood-relatives and environment. There is more literature about the assumed public stigma in the USA. Gusson and Tracy (1972) state in their article (literature review) 'The phenomenon of leprosy stigma in the Continental United States', that strong public stigma has not actually been scientifically demonstrated. According to them, the evidence is equivocal; leprosy may be stigmatised to some extent, but so are other chronic diseases. They warn that those responsible for the treatment of patients may need to think in terms of alternatives to presumptions of public stigma. I want to add that I have not found literature about research that has been done to examine if there are differences in attitude towards leprosy between the many different ethnic groups that are living in the USA. This could be interesting, because comparisons could be made with the Netherlands, where more than ten percent of the inhabitants are allochtonous.

1.3.4. Patients' perception of the medical treatment and the attitudes of the health care providers

According to Pascoe (1983), research on patient satisfaction indicates that such information does have a role in evaluating primary health care and explaining health-related behaviour. Patient satisfaction can serve as an outcome measure of the quality of health care, and provides a consumer perspective that can contribute to a complete, balanced evaluation of the structure, process, and outcome of services. Patient satisfaction is also predictive of such health-related behaviours as compliance and switching providers, and is related to self-reported improvement in health.

'Satisfaction is related to the affective quality of the provider's manner, the amount of information conveyed by the provider, the provider’s technical and interpersonal skills and the length of the medical visit' (Hall et al. 1988).

There are different models to measure patient satisfaction. Linder-Pelz (1982) tested the Fishbein and Ajzen’s attitude theory. This theory states that attitudes are determined by the interaction of beliefs (expectations) and valuation (values). She could not support the theory and developed her own model with more psychological theory-building. This model was again evaluated and criticised by Pascoe (1983).

Patients may have a complex set of relevant and important beliefs, which influence their opinions on the quality of their services. Through open-ended questions, people express themselves in their own terms. This avoids misinterpretation and gives patients the opportunity to express their concerns about different aspects of care (Williams, 1994).

Expectations and experiences of people are subjective and may be influenced by factors outside the health care system (Sitzia and Wood, 1997). Specific aspects of the health services may be judged as more important (e.g. health education, privacy, attitude of health personnel, distance). In developing countries leprosy patients are often marginalised and low quality of those health services might be an extra reason for avoidance of leprosy.
services and defaulting. This could be the same in the Western health care setting (addition of the researcher).

An interesting remark about how health care providers in the Western situation reacted is written by Aya Brandsma (1980, page 17). Brandsma worked at that time as a nurse on the dermatological ward in a Dutch hospital and noted that the term 'leprosy' was not used on his ward. This precaution was taken, because the health care providers feared that fellow patients on the ward (consciously or unconsciously) would react with stigmatisation. They might refuse to be in one room with a leprosy patient. This was the reason why the health care providers use the term 'morbus van Hansen' (Hansen's disease).

1.3.5. Perception of a chronic illness

Different aspects of the perception of chronic illness are covered in literature. Hereunder follows a description of what has been written by different writers about the aspects of autobiographical disruption, loss of self, uncertainty and the 'why' aspect. I think that, although the literature originates from experiences in Western society, many aspects are universally applicable

**Autobiographical disruption**

M. Bury (1991) describes the term 'autobiographical disruption' in relation to his chronic illness. He explains that his life has taken another track than he had planned. His chronic illness disrupted the 'normal course' of his life. The expectations for his future were totally disrupted. Of course, many events in life can constitute an autobiographical disruption. But to understand the feelings of a person with leprosy (and other persons with a chronic illness) better, it is important to realise that the diagnosis and the fact that a person suffers from a chronic illness intervenes with his own life history.

**Loss and redefinition of self**

K. Charmaz (1983) discusses the loss of self: a fundamental form of suffering in the chronically ill. The chronically ill person observes his/her self-image crumbling away without the simultaneous development of an equally valued new one. As a result of his/her illness, the individual suffers from (1) leading a restricted life (2) experiencing social isolation (3) being discredited and (4) burdening others. These four sources of suffering all have effects on the consciousness of the ill person.

In my opinion, many factors within and around the chronically ill person will influence the degree of suffering and, with this degree of suffering, also the degree of loss of self. Although the complete loss of self is unrealistic, a partial loss is possible. In my view, every person who has a chronic illness develops his/her own particular redefinition of self which is unique and necessary to cope with a specific disability, within a specific society, and within a specific time-frame.

**Uncertainty**

In 'the experience of illness', P. Conrad (1987) mentions the fact that chronic illness is surrounded by uncertainty.
First there is the discovery, that ‘something unusual is going on’.

The second type of uncertainty is the medical uncertainty. There may be a period of time during which the healer (physician) does not know what is going on. The diagnosis of leprosy ends what Balint (1972) has called ‘the unorganised stage of illness’. Knowing the diagnosis can be a point of reference from which a leprosy patient can ‘move on’ with his/her illness experience.

The third type of uncertainty may come from the diagnosis itself. While a leprosy patient can feel great relief by being diagnosed with leprosy and being treated for it, he/she also experiences a new set of uncertainties. Will the medication work? Can I continue to do my work? Will my family accept me with leprosy?

The fourth type of uncertainty Conrad describes is the trajectory uncertainty. What will happen to a leprosy patient in the future? Will his/her condition improve, or will it deteriorate?

I am, I have, I had

A distinction is made between ‘I am’ and ‘I have’ illnesses by Sue. E. Estroff (1993). Most of the time leprosy will be characterised by the outside world as an ‘I am’ illness. ‘He is a leper’ is well-known terminology in the English language.

It will be interesting to follow this ‘I am/I have’ aspect of illness experience for the person suffering from leprosy both during and after treatment and in relation to the degree of disablement and the different life situations around the person (at home, at work, abroad, etc). If leprosy is diagnosed in an early stage (with only skin lesions or in the beginning of an inflammation of a nerve), there is a possibility that the person will be cured after MDT treatment, without any signs of a former leprosy infection. It is possible that leprosy then changes from an ‘I am’ illness to an ‘I had’ disease. This could be seen in relationship to the change from chronic illness to infectious disease. I use the words illness and disease on purpose in an alternating order in the former sentence. Illness has the subjective aspect, which is also present in the fact that the situation is chronic; a part of your identity; ‘I am’. Disease has an objective aspect, expressed in the biomedical term infectious; no part of your identity; ‘I have’.

Why?

‘Why me, why this, why now?’ is the title of a book, written by an American psychologist called Robin Norwood (1992). Specialised in relationship-therapy, Robin Norwood divorced thrice. After her third divorce she was so confronted with the question why, that it took her more than seven years to find a satisfying answer. She found her answers on an esoteric pathway and described them in her book.

A chronic illness is, like the third divorce of Robin Norwood, an unwelcome and usually unexpected life event. If people are confronted with unexpected, unwelcome changes in their lives, they normally react on this disruption of their life biography with asking ‘why?’ It is an attempt to try to find meaning in their life. There are many ways to find such meaning. The way in which people try to find these answers, and try to live with them,
depends on the way they experience the world within and around them, i.e. their worldview.

2. Objectives and research questions

Objective

The main objective of the study is to identify the 'emic' view of immigrant (mostly Surinamese and Indonesian) leprosy patients on the influence of their illness on their position in Dutch society. At the same time, their perception of treatment in the Netherlands will be explored.

Specific objectives:

1. To describe the views of immigrant leprosy patients concerning:
   a. The etiology of their ailment.
   b. The consequences of their ailment for their position in Dutch society, particularly among their close relatives, their friends and neighbours, and their colleagues.
2. To investigate if the symptoms create problems for the patients and, if so, how they cope with these problems.
3. To assess patients' views of their medical treatment

Research questions

The main research question is:

- Do immigrant leprosy patients experience problems with their disease in Dutch society and if they experience problems: how do they cope with them?

More specific research questions are:

1. What do they know about the disease leprosy?
2. What do they believe about the cause(s) of leprosy?
3. When leprosy was diagnosed, how did they feel about the future?
4. What were they afraid of when leprosy was diagnosed?
5. What did they expect when leprosy was diagnosed, and why?
6. How do people in their environment (spouses, blood-relatives, their fellow-immigrants, the neighbours, people at school and/or at work) react, assuming they know about the diagnosis leprosy?
7. Do they experience ethnic differences in the reaction to their disease (own culture versus Dutch culture)?
8. What symptoms and complications do patients experience and how do they rate them in terms of seriousness?
9. Do the serious symptoms and complications affect their social life and, if so, how?
10. If serious symptoms and complications affect their social life, how do they deal with it?
11. How do they perceive the attitude of the medical staff towards them?
12. How does leprosy influence the way in which they spend their leisure time?
13. Did they experience a change in their self-perception (who am I, what am I) since the diagnosis leprosy was confirmed?
14. What are their wishes as regards their medical treatment?
15. Do they have any recommendations that can help them to cope with their condition in Dutch society?
Note: Elements of (expected and experienced) stigma and self-stigma are intertwined in most of the research questions above (3-14).

3. Methodology

Study type, sample, data collection techniques

3.1 Study type
The study is an exploratory, descriptive study.

3.2 Sample
The study population is the group of immigrant leprosy patients who are under treatment in the Netherlands. The group consists of approximately 150 patients. The sample is taken from the leprosy patients registered in Leiden (LUMC) and Amsterdam (AMC).

The technique of snowball sampling was used (Patton, 1990, p 176). The medical key-informants brought me in contact with the leprosy patients. These key-informants wished to make a selection of patients who came for treatment in the research period 14 May to 2 July 2001. On consultation days, an “on-the-spot” selection was made of twelve patients for interviews at the hospital. Dr. Ben Naafs of the LUMC kindly requested permission by telephone from two of his patients to interview them at home. One leprosy patient (a young man from Venezuela) did not speak Dutch and hence we communicated in English. All other interviews were conducted in Dutch. For practical reasons, I translated the guidelines for the interviews (Annex 4-8) into Dutch.

The medical doctors thought that some patients were not suitable for interviews. This was based on the fact that some leprosy patients had been too heavily affected, physically and/or psychologically. Another reason was that the leprosy patient might feel unsafe by being interviewed, due to them being illegal aliens or other such problems. We (the key-informants and myself) realise that there is a bias in the selection of patients, as a result of the above-mentioned restricted procedure. However, I tried to come into contact with interviewees that differed in gender, age, degrees of symptoms and complications and cultural background.

3.3 Data collection techniques
1. Information from three key-informants. An interview with two medical doctors in Amsterdam and Leiden. The third key-informant is a researcher, who has extensive experience with anthropological research in the field of leprosy in developing countries. I obtained much and very useful information from this researcher by means of personal communication and guidance with the project proposal, as well as the reading of the thesis.
2. Interviews with three GPs:
   a. A GP who has experience with the management (4) of immigrant leprosy patients.
b. A GP who has no experience with the management of immigrant leprosy patients.
c. An interview with another GP in Maassluis.

3. In-depth interviews with fourteen leprosy patients under management in the AMC or LUMC.
4. In-depth interview with one spouse.
5. An interview with a nurse from the AMC and one nurse from the LUMC, both directly involved in leprosy care.
6. Participant-observation during consultation of immigrant leprosy patients who visit the dermatological out-patients’ department of the AMC (Amsterdam) and the LUMC (Leiden).

Ad 1.

The two medical doctors are the main health care providers for immigrant leprosy patients in the Western part of the Netherlands. Both key-informants have extensive experience with leprosy and leprosy research and are very knowledgeable about the current health care with respect to leprosy patients in the Netherlands. They are interviewed with the aid of an interview guideline (Annex 4). They brought me into contact with the leprosy patients (see 3) and the nurses (see 5). The third key-informant, a researcher, is very knowledgeable in the anthropological and public health field of leprosy research in developing countries, and is in fact one of the core persons who guided the research proposal.

Ad 2.

GPs have their own medical practice in the community. In the Netherlands, it is common that patients consult their GP for all kind of medical, psychological and sometimes social problems. The general practitioner either treats the patient himself/herself, or provides a referral. Because of this multifaceted function of the GP, it is very well possible that an immigrant patient will first contact his/her GP, who should be able to suspect leprosy and its complications. Hence, it is necessary that a GP who treats immigrant patients has a basic knowledge of leprosy.

These interviews were conducted to get more information about the attitude towards and knowledge of leprosy from medical doctors working in the community in the Netherlands (Annex 5). The first two GPs are assumed to have the same basic biomedical knowledge of leprosy. The GP who has experience with the management of (an) immigrant leprosy patient(s) was chosen at random as being the practitioner of one of the interviewees during the last part of June. The GP with ‘no experience’ was chosen at random from the GPs in my hometown, Maassluis.

I added an interview with a third GP, also in Maassluis. Talking about my research, she told me that there was a leprosy patient in her practice. And so it seemed a natural step to ask her more about her own experiences.

Ad 3 and 4

The interviewing has been done with a high degree of flexibility. I used an interview guide (Annexes 6 and 7) on the specific research questions, to ensure that all issues are discussed (Hardon et al., 1994:149). The questions were open-ended in as far as this was possible.
('what?', 'how?', 'can you?', 'do you?'), because in this way they gave the interviewee room to answer from his/her own experiences, feelings and thoughts (Patton, 1990:296). Twelve interviews were conducted in the hospital (AMC or LUMC), and an additional two interviews took place in the interviewees' homes.

Ad 4.
On only one occasion was it possible to get permission from the leprosy patient to talk to his spouse (Annex 7).

Ad 5
I planned to conduct a Focus Group Discussion (FGD) with both leprosy management teams of the AMC and LUMC, but unfortunately this was not feasible. The LUMC does not actually work with a real team and in the AMC it was impossible due to logistical and time constraints. In both hospitals I have replaced an FGD with an interview with the nurse who is most engaged in leprosy management (Annex 8).

Ad 6
During the research period of six weeks, I attended four consultation days at the dermatological outpatients' department of the LUMC, and two consultation days at the AMC. Immigrant leprosy patients visited these clinics on those days. During these consultations I was able to get an idea about the organisation of the ambulatory care with respect to leprosy patients, the interaction between the medical staff and the leprosy patients, and the attitude of the medical staff towards leprosy (care). Both neither the AMC nor the LUMC has a patient registration database linked with the diagnosis. However, I could get some quantitative data (how many leprosy patients under treatment, ratio male/female, length of treatment, different aspects of treatment) from the LUMC via Dr. Ben Naafs. Furthermore, Prof. Dr. Faber from the AMC referred to the outcomes of the article of Post (et. al., 1994), see note 10.

In the research proposal I had planned at least ten interviews with leprosy patients. In practice it was possible to conduct fourteen interviews within the defined timeframe. Before each interview, I wrote the personal data of the interviewee on a numbered sheet. During and after every interview, I made notes on that same sheet about particular facts that struck me. Twelve out of the fourteen interviews with the leprosy patients have been recorded on a tape recorder and fully transcribed by the researcher. This procedure takes about four hours or more for a one-hour interview. During the last two interviews, I only took notes; on the one hand because I felt this would be sufficient, using the former experiences with the twelve interviews, and on the other hand because of practical reasons (time-limit). The interview with one of the spouses has also been recorded and fully transcribed. At the request of the couple, this interview took place together with the interview of the partner-leprosy patient. From all the interviews and observations I have tried to write down what seemed most interesting and important to me for the research, whilst being aware that personal bias will be involved.
4. Presentation of data

Interviews with
4.1 Fourteen leprosy patients (Annex 6)
4.2 One spouse (Annex 7)
4.3 Two nurses (Annex 8) together with observations at the AMC and LUMC
4.4 Three GPs (Annex 5)
4.5 Two key-informants (Annex 4)

The observations I made during the interviews are written down, combined with the presentation of data from the interviews. However, I thought it would be clearer to mention the data from the interviews with the nurses the other way round: i.e. under 4.3; the observations at the leprosy management centres of the LUMC and AMC.

4.1 Data from fourteen interviews with leprosy patients

4.1.1. The main categories of data collection include:
- Personal data
- Knowledge (signs and symptoms, cause, treatment, complications)
- Beliefs (causes, treatment)
- Perception at diagnosis (future, fears, expectations, reasons); stigma?
- Reaction environment (self, spouse, blood-relatives, environment); stigma?
- Ethnic differences (own culture, Dutch culture); stigma?
- Experience with symptoms/complications (seriousness, social life, coping)
- Leisure time
- Attitude of medical staff (stigmatisation)
- Self-perception
- Wishes
- Recommendations

4.1.2 Sample

The study population is the group of immigrant leprosy patients who are under treatment in the Netherlands. The group consists of approximately 150 patients under management in three Academic Medical Hospitals. Data concerning this group of patients are comparable with the outcome of Dr. Post's article (et al., 1994), see note 10.

The sample is taken from the leprosy patients under management (4) in Leiden (LUMC) and Amsterdam (AMC). Dr Ben Naafs provided me with statistics of LUMC. In total there are approximately 50 leprosy patients under management, of which the male:female ratio is 3:2. Ages range from 17 years old to 80 years old. In the older section, Indonesian immigrants are represented who immigrated to the Netherlands around the 1950's. The younger group consists mainly of refugees and immigrants from Surinam, who immigrated to the Netherlands more recently (from the 1970's onwards).

4.1.3 Personal details

I was able to interview two women and twelve men, of whom nine persons are under management in the LUMC and five persons in the AMC. The ages range from twenty-five
to eighty-five years old. The two women were born thirty-eight and forty-five years ago in Paramaribo, the capital of Surinam. The twelve men came from Bonaire (Dutch Antilles), Venezuela (the youngest), Mauretania (Western Africa), two from the Netherlands (born in Indonesia) and nine men were originally born in Surinam. So a total of eleven out of the fourteen interviewees are of Surinamese origin. Ten of the Surinamese interviewees said that they were born in Paramaribo. The eldest interviewee, eighty-five years old, was born in the interior of Surinam. He came to Paramaribo when he was twenty-three years in order to stay in one of the leprosy-colonies. All of the fourteen leprosy patients came to the Netherlands in the period 1946 to 1998. The diagnosis of leprosy in this sample was made between 1938 and 1999, respectively in Surinam and in the Netherlands (12).

Of the fourteen interviewees, seven are married, four cohabitate, two are single and one is a widower. One of the singles (28 yrs) has not yet found a suitable partner, but expects to find one soon. The second single (50 yrs) is now severely handicapped. He had partners in the past when he was less handicapped. He thinks it is better to remain single because of his character, in combination with his ailment.

The widower (eighty-five years old) lived for more than fifty years together with his wife. He met his wife in a leprosy colony near Paramaribo. Like her husband, she was also affected by leprosy. They have two children. Ten out of the fourteen people have one or more children. Four patients are childless. One of them chose to remain so because of his deformities. One other interviewee had relationships with women in the past and said he did not have children due to his busy life. The two remaining interviewees intend to have children in the future (25 and 28 years old). All of them completed primary education in their country of origin.

Nine persons have attended secondary school either in their country of origin or in the Netherlands. Of those nine persons, three have attended college and one person has a University degree in economics. Professions mentioned by the interviewees are: teacher, electrician, engineer, computer technician, nurse, school porter, wood-factory worker, construction worker and aid to the police. During interviews they mentioned that their income derived from the following sources: four persons had a regular job, four persons had a pension, four persons were not fit for duty and received income because of a former job (WAO), two persons received social welfare.

4.1.4 Knowledge and beliefs about leprosy

'Knowledge is understanding or all that is known. Belief is the feeling that something is real and true'. Those definitions are written in an English-Reader's Dictionary (1969). Having interviewed fourteen people about the subjects knowledge and belief, I realize that the two concepts are intertwined and many times mixed up by most interviewees. I will come back to this phenomenon in the next chapter, which concerns data analysis.

Two persons mentioned that leprosy is hereditary, or that it occurs in families. One of them believed that leprosy occurs in alternating generations. His translated words to explain this skipping are as follows:

(Mr T, a Surinam-Chinese-Creole man, 60 yrs old, 28 yrs in the Netherlands)

'Yes, it is hereditary. Why I tell this? If a person has leprosy, like I have seen it in Surinam, if you should have leprosy and we should get a child, then this child should not get leprosy. But there is a risk, if that child
would get children again, later on, that one of those children will get the disease. So if we talk about curability, complete cure, I assume that this is the terminology, that a disease is cured, then it should stop with my person. Well, I got children already. So it is still possible, that my grandchildren get it. But if I should procreate children from now onwards and if the medical doctor tells I am cured now, then the grandchildren of those children should not get it, I suppose'.

(Mr W, a Surinamese-Creole man, 46 yrs old, 12 years in the Netherlands)
Although I had taken my medication and although I am still monitored by the doctor, I still have the idea that I cannot have leprosy, because it does not occur in our family'.

Eleven persons mentioned that leprosy is contagious. The exact terminology ‘contagious’ was not much used. But it was mentioned in the context of catching the disease through contact with someone or something. Six of the eleven people explicitly mentioned ‘germs’ as the source of infection.

(Mr B, a Surinamese-Hindustani man, 64 yrs old, 40 yrs in the Netherlands)
‘I was about 18 years old when I fell into a ditch, next to our house. Unfortunately I wounded my right wrist on a piece of glass inside the ditch. A leprosy patient lived at that time in a house beside that ditch. I know that he cleaned his bandages in the water. I think I got leprosy because my wound came into contact with that contaminated water’.

(Mr D, a Mauritanian man, 28 yrs old, 5 yrs in the Netherlands)
‘I do not know exactly where leprosy comes from. It has not been told to me. The medical doctor explained to me that at the time I was a small boy in Mauritania, I probably had a friend that got leprosy. You play together and after that you can get leprosy as well’.

(Mr P, a Dutch man born in Indonesia, 65 yrs old, 55 yrs in the Netherlands)
‘Well, I asked the medical doctor about the cause of leprosy, when I knew I had leprosy. I thought it was strange. I do not have a contagious form of leprosy- I believe there were three forms-but how is that possible? They have told us that it probably arose because of malnutrition. You walked there (4) barefoot, so it could be possible that you had a small wound on your feet. But from where it came, we actually do not know. I said to myself, well, as a small child there were Javanese men, who smoked cigarettes, aromated with cloves—well that was of course great and as a small boy I found it very interesting. So there is a possibility that I took such a thing (a used cigarette) in my mouth and that I then contracted it.... that could be possible.... Well, walking barefoot, malnutrition, but I never had big wounds, no, I cannot remember’.

(Mr J, a Surinamese-Maroon man, 85 yrs old, 12 yrs in the Netherlands)
‘So if you ask the medical doctors what is the cause, they answer that it is a germ.... It is not possible through the open air, when it comes into your body it can breed, it can multiply, but as soon as it comes into the air it will die. That is what I know from the medical doctors, but where it comes from, that explanation we never got’.

Other persons mentioned, that ‘it is in the blood’ or that you have eaten something, which is against your blood.

(Mr H, a Surinamese-Creole man, 50 yrs old, 27 yrs in the Netherlands)
‘Actually that leprosy, look, that leprosy it could.... well.... yes, it is a germ. If you do not have it, probably your blood can not come over it if you cat pork meat and you also have that fish without scales, that catfish. That is hot (15) as well, and if you get leprosy, then you have to abstain from those things, because otherwise it does not fit with your blood. And then you can get skin rash. Then you are aware, listen this is not okay, that disease settles at different sides of your body.
Catfish, pork, everything that is hot. But if you can also abstain from cow meat, well it is not that bad. But you should not use too much of it. But pork that is the biggest problem. I also observed it, when I ate canned food from the brand Unox. Those products are made from pork, and you know, those hot dogs, those are all pork, I never use it. I have tried it a few times, but then I observed, then it* appeared’.
* ‘it’ means in this context: the skin lesions typical of leprosy (note researcher).
One of the female leprosy patients, a nurse, was diagnosed with leprosy three years after she arrived in the Netherlands. She is aware of the biomedical concept that leprosy is caused by a germ with a long incubation period. She is convinced of the fact that leprosy appears more quickly in a cold climate, like in Holland, rather than in a warmer climate, like in Surinam.

To be cursed is another explanation of the cause of leprosy. This explanation was given by people, who at the same time believed that the disease was hereditary or was caused by eating certain foodstuffs, contamination by germs, or other sources of contagion. The interviewees referred to a curse in the biblical context as well as in the context of indigenous belief.

(Mr W, a Surinamese-Creole man, 46 yrs, 12 yrs in the Netherlands)
'Look, I can easily tell it to you. You Dutch people are open to it.... lets say, for the Surinamese it is different. Certain people do not understand it. They think you are cursed. By your ancestors or it is a pursuit or something like this. That is what they think'.
When I asked him what he thought about these ideas himself, the interviewee said he did not support them.

(Mr B, a Surinamese-Hindustani man, 64 yrs, 40 years in the Netherlands)
'People in Surinam at that time had the idea that leprosy came from contact'.
On my question “Were there other ideas as well?” the interviewee recalled the following:
'Look, Negroes have these kind of things, they say in such a case: 'they have done wisi (16) on me. That is rubbish, because when I was there, I mean in the leprosarium, there was a 'boslanderwood' (17), a really Hugh guy who had leprosy. You could see it on his face, those nodules, etc. When I was busy playing billiards, he came to me. I shouted to him to leave me alone and I used some curse words. I told him: "If you beat me I will make sure that you will never beat anyone again". Luckily he left. But after that he became very, very ill. I do not know exactly what his problem was. But he told everyone that I had put 'wisi'on him. I confirmed this to others, although I myself do not believe in it'.

Two other persons mentioned that to be cursed in the biblical context is one of the most important beliefs in their Christian communities.

(Mr T, a Surinamese-Chinese, 60 yrs old, 35 years in the Netherlands, Roman-Catholic)
'In my time they thought it was a biblical curse. Yes, that is what they thought at that time. That is how I experienced it. A cursed child......'
To my question: "Who said this?", he replied:
'Neighbours, they curse on you. The curse of God and so on......'

(Mr J, a Surinamese-Maroon, 85 yrs, 12 years in the Netherlands, Evangelist ('Evangelische Broedergemeenschap')
'The medical doctors cannot even tell you how it originated. You know, they have fought to conquer it, but how it originated, until now ... I think, according to me, I think it is a curse. Because look, in the bible, there yes, also lepers are mentioned and Jesus has cured ten of them. Only that one person came back to thank him, nine others did not return. So if you ask all those doctors how it originated, they say it is a germ....'

Knowledge and belief seem to be intermingled and generally a single person mentions more than one cause, idea and/or belief at the same time. In this research, twelve of the fourteen interviewees mentioned that leprosy has more than one cause, which supports the multicausality concept that was described in this thesis under 1.3.1. (9).
4.1.5 Perceptions at diagnosis

4.1.5.1 Age and place

The age at which the fourteen interviewees were diagnosed with leprosy ranged between nine and thirty-six years old. Four of these leprosy patients were the age of 15 years and younger; five were between the ages of fifteen and twenty-five; and the remaining five interviewees were older than twenty-five years.

Five persons were diagnosed in the Netherlands. The diagnosis took place in the period 1991 to 1999. The countries of origin of those five persons were respectively Mauretania, Venezuela and Surinam (one man, two women).

The diagnosis of four of the five persons was ‘technically’ adequate. They themselves reported their skin lesions in an early stage to their GP and were properly referred.

One of them was a Surinamese man. Ten years ago he consulted his friend, who is a medical doctor in Surinam, by telephone because he had discovered insensitive skin patches again. He thought himself of a re-occurrence of leprosy, as he had been treated for this disease the previous year in Surinam. His medical friend confirmed the self-diagnosis simply by hearing the symptoms. The Surinamese medical doctor had been studying in the Netherlands and advised the interviewee to get in touch with the dermatological policlinic at the AMC as quickly as possible, which he did.

The fifth person who was diagnosed in the Netherlands was the other Surinamese woman. Her referral did not go as smoothly as the other three patients mentioned previously. Ten years ago her leprosy was finally diagnosed after an admission to the hospital. She was referred to the specialist of internal diseases, because her GP did not understand why her physical condition had deteriorated so quickly. She was diagnosed with ENL (11), a leprosy reaction, one of the complications of leprosy.

For another interviewee the diagnosis was a more complicated process. At the time of onset of the leprosy symptoms, he lived in the Netherlands. But he presented himself with a neurological problem only, without any skin patches. His complaint was insensibility and weakness of the fifth finger of the left hand. The consulting neurologist did not recognise this neuritis (nerve damage) as being due to leprosy. After one year the interviewee’s problem had still not been solved and, because of this, he went to Surinam. There he got confirmation of his self-diagnosis straight away: neuritis of the fifth finger, due to leprosy. He started his MDT treatment (5) in Paramaribo and returned to the Netherlands with a letter about the diagnosis and the request for further management in the Netherlands.

In total three (50%) of the above mentioned six interviewees themselves had thought of having leprosy before they consulted a medical doctor (self-diagnosis).

The other eight persons were diagnosed in Surinam, Bonaire and Indonesia in the period 1938 to 1986. According to them, there was not much delay between consultation of a medical doctor and the actual diagnosis. Two of them mentioned self-diagnosis.
4.1.5.2 Future

The moment a patient hears (s)he is diagnosed with leprosy, it is obvious that all kinds of thoughts enter his/her mind. One of those thoughts could regard the future. ‘What will the future be like, having this disease?’. I requested all fourteen interviewees to try to remember the period directly after the diagnosis of leprosy. This meant going back in time from sixty-one years to two years. But despite the time lapse, all of them were able to answer this question forcefully and in doing so, some of their voices resounded with emotion and hesitation.

Mr R, a young man from Venezuela (25 years old, three years in the Netherlands, diagnosed two years ago in the Netherlands) expressed no fears or negative thoughts about his future:

‘I trusted the medical doctors in the Netherlands. I had no fear for the future when I heard that I had leprosy. I took my medication and everything had vanished. I had swollen and painful hands and feet, but now everything is okay.’

Other interviewees expressed more worries about their future in the period after the diagnosis.

Mr B, a Surinamese-Hindustani man (64 years old, 40 years in the Netherlands, diagnosed 44 years ago in Surinam)

‘At the moment of diagnosis I realised that my career as a teacher would be destroyed (je zag je carrière aan je voorbijgaan). If you are not strong enough or if you are not that intelligent, then you are lost (verloocht). You are still alive, but you do not have any future’.

Five interviewees said that they were particularly afraid of becoming mutilated. Their data are:

<table>
<thead>
<tr>
<th>Male/female</th>
<th>age yrs</th>
<th>as immigrant yrs ago</th>
<th>age at onset yrs</th>
<th>country of diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>F (Surinam)</td>
<td>38</td>
<td>12</td>
<td>9</td>
<td>Netherlands</td>
</tr>
<tr>
<td>M (D. Antilles)</td>
<td>38</td>
<td>25</td>
<td>20</td>
<td>Bonaire</td>
</tr>
<tr>
<td>M (Surinam)</td>
<td>50</td>
<td>27</td>
<td>35</td>
<td>Surinam</td>
</tr>
<tr>
<td>F (Surinam)</td>
<td>45</td>
<td>10</td>
<td>10</td>
<td>Netherlands (self-diagnosis)</td>
</tr>
<tr>
<td>M (Surinam)</td>
<td>46</td>
<td>12</td>
<td>13</td>
<td>Netherlands (self-diagnosis)</td>
</tr>
</tbody>
</table>

The third patient (Mr B, 50 years) is the only patient who has visible deformities.

The fourth patient (Mrs S, 45 yrs old), said:

‘I was afraid, I was disturbed by thinking of the mutilated leprosy patients I have seen in Surinam and on television. I was a teacher at primary school and thought “How will I continue? How will they accept me?” At the teacher-college in Surinam I had heard about the leprosy colonies and about the signs and symptoms of leprosy. I can still remember the stories of one leprosy worker in Surinam, called Peerke Donders. Yes, I had a panic reaction when the diagnosis was confirmed. I saw myself mutilated”.

The last patient (Mr W, 46 yrs old) said:

‘I was definitely a bit afraid (ik was wel een beetje bang), because I knew quite well what leprosy was. What it was all about. Because when I went for treatment in Surinam, I saw people who were mutilated by leprosy. That is the reason why I took my medication very punctually’.

All four above-mentioned Surinamese patients knew leprosy patients with severe disabilities in their surroundings (Paramaribo), which had a significant impact on them. But
they mentioned that they had also seen mutilated patients on television or posters (in the Netherlands and in Suriname). The interviewee from Bonaire did not recall having seen any mutilated leprosy patient on the island, but he also referred to television and posters. The television programmes and posters did not show leprosy patients from Surinamese origin, or from Bonaire, but rather from Africa and Asia only. All three interviewees felt that it would have been more shocking to them if they had seen people from their own community on television or on billboards.

Five men mentioned that their world collapsed from the moment they knew they had leprosy.

(Mr T, a Surinamese-Chinese man, 60 yrs old, 35 years in the Netherlands, diagnosed 51 yrs ago in Surinam).

'...My studies were disturbed by my illness. I could not finish my studies at secondary school. I was busy finishing ULO-A, and succeeded. I was to continue with MULO (13). But because the symptoms of leprosy started again, I had to leave school. I was so disturbed, that I nearly became crazy. This fact has played tricks on me during my whole life (Dat heeft me mijn hele leven parten gespeeld). My family is large. We are six boys and four girls. All of my brothers and sisters have studied at University. But I could not finish my studies. Everything I know is self-acquired. My father was a rich man, of Chinese origin. He contacted the best pharmacists in Paramaribo in order to find a cure for me. But there were no medicines at that time. I got vitamins and medicines to recuperate'.

(Mr W, a Surinamese, 46 yrs old, 12 yrs in the Netherlands, diagnosed 13 yrs ago in Surinam).

'...Then I thought, well the world has collapsed a little bit. (de wereld is een beetje in elkaar gestort). Yes, there was also a period where I thought of it constantly (waarin ik er constant aan dacht). Well, a few years ago I thought differently about it. I visit the polyclinic regularly and I often talk about it, so well, I am in a period of life now in which I am able to process it quietly. So to be honest (om eerlijk te zeggen) I don't have any problem with it'.

(Mr K, a Surinamese-Creole-Chinese, 60 yrs old, 28 yrs in the Netherlands, diagnosed three yrs ago in Surinam).

'My world collapsed (mijn wereld die zakte ineen....). Because if I tell you...well.... leprosy is not something which I can give to you, even if I should touch you. But Surinamese people who do not know much about it, who did not read about it, because cancer is worse than this... but.... people start to avoid you. It is viewed that badly among Surinamese people (zo erg is het onder Surinamesen). A Dutch man is different.

The diagnosis also had a great impact on the eldest patient:

(Mr J, Surinam-Maroon, 85 yrs old, 12 yrs in the Netherlands, diagnosed 61 yrs ago in Surinam)

'...Now I feel good, but in the beginning I was completely broken... In the beginning I was broken (in het begin was ik kapot), because your complete youth goes to the dogs (je hele jeugd is naar de maan). I had just confessed, I was just engaged as well... and all of this I had to let go (heb ik moeten laten varen). Well at that time I was busy, I was training to be a carpenter, that was my profession, of course I had to stop with all of that (maar dat alles moest ik laten natuurlijk...). Well, then it had vanished. Then your future had vanished. Because at that moment you know, you are written off as far as the world is concerned (je bent van de wereld afgeschreven).

A Dutch man returned to the Netherlands in 1946.

(Mr P, 65 yrs old, born in Indonesia in 1936, 55 yrs in the Netherlands, diagnosed in Indonesia in 1941)

His parents did not tell him that the diagnosis was leprosy, but instead talked about a nerve problem (zenuwaandoening). When he was 19 years old he visited the leprosy management centre in Rotterdam and he saw a map indicating the world-wide spread of leprosy in the waiting room. Then it suddenly became clear to him that his nerve problem was due to leprosy. By that stage he had been in the Netherlands for four years and was studying at University. He describes his awareness as follows:
At that time I was 19 years old. I saw that map and I thought something like "well now, what's this?" (en ik dacht van nou wat is dat?). And that's when it all came to me (kwam dat hele verhaal). Well and then my world collapsed somehow, because well, okay and then you started to wonder what will be the consequences and those kind of things.

Another Dutch interviewee told me that the diagnosis brought a lot of thoughts to his mind (Mr Z, 78 yrs old, born in Indonesia in 1922, 50yrs in the Netherlands, diagnosed in Indonesia in 1945)

"Well, eh, it was a terrifying idea (een schrikbeeld voor je)...a despair...you don't know what to do with yourself. By then the disease was incurable and if you are raised as a christian, with those taboo stories from the Bible...That was actually something horrible for me. Only later on, years later, you discover what leprosy is in reality.

When I asked what he expected of the future when he finished his relationship with his fiancee he said:

"That I...would be in for a difficult death... and that is a burden I could not put on anyone. Not any girl."

Many years later after the diagnosis of leprosy, this interviewee married a Dutch nurse and is still married to her.

4.1.6 Stigma and self-stigmatisation

4.1.6.1 Support from spouse and family

During the interviews it became clear that most of the spouses and family had supported the interviewees after their diagnosis with leprosy. The following table gives more insight into the support as it was and is experienced by the leprosy patients.

<table>
<thead>
<tr>
<th>Spouse and family support</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse supports only</td>
<td>5</td>
</tr>
<tr>
<td>Spouse did not support</td>
<td>1</td>
</tr>
<tr>
<td>Everybody supports</td>
<td>2</td>
</tr>
</tbody>
</table>

Some comments on the above-mentioned figures:

Eleven interviewees have a partner with whom they live (married or cohabitation). There are six people who mention that they are supported by the family and spouse. The remaining five persons do not mention support from their family. With regard to four of these, the family is not in a position to provide any support because they are not aware of the diagnosis leprosy.

The interviewee who experienced no support from his family, despite their awareness of the diagnosis, tells a moving story about it.

He is a Dutch man, raised in a Protestant environment in Indonesia and was diagnosed with leprosy when he was 18 years old. His mother reacted with shame and revulsion to the diagnosis, but in Indonesia she did not deny him access to the house. She washed his clothes, bedding, dishes and cutlery with lysol (an antiseptic detergent) and she kept away from him as much as possible. During the war she lost her other son in the camps (14). The three of them (parents and the interviewee) survived the war. They repatriated to the Netherlands in 1951. Most other Dutch-Indonesians had repatriated much earlier, just after the war. But these parents decided not to return to the Netherlands at that time. They felt ashamed for the family because their son was already displaying clear signs of his leprosy.

On many occasions his mother openly blamed him for the fact that she had lost all of her
acquaintances. Directly after they had returned to the Netherlands, she told her son never to come to her home anymore. He had to stay some years in the sanatorium Heidebeek (3), after which he could integrate into Dutch society.

He (Mr Z, 78 yrs old) has the following explanation for why his mother kept him at a distance:

'Yes, I think my mother was afraid to become infected. You see, those delusions from the bible (waardenbeelden uit de bijbel). Well actually, that everybody should keep distance.'

The person who did get support from his family at the beginning of his leprosy, but not from his wife, divorced her at a later stage in the Netherlands. This Surinamese man (64 yrs) has been cohabitating for more than eighteen years with the mother of his 18 year old daughter. But he has never told her that he has leprosy (see secrecy 4.1.6.4).

Parents and sisters are most of the time the family members who support the interviewee.

The two remaining persons, who say that ‘everybody supports’ are the young man from Venezuela without any symptoms of leprosy and a severely handicapped Surinamese man. Most of the interviewees, who did not keep the leprosy diagnosis secret, experienced support from their spouses and relatives. It is of course not possible to support someone if you do not know anything about his/her condition. The Surinamese wife, who heard from her GP that her Surinamese husband was diagnosed with leprosy, eleven years after he had heard this news himself, has not hesitated to support him. Nothing has changed in her attitude towards her husband, according to him.

4.1.6.2 The surroundings

The interviewees tell about reactions of the surroundings, which they have experienced themselves. But they also talk about reactions, which they expect to experience and actually did not experience themselves. Therefore, I have categorised the data about the reactions according to experienced reactions and expected reactions.

Experienced reactions:

(Mr T, a Surinamese-Chinese, 60 yrs, experiences of 51 yrs ago in Surinam)

'Those people just reject you (stoten je gewoon af). You remain stigmatised (gebrandmerkt). It is like pain. You have to be constantly on your guard (op je hoede zijn).

Some people spit on the floor, just in front of you. They do not play with you. They keep to themselves and don’t bother with you (ze bemoeien zich niet met je).'

(Mr Z, a Dutch male, 78 yrs, recent experience in the Netherlands)

'In my hometown they have a statement: ‘They are brazen-faced’ (die hebben het vel van de ‘bollen’ voor de kop”; a bol is a bull). My wife once visited a birthday-party. The moment she entered the room, the hostess loudly announced: ‘This is the wife of the guy who has leprosy’. Don’t you think that’s nuts? (getikt hé?). After that incident my wife stopped visiting that woman’.

(Mr K, a Surinamese-Chinese-Creole, 60yrs, experience up to now)

‘My brother-in-law had leprosy back there in Surinam. My sister-in-law forced him to wash his cutlery and plate separately from the rest of the family’.

(Mr P, Dutch male, 65 yrs)

‘During the introduction period at the University I wanted to become member of the student-association called ‘het koor’. I was one of the ‘kruisfoeten’, those new members that got a cross painted on their bald-shaved heads. Well, the doctor who guided the initiation committee of the student-association (ontgroenings
committees) did not know much about my disease. And the committee stated that during the initiation period they had to be careful with newcomers (‘voeten’). So the ones with special diseases, like my nerve problem, were singled out. So you had always something special. But it was actually more easy to be a ‘kruisfoet’, because then it was not all that difficult.

Expected reactions:

(Mr M, a male from Bonaire, 38yrs)
‘This one cannot walk, how should you act’. (He can’t walk. How should one act towards him)

(Mr B, a Surinamese-Hindustani male, 64 yrs)
‘If anybody saw that ‘this person has leprosy’, then one was shocked, they shrunk back.
The other person can be boneheaded (oerstom), but the fact that you have been ill makes you inferior (maakt je minder), not equal’.

(Mr H, a Surinamese-Creole male, 50 yrs)
‘It is not possible to get a relationship with a woman, you disgust them (zijn vies van je)”.

(Mr D, a male from Mauretania, 28 yrs)
‘If I tell about my illness, then people keep me at arm’s length (gaan de mensen me een beetje afweren)

It is clear that experienced and expected reactions from the surroundings are all centred around the themes of ‘rejection and repulsion from the community’ and to be ‘special’, someone to be afraid of, a devalued person. In short: stigmatisation.

4.1.6.3 Autochthonous and allochthonous Dutch: patients’ perception

1. The question: “Can you tell if you experience differences in the way the people from your culture of origin react and how autochthonous Dutch people react to the fact that you have/had leprosy?” could not be answered by eight of the people. They did not talk to any autochthonous Dutch people about their leprosy and did not have any idea whether there would be differences between the two groups.

2. Six persons, however, were convinced that there is a huge difference in the approach between the Dutch, Indonesian and immigrant Surinamese people towards leprosy.
They said that they did not (expect to) experience problems with the Dutch autochthonous community. They felt the Dutch treated them normally. But it is different within the immigrant Surinamese community and in the Indonesian community. There the approach toward leprosy has another connotation, which will be further explained under the paragraph about stigma (data collection and data analysis).

The interviewees expressed the following ideas about this subject:

(Mr B, a Surinamese-Hindustani man, 64 yrs, 40 yrs in the Netherlands)
Look, I think it is different here. If one knows here: it is not contagious, then it is not a problem.
But the Surinamese react differently. They try to put you down and degrade you.

(Mr H, a Surinamese-Creole man, 50 yrs, 27 yrs in the Netherlands)
Well eh...look eh..., those Dutch people, well those people just live normally with you. It is different with our Surinamese. They reject you.

(Mr T, a Surinamese-Chinese man, 60 yrs, 35 yrs in the Netherlands)
Oh, with the Dutch people (Nederlanders) I have never had any problems. Neither here nor back in Surinam. But the Surinamese in Paramaribo spat on the floor in front of you.
(Mr Z, a Dutch man, born in Indonesia, 78yrs, 50yrs in the Netherlands)

When I came to the Netherlands, in the ‘Havenziekenhuis’ (hospital) in Rotterdam, leprosy was treated just like a cold. In Indonesia it was different. It was as if you were a pariah. The people in Indonesia kept their distance from you (ze gingen met een boog om je heen).

Later on I understood that it is not that easy to become infected by leprosy. In the Netherlands it is nearly impossible. Otherwise, I would never have married.

4.1.6.4 Secrecy

All interviewees keep their disease a secret in one way or another.

Three people only told their wives. But one of them did not tell the diagnosis himself to his wife. He is married to his wife for 25 years now. The details around this secrecy have been mentioned before under 4.1.6.

One person told his wife and some of his children. He has three children, but only two know about his leprosy, because the third daughter talks too much. In this way it could reach the Surinamese community.

(Mr K, a Surinamese man, 60 yrs, 28 yrs in the Netherlands)

‘When I am dead they, the children, can tell it. But not yet to their partners. I have got a daughter who talks too much (die kwckt). She does not know about it’.

And his partner added: ‘Even his sisters do not know about it’.

The interviewee again: ‘And if you had been a Surinamese doctor I would not have told you about my problem.

His partner added: ‘Because then the rumour will spread’.

Two persons informed their wives and all of their children.

The two women told their husbands and mothers.

One person kept it completely secret after he arrived in the Netherlands. It is the Surinamese man (Mr B, 64 yrs, 40 years in the Netherlands, diagnosed 44 years ago) mentioned previously, who divorced his former wife. He cohabitates and has a daughter of 18 years old.

He mentioned that some years ago he took his daughter to the dermatological polyclinic and asked the dermatologist to examine her for possible early symptoms of leprosy. He arranged it in secret together with the medical doctor. He did not tell his daughter the real cause of the medical check-up. Fortunately, there were no medical problems.

Four people have told different people from their own community. Two men are of Dutch origin, 78yrs and 65 yrs. They also told it in their former jobs. The eldest of the two told it only some years ago to acquaintances. Before that, his wife was the only one in his neighbourhood who knew that he had leprosy. One other person is of Surinamese origin and is well integrated in Amsterdam. The fourth man comes from Venezuela and is the only one, out of the sample, who considers leprosy to be a normal disease.

One young man (Mr D, 28 yrs, three yrs in the Netherlands, diagnosed two years ago) is from Mauretania. He did not tell anybody in the Netherlands about his leprosy, not even at his work (assistant-policeman). But he informed his sister.

‘I told my elder sister. I have only one sister and no brothers. I met her in January during my holidays in Senegal. I asked my sister if she knew anyone in the family who has leprosy. She said ‘no’. I showed her my
skin lesions. I told her that the doctor had informed me that I had leprosy. She advised me to trust Europe, as one has good medication there. We did not tell her husband.

4.1.6.5 Self-stigmatisation

Earlier in this paper I tried to describe what self-stigma signifies (see 1.3.2). In order to make the concept more clearly to the reader, I will repeat the description again.

'Self-stigma is another aspect of stigmatisation. It is the fact that someone feels (s)he is not fully socially accepted, avoids social contacts because of this and restricts him/herself in certain activities, which is actually not demanded from the outside world.

In some of the interviews I found that the ideas and life-events of the interviewees suited the above-mentioned definition of self-stigma.

One of them mentioned that he did not want to be promoted at his work. He was diagnosed in 1957 in Surinam. The only outer sign of leprosy was some atrophy (thin) muscles of his hands. He had a good job as an administrator in the Netherlands and was asked to strengthen the managing board of the company. He refused and told me that he was afraid that he would get too much attention. In this way, there would be more chance that someone from the Surinamese community would find out that he had leprosy. If this happened, he expected to get many problems. 'They would try to put you down'. (Mr B, a Surinamese-Hindustani man, 64 yrs, 40 yrs in the Netherlands)

Some people said they had the feeling they could not express themselves freely. 'Well, you live a kind of hidden life' (Je leeft gedekt) (Mr T, a Surinamese-Chinese man, 60 yrs, 35 yrs in the Netherlands)

Mr W, a Surinamese man, 46 yrs old and since 12 yrs in the Netherlands, also describes a situation along these lines. 'I sometimes have the idea that I enclose myself a little. I do not communicate much.'

One man, who was born in Indonesia (Mr Z, 78 yrs old) did not want to burden any girl with his disease. 'And then I got to know a girl. She lived in our street. And...I did not know anything about that disease. I only knew that you were a danger for others. She liked me. I treated her very rudely, because I thought that I could not burden her.'

Another interviewee, Mr K, a Surinamese-Chinese-Creole, 60 yrs old and since 28 yrs in the Netherlands, reveals that he feels guilty and has to think about this feeling of guilt everyday. He did not tell one of his daughters that he has leprosy, as she talks too much. Another fact that bothers him are his hands. In some instances one can observe that some of his handmuscles have become more thin. He is very much aware of this fact and always tries to put his hands in a position that is less revealing.

Self-stigma seems to be something that can vary from person to person, depending on the situation. But is its grounds lie in the fact that the person thinks (s)he can not fulfil the demands of the community.
4.1.7 Leisure time

Thirteen of the fourteen leprosy patients I have interviewed mentioned that they have a hobby. Among the hobbies are football, dancing, do judo, computers, playing billiards, visiting friends, their jobs as teacher and nurse, gardening, voluntary work in a committee and physical training. Some people said that they had developed handicaps in the course of time. Because of that, some desirable hobbies were out of bounds. However, the person who has computers as his hobby is 78 years. He learned to use a computer about 10 years ago and types with the remaining parts of his fingers.

Two of the hobbies are very special to me and I would like to discuss them a bit more.

Mr T, a Surinamese-Chinese man, 60 years old has raised a dog-breed ‘Dobberman-Pincer’ and is internationally known for this. He has won many competitions and once nearly obtained a world-title. Ownership of houses was also a hobby for him. He has just sold the biggest lot of his houses. In the event that he dies, his son would not have to bother about these properties. He remarked: ‘I have achieved a lot in my life’.

Ten years ago another Surinamese-Creole man, Mr H, 50 years old, played in a professional musical. At that time he was also a musician and had been on television several times. He has become handicapped because of his own neglect (his own words). Two years ago he got an artificial leg. He has a motor scooter now and plays mouth-organ at a market in Amsterdam. He has a studio at home where he draws and paints. Somebody recently organised an exposition of his art in the hospital. This interviewee seemed very happy with his present life.

Leisure time is an important part of social life in the Netherlands. The above data show the interviewees spend this time in very different ways. They have taken the opportunities Western society offers in their own ways and within the limits possible for them, sometimes with surprising results.

4.1.8 Patients' ideas about their medical treatment and about the attitude of the medical staff

Eleven out of fourteen interviewees were happy that their medical treatment could take place in the Netherlands. The availability of good medical treatment was one of the motives to immigrate for some of the Surinamese patients and for the interviewee from Bonaire. They were satisfied with the management and the approach of the medical staff.

Three interviewees expressed satisfaction, but not completely. Among them were the two Dutch people. They observed that there was sometimes a delay in the medical treatment. The reasons given for this delay were different, but medically preventable (note researcher).

Two persons mentioned that the GP did not refer in time. They did not recognise a leprosy-reaction (11) in the patient. One of them also remarked that:

‘The medical staff talks about you, but not with a person’.
One of the Surinamese interviewees, Mr K, was not at all satisfied with the initial period around the diagnosis. He had to travel to Surinam in order to get his self-diagnosis of leprosy confirmed. 'I am going to tell you, I am not going to belittle any Dutch doctor, but here they do not know enough about leprosy'.

All of the interviewees had the feeling that the medical staffs in the leprosy management centres of the AMC and LUMC is very much concerned with their patients. They trusted them and one of the interviewees talked about the doctors in superlatives ‘I owe my life to them. If they had not saved me, I would have died from a very severe infection of my leg. It was all over my body, that infection. They are top-class’.

4.1.9 Self-perception

The most difficult questions during the interviews were, in my view, those dealing with self-perception and self-esteem. This subject could only be touched upon at the end of every interview, when there was an atmosphere of trust.

I prepared the interviewees for these questions by telling them that some researchers had found that patients, who have a chronic disease, have particular experiences with the perception of themselves. Everybody could choose between three statements: I have leprosy, I am somebody with leprosy, or I had leprosy. Some of the interviewees seemed very sensitive to the term ‘leprosy’. For them I initially introduced the terminology using another chronic disease. Such as: I am a patient with rheumatism, I have rheumatism and I had rheumatism. I then switched to leprosy.

Two persons stated ‘I am a leprosy patient’. Five persons could identify themselves much better with the terminology ‘I have leprosy’. The remaining seven patients said they thought the term ‘I had leprosy’, suited them most.

One of the persons, who chose for the ‘I am’ term, said he did so because he is severely mutilated. Another person chose it because his whole life has been determined by leprosy. He could not study at the University, like his other brothers and sisters.

The persons who identified themselves with ‘I have leprosy’ explained to me that they chose this term because they were under treatment. Three of them used medicines and two of them were under treatment because of their complications, like foot problems. One person said he had the feeling that the disease festers (voortwoekert).

‘I had leprosy’ was suited to people both with visible deformities as well as those without any complications. They all explained that they viewed leprosy as a disease that had been cured with medication.

I have tried to probe in order to understand more about the patients’ self-perception. It was impossible for me as an interviewer to go very much into depth. The timeframe of this research was too short to meet the interviewees more than once, which would perhaps have given more interesting results. However, even during an interview of one hour, much can be discussed.

I found that most interviewees stressed that the diagnosis leprosy in itself had a significant psychological impact on them. One man (Mr Z, 78 yrs) puts it like this: ‘You are psychologically completely disturbed (Je zit psychisch volkoren in de knoop). I only got over it after I
retired. It is a cross that you have to bear. You have to accept from yourself, that you are a normal being as well.

Others mentioned the uncertainty concerning the development of their leprosy. Most of them realised that you can never be certain as to how the process of leprosy complications will develop. They did not only think about the insensitivity of their hands and/or feet and about their mutilations, but were also aware of the fact that they can develop symptoms that look like leprosy (leprosy-reaction see 11) at any time. Some expressed their fear about this. One Surinamese man was treated with Prednison for a long period because of a leprosy-reaction. The results were not fully promising and he wondered what he would look like physically in 10 years from now. One person asked himself: 'why me?'.

Two of the interviewees said that they could accept their illness now. One of these persons (Mr R, 25 yrs from Venezuela) does not have any complications. The other person (Mr W, 46 yrs from Surinam) is severely handicapped at both hands. He tells: 'Well, I think that since I became ill, I have learned to handle my emotions. I have learned to accept the situation. And if I do not talk about it, if nobody knows what illness I have got, well then I can continue with it easily. So that is what I try.'

4.1.10 Patients' statements about leprosy

I selected the following statements from the interviews with leprosy patient. In my opinion, the statements were told to me in way that clarifies much about the experiences patients have with their illness. The term 'stigmatised' or 'branded' was used by four interviewees in total, but each is only mentioned once hereunder.

- Leprosy kills you (Lepra maakt je dood). Leprosy is really terrible (Lepra is echt verschrikkelijk).
- Leprosy is strong (Lepra is sterk).
- Leprosy is a normal disease (Lepra is een gewone ziekte).
- You are stigmatised by leprosy (Door lepra ben je gebrandmerkt).
- You are really branded (Je krijgt een stempel opgedrukt).
- Leprosy catches you (Lepra pakt je).
- Leprosy is only over when you die (Als ik dood ben is de lepra pas over).
- A disease with which you are cursed (Een ziekte waarbij je vervloekt wordt).
- Use the term 'Hansen's disease' and not 'leprosy', please. (Gebruik de term ziekte van Hansen en géén lepra).

The person who viewed leprosy as a normal disease is a male from Venezuela, 25 yrs old, who has no leprosy complications. He was diagnosed two years ago in the Netherlands, and has now lived in this new society for a total of three years.

The first remark is from a man originally from Bonaire and the last remark is made by a Dutch leprosy patient, 78 years old. The remaining ideas about leprosy are from Surinamese men, ranging in age from 46 years to 64 years.

4.2 Interview with a spouse

Eleven of the fourteen interviewees live with a partner: husband, wife or girlfriend. It was only possible to interview one of the partners.
I have visited the homes of two of the interviewees. On both occasions the partner was present, but in another room. I have asked one of these interviewees explicitly if I could talk to her husband as well. She told me that her husband was too shy to talk.
At the end of our interview he came into the living room to prepare a bottle for the baby. At his side was another child, a five-year old son. I just greeted him, but did not ask him anything......
Other interviewees with whom I talked at the hospitals made it explicitly or implicitly clear that they did not wish their partners to talk to me.

I spoke with the wife of a Surinamese-Chinese-Creole man. He is 60 yrs old and lives in the Netherlands since 1973 (28 years). A neurologist in the Netherlands missed the diagnosis.
But the interviewee took the initiative to travel to Surinam, where his self-diagnosis was confirmed. He and his wife have three adult children. Two of them know about their fathers’ leprosy diagnosis, but their partners are unaware, according to the couple. The wife came into the consultation room during the interview and was willing to stay. I conducted the rest of the interview with the couple.

In Surinam the male interviewee had close friends who were affected by leprosy. Cases of leprosy were also known in his wife’s family, one of whom was the husband of the wife’s sister in Surinam.
Both wife and husband told me that they thought leprosy was hereditary. Because of this, the wife was not at all afraid of contamination with leprosy. She said that it was not a burden to her to live with someone who had been diagnosed with this disease. She was surprised at the time the diagnosis was made. She would never have thought that a nerve problem of the little finger could be leprosy. She did not foresee any obstacles for the future, nor was she worried about the curability of leprosy. But she agreed with her husband that it would be better to keep secrecy in the Surinamese community. She said: “You never know what other people can do to you”.

And her husband completed her words as follows:
‘I feel unhappy. I mean, well it is something I have never told my wife, but it returns to my mind every day. It is frustrating. I am afraid that my surroundings will discover my problem. I am always busy trying to hide it.’

I have tried to give an impression of the interview with a spouse. I realise that only one interview gives limited information and that the information itself is perhaps also biased because of the presence of the partner. But I thought it would be worthwhile to include because of the perspective of the ‘significant other’.

4.3 Organisation of the leprosy management centres at the LUMC and AMC; observations and interviews with nurses

4.3.1. AMC

Leprosy patients visit the dermatological policlinic on Mondays. On that day, Prof. Dr. Faber is available for supervision. He supervises the work of the medical doctors who are specialising in dermatology. At the same time, he supervises the work of the male nurse who cares for those leprosy patients who require foot care, or other special medical care.

The male nurse, called B., has worked as a nurse for more than 13 years. He has worked at the dermatological ward for many years. If leprosy patients were admitted to the ward, he was the one to take care of them. For the past two years, he has been involved in the
dermatological policlinic. He is the only nurse that cares for the leprosy patients who need special care for their feet. He knows most of the patients by name and can tell much about their life history. He has always had special feelings for leprosy patients.

B. also takes care of the patients if they need other special care, such as orthopaedic shoes, a wheel-chair, a cast or adaptations in their homes. He tries to contact the orthopaedic surgeon, the shoemaker and social worker, if necessary. He has made an instruction leaflet for the patients, in which he explains how they should care for their insensible feet. This leaflet is also used for diabetic patients with foot problems. He sometimes gives an information folder to new patients. This folder informs them about leprosy and is titled ‘Lepra’ (leprosy).

B. says that it is not easy to find someone among his colleagues who is willing to replace him during his holidays or free-time. He has noticed that many of his colleague-nurses do not like to work with leprosy patients. B. thinks it has something to do with aversion to the mutilations and the fear of infection.

B. never uses the term ‘leprosy’ if a patient is nearby. He talks about ‘de ziekte van Hansen’ (Hansen’s disease).

I asked B. if he could try to make associations with the term ‘leprosy’. The first things that came to mind were the adaptations (orthopaedic shoes, etc.) necessary for the leprosy patients.

4.3.2 LUMC

The organisation of the leprosy management clinic in Leiden is very different. The patients come on Friday afternoons. Dr. Ben Naafs, dermatologist is the consulting medical doctor, who is assisted by medical doctors specialising in dermatology. Dr. Naafs also works at Universities in Brazil and Kenya, and spends some five to six months per year outside the Netherlands.

At both the AMC and the LUMC, blood is taken from the leprosy patients on a regular basis. This blood is used for research purposes. One of the male nurses (R.) has the task of taking the blood at the policlinic. I interviewed him at the last day I visited the policlinic.

Nurse R. meets many leprosy patients regularly, because they are referred to him to give blood straight after they have visited the policlinic. He has noticed that many of the newly detected leprosy patients are of Surinamese origin. He hears many of their stories and understands how difficult it can be to be affected with leprosy. Many of the patients apologise for being handicapped. He has observed that those who have problems with their hands try to hide them. Others never shake hands with anyone (self-stigma, note of the researcher).

He likes his task, but expresses the wish to be more informed about the clinical aspects of leprosy. This could be done during clinical meetings for the nurses of the dermatological policlinic and ward.
On my question as to what kind of associations R. had with the word leprosy, he responded: mutilations, Africa

4.4 Interviews with key-informants

The interviews with the two dermatologists at the AMC and LUMC did not take place at one time. Although both medical doctors work under time pressure, it was possible to talk with them about their ideas concerning the management of leprosy before the research started. Also during the period of research they were both very cooperative in supplying me with information and providing practical help. I was impressed by the enthusiasm and dedication both colleagues have for their job and especially for leprosy patients. I have observed the same with regard to the above-mentioned nurses.

We discussed the training of the different types of medical doctors on the subject of leprosy. I was told that all dermatologists in the Netherlands get refresher courses about leprosy on a regular basis. All medical doctors that are specialising in dermatology come into contact with leprosy patients during their training. The group of these trainees consists at the moment of several medical doctors who have been working in developing countries and will be interested and acquainted with leprosy in this way. Both key-informants had the following associations with the word leprosy:

Infectious disease—treatable—a change on nerve damage; this has to be minimalised.

Treatable—leprosy reactions, that are sometimes difficult to be treated medically.

One doctor observed that leprosy reactions pursue the patients.

The other medical doctor had noticed the following: once someone working in the medical field has dealt with leprosy (kennis heeft gemaakt met lepra), it will never let you go (je komt er niet meer van los).

4.5 Interviews with GPs

I have been able to interview three GPs. One was chosen at random from the names of GPs in the telephone book for my hometown Maassluis (a). One practitioner had an interviewed leprosy patient in his practice (b). The third GP that I have interviewed is another GP in Maassluis. When I spoke to her about the subject of my research she spontaneously informed me that there is a leprosy patient in her practice. She was willing to share her ideas with me (c).

I specialised as a GP myself and graduated in 1987. I worked as such in the Netherlands for more than seven years. Because of my own background, it was easy to come into contact with the GPs. It was nice to talk about leprosy management together. But I realised that most of the GPs who are working in the Netherlands will only be confronted with leprosy during their medical studies.

I have made a summary of the data that looked interesting and important to me.

When I asked the GPs of their associations with the word leprosy, they responded as follows:
The images you see on television or billboards when Netherlands Leprosy Relief is carrying out a fundraising campaign (als er weer een collecte is) (a) Mutilations and sensibility disorders (b) Problems with insensitivity (c); they all seem to associate leprosy with mutilations.

All three GPs mentioned that the leprosy patients in the Netherlands are immigrants. They identified Surinamese and Antillean patients as the biggest groups with whom leprosy can be detected.

I tried to discuss what kind of basic knowledge a GP should have about leprosy management and asked them what they knew about the first signs and symptoms of leprosy.

The GP who has no experience with the management of leprosy knew that the first sign of a leprosy infection can be a hypopigmented skin patch with insensitivity. The GP with an interviewee in his practice mentioned that he saw this patient very rarely. He was very well informed about leprosy management. He explained that he had studied leprosy because he had missed the diagnosis at the onset of leprosy in his patient many years ago. The GP in Maassluis who had a leprosy patient in her practice not known to me, said she had never met the patient at all. She was not completely sure where the patient was managed for his leprosy. She thought it could be worthwhile to give more attention to the subject in refresher courses for GPs and in Dutch medical literature.

None of them was aware that the AMC and LUMC are leprosy management centres.

On my question as to what they should do if they suspected a patient to be displaying the first signs and symptoms of leprosy, they all answered that they should consult a ‘local’ dermatologist.

It was clear that none of the three GPs was aware of the signs and symptoms of leprosy reactions. Knowledge about leprosy reactions is important for those GPs who have immigrant patients in their practice who are already affected by leprosy or who may develop leprosy for the first time. Early treatment of leprosy reactions can prevent nerve damage and therefore the early diagnosis of leprosy reactions prevents leprosy complications (11).

5. Analysis of the data

5.1 Knowledge and beliefs

It is difficult to distinguish between knowledge and beliefs as expressed in the ideas of people. All depends on the conceptual framework from which the person analyses. In the medical world the ‘biomedical’ perspective is called ‘knowledge’. A patient has knowledge if(s)he knows that leprosy is caused by a germ and that leprosy is a contagious disease spreading from human to human. The biomedical perspective dispatches other ideas about the cause of leprosy as beliefs.

A close look at the interviews of the immigrant leprosy patients shows that most of the interviewees simultaneously have different ideas about ‘the’ cause of his/her leprosy.
Patients mention that the origin of their disease is a germ and at the same time they talk about ‘a curse’. They say that leprosy is caused by contact, while simultaneously assuming that it is hereditary. Hot food is assumed to be a cause, but leprosy is also ‘in the blood’.

Eleven of the interviewees mentioned that their disease was contracted through direct or indirect contact with leprosy patients; through the ditch, family members, friends and other people in the village (see also Varkevisser & Moreira, page 34). Patients have their own concept of the infectiousness of leprosy. Most of the interviewees told me that the medical staffs have informed them about transmission of ‘germs’. It seems that they have interpreted it in their own way. ‘Germ’ is a concept integrated in the knowledge and beliefs of the interviewees without the connotation of the biomedical perspective. Contagiousness is a recurrent concept, but has little connection with ‘biomedical infectiousness’. The Indigenous Contagion Theory according to Green (Green 1999) seems an appropriate clarification for these findings.

The Mauretanian immigrant leprosy patient (28 yrs) explained that he contracted leprosy when he was a small boy. He said that he must have been infected in Mauretania because he had played with a small friend at that time. That small friend must have been ‘invisibly’ infected. This notion of infectiousness through contact is the essence of the information he has remembered from the recent explanation a Dutch doctor has given him about ‘the’ cause of leprosy.

Immigrant leprosy patients have more perspectives than only the biomedical. They often identify more than one cause for their disease. Green (1999) and Varkevisser & Moreira (2000) also mention ‘multicausality’. The term ‘multicausality concept’ could be clarifying for the fact that people think in terms of multiple causes of their disease and not about ‘the’ cause. Immigrant leprosy patients are not an exception to this statement. Herewith I would like to quote Varkevisser & Moreira (2000): ‘In short : a mixture of traditional, religious and ‘modern’ ideas of causation, but none of them to the point from the biomedical perspective’ (page 47).

5.2 Perceptions at diagnosis

‘For many patients, the diagnosis of leprosy came as a shock’ (Varkevisser & Moreira, 2000, page 45). The immigrant leprosy interviewees expressed the same feelings, except for one Venezuelan man, who was not at all bothered about any future problems. The reason for this could be, that he had no close experiences with leprosy patients, neither in his country of origin, nor in the Netherlands. His family back in Venezuela had also reacted very calmly.

But to most of the patients, the diagnosis brought worries about their future. They were not sure how things would develop. Some of them expressed fear of becoming mutilated over the course of time. For one patient out of five, this recently became reality.

Other patients declared that their world collapsed. They expressed this feeling very energetically. Bury (1991) describes this experience as an ‘autobiographical disruption’. The interviewees mentioned many more negative thoughts and feelings about their future. Most of them had experience with leprosy in their country of origin. Many mentioned the television-films and billboards used for fundraising by NLR. They show African or Asian leprosy patients that are severely deformed. The patients represented in the films and on the
billboards are missing their fingers, nose or (part of) their leg. Four of the interviewees were very much against this way of propaganda. But they mentioned that they would have felt worse if their own ethnic community would have been represented in the advertisements.

The ages of the immigrant leprosy patients whom I have interviewed range from 25 to 85 years. Most of them are of Surinamese origin (nine out of fourteen) and are male (twelve out of fourteen). The circumstances under which they heard the diagnosis for the first time differ in time (1938 till 1999) and place (the Netherlands, the country of origin). Two leprosy patients have been admitted in leprosy colonies in Surinam, one person stayed for some time in sanatorium ‘Heidebeek’ (3) in the Netherlands. Despite of all these different personal histories most of the interviewed immigrants have succeeded to make their lives more or less worthwhile.

Most of their worries for the future have been turned into less severe life circumstances than expected. It has to be taken into account that the leprosy patients have immigrated to a Western society, where they got/get opportunities to develop. In section 5.4, I will comment on this idea more extensively.

5.3 Stigma and self-stigmatisation

One patient did not reveal the diagnosis leprosy to anyone after he arrived in the Netherlands forty years ago. His partner, with whom he has an eighteen year old daughter, is also unaware of his disease. He mentioned that he felt very lonely with his ailment. One other interviewee, who was diagnosed in Indonesia at the beginning of World War II, was abandoned by his parents when the family repatriated in 1951. It is impossible in this study to deeply explore the reasons for this behaviour. But it is obvious from the history of the patient, that the parents have also suffered. The mother blamed the patient that she lost all her acquaintances in Indonesia because of his leprosy. And the family repatriated late, because they did not know how to act towards their Protestant family. Their son had leprosy with deformities. According to their Christian belief, he was cursed by god. From the reaction towards their son it seems as if this curse has spread to them as well. But the majority of the interviewees received support from their spouses and/or family when they revealed their ailment. They described how they experienced support in their country of origin as well as in the Netherlands. And the ones who had the courage to reveal their leprosy to people in their surroundings were actually not rejected by them. The patient who described the hostess of a birthday party announcing his wife as being the spouse of a leprosy patient is an exception. It should be noted that every patient told that (s)he made a selection of the acquaintances and friends whom they informed.

In this thesis I have provided the data about secrecy in a separate chapter. Those data show that every interviewee expressed cautionness regarding being frank about their diagnosis. But it is clear from their stories that openness about the leprosy diagnosis usually results in support for the patients.

In the abovementioned context, the interviews show a difference between expected and experienced stigma (Varkevisser and Moreira, 2000, p. 71). I quote: 'The fear of being deserted by spouse, relatives and community members was far higher among female and male patients than they in reality experienced'. The same can be said for the Surinamese man, married to his wife for twenty-five years, who did not tell her about his leprosy.
himself. He was under treatment for more than twelve years and the family GP, not knowing about the secrecy, openly discussed the patient's leprosy with his wife. When I asked this forty-six year old man why he had not told his wife, he said that he was afraid that she would leave him. The interview took place more than one year after the disclosure of his secret. The couple is still together. In the chapter about the reaction of the surroundings in this thesis, the experienced and expected reactions of those surroundings are discussed. These have to be seen in relation to the above-mentioned concept of the difference between expected and experienced stigma.

Bainson and van den Borne (1998) state that stigmatisation of the leprosy patient has two basic components: perception of a negative attribute to leprosy and devaluation of the leprosy patient. The interviews indicate that, in the past, some of the leprosy patients have indeed experienced the effects of these components in their country of origin. One interviewee described how people spat on the floor, just in front of him. This event goes back to the 1940's. At that time there was no 'biomedical' cure for leprosy at all. Many leprosy patients became mutilated; a complication of their disease. The interviewee did not develop any visible signs of leprosy, but he suffered tremendously as a child. On top of the humiliation described above, he had to leave school and could never attain the education he originally had in mind.

In the context of stigmatisation, it was interesting to analyse if and how the patients experienced a difference in approach between autochthonous and allochthonous Dutch people. Most of the interviewees (nine out of fourteen) are of Surinamese origin. I got the impression that most of them feel integrated in Dutch society. In daily life they deal with the autochthonous and their own allochthonous Surinamese community.

Five of the Surinamese patients stated very clearly that they did not expect or observe stigmatisation from the autochthonous community. One of them expressed it as follows: "Dutch people, well those people just act normally with you". The four other Surinamese interviewees could not give comment on the approach of the autochthonous Dutch people, because they had never spoken to anyone from that community about their leprosy.

All Surinamese mentioned that, according to them, their own community rejects leprosy patients. Nobody could give any example of their own experiences of stigmatisation within their community while living in the Netherlands. But all of them talked about their fear of it.

The only story I heard about rejection in the Surinamese community was told by the nurse of the AMC, whom I interviewed. One of his Surinamese patients once told him that he had to stay in a separate room if he visited a birthday party. He also got disposable plates and cutlery.

It seems that fear of stigmatisation within the Surinamese community (expected stigma) is far more outspoken than that actually experienced (experienced stigma).

Nowadays, leprosy is a rare disease in the Netherlands. It disappeared from this country during the seventeenth century. For autochthonous Dutch people, leprosy is no longer perceived as close enough to be a problem. An interesting observation, which supports this statement is the fact that many of my friends, acquaintances and even anthropological scientists at the UVA were not aware of the existence of leprosy management clinics in the Netherlands. Leprosy is also known as an infection that can be treated with medication. For
these reasons, leprosy does not have the same affective connotation for autochthonous Dutch people as it has for Surinamese and repatriated Dutch-Indonesian inhabitants. Bainson and van den Borne (1998) mention three main reasons for different affective responses towards leprosy. Varkevisser and Moreira (2000) state, on page 33, that visible signs of leprosy, in particular deformities, appear to be the major indicator for stigmatisation. My impression from the interviews is the same. But fear of contamination could also be an important factor (Weiner 1986). Deformities are considered infectious in themselves. The story about the separation of the deformed leprosy patient at the birthday party and the use of disposable articles clearly illustrates both concepts (stigmatisation because of deformities and because of fear of contamination) (see also Varkevisser et al., 1998).

Self-stigma is another aspect of stigmatisation. Someone feels (s)he is not fully socially accepted, avoids social contact and restricts him/herself in certain activities, which is actually not demanded from the outside world. I have observed different ways in which self-stigma is expressed (see paragraph 4.1.6.5). If stigma could be reversed, self-stigma would also reverse at the same time.

In the former paragraph I have mentioned that some of the interviewees felt stigmatised by the programmes on television and the posters used by for fundraising by NLR. The interviewed leprosy patients do not appreciate images of mutilated leprosy patients and they state that this way of fundraising is stigmatising in itself. Some suggested that it could be a good idea to show leprosy patients without any visible deformities. In this way, the possibility of curing leprosy could be emphasised. But none of the interviewees would like to present him/herself on television or a billboard for fundraising.

During the interview with the nurse at the AMC, he mentioned that the term ‘leprosy’ is not used on the dermatological ward. The medical staff uses the term ‘ziekte van Hansen’ (Hansen’s disease) (Aya Brandsma 1980, page 17). He also does likewise during his own contacts with the leprosy patients (told and observed by me). The nurse thinks that leprosy patients will be stigmatised by fellow-patients if those people know the diagnosis. The term ‘ziekte van Hansen’ is not known by the general public and should be ‘not stigmatising’. Gusson and Tracy (1972) state in their literature review concerning the phenomenon of leprosy stigma in the Continental United States, that strong public stigma has not been actually been demonstrated scientifically. But in the case of a medical ward, the fellow-patients are closer by the leprosy patient than is the general public. The interviewed nurse refers in his story to the fear of infection (by fellow-patients, but also by medical staff) with resulting stigmatisation as mentioned above.

One of the interviewees (Dutch, 78 yrs old and with severe deformities to hands and feet) expressed very clearly that he was disgusted by the term ‘leprosy’ and prefers other terminology. This can be understandable, given his life history, but other patients mentioned that they did not care about this term for their disease. In Annex 10 I have provided local expressions for the words leprosy and leprosy patient as communicated to me by some of the interviewees.

It should be clear that stigma is an important topic for immigrant leprosy patients and that it still has a great impact on their daily lives.
5.4 Self-perception

For most of the interviewees, leprosy is a chronic disease. They have to visit the policlinic for check-ups over a long period of time, even after they have finished their MDT. The reasons for medical management can be very different. It appeared to me that many of the interviewees were also bothered by leprosy reactions, either in the past or recently. The consequences of these leprosy reactions can be nerve damage, which can result in deformities. Patients are also invited to the leprosy management centres because they are involved in medical research, for which blood has to be taken on a regular basis (half yearly).

Patients are confronted with a chronic disease, of which the outcome is uncertain. One of the patients described it very much to the point: “The disease festers”. They have to live with this uncertainty (Conrad, 1987) and this can bother them. A Surinamese man who was treated with prednison-medication because of a leprosy reaction expressed his uncertainty as follows: “I wonder what I will look like physically ten years from now”. Obviously he is thinking of deformities.

In the paragraph about the perception at diagnosis (5.2), I stated that the patients who talk about ‘a collapsed world’ are in fact referring to an autobiographical disruption as mentioned by Bury (1991).

The fact that I conducted only one interview per patient made it difficult to talk about loss of self and redefinition of self as mentioned by Charmaz (1983).

I gave a choice of three statements of which one should be chosen by the interviewee. I am a leprosy patient was chosen twice. I have leprosy five times and I had leprosy seven times. The concept of ‘I had’ is not mentioned by Charmaz. I added it because I think that patients who perceive curability of a disease do not talk about I am or I have. They talk about leprosy as a past disease, a cured infection, something like a cold. Surprising in this context is the fact that one of the interviewees mentioned the attitude of the medical staff in the Havenziekenhuis in Rotterdam towards leprosy as corresponding with treating a cold.

I am a leprosy patient seems to have a connotation of identification with the disease. The two patients who chose for this terminology were both Surinamese and were diagnosed a long time ago in Surinam. Their lives had been severely influenced by leprosy: physically, psychologically and socially.

I have leprosy was mentioned because people experience the fact that they are under medical treatment (medication or management of complications) as a sign that they have leprosy.

I had leprosy was chosen by most of the patients (50%). They mentioned that the infection was cured and so their leprosy was over. Some of them had severe mutilations for which they came to the leprosy management centre regularly. Despite this fact, they mentioned the terminology ‘I had leprosy’ as their choice. This is different from three of their fellow patients, who chose the concept ‘I have’.

Although it seems that some of the leprosy patients have similar physical symptoms derived from a similar chronic disease, their self-perception differs much. This could be explained by the fact that self-perception is determined by so many factors (social...
background, character, culture of origin, social and personal opportunities, etc.) that it is nearly impossible to generalise. But from a psychological point of view it can be interesting to study self-perception.

5.5 Leisure time and daily life

In Dutch society leisure time can be an important part of your daily life. Especially when you have the opportunity to spend your time on a nice hobby, life can be much more interesting (personal experience).

Thirteen of the leprosy patients that were interviewed mentioned that they spend some of their free time on a hobby. My impression from the interviews is, that some of the patients put much effort into their hobby. They wanted to be excellent at it and this gave them a feeling of self-esteem. One patient mentioned: ‘I have achieved a lot’.

The way Dutch society (like other Western societies) is organised also provides opportunities for people to spend their leisure time in a useful and/or relaxing way.

Some of the interviewees mentioned that they needed adaptations to live a normal life. Two mentioned a motor scooter, several had orthopaedic shoes and one patient had an artificial leg. These facilities make life more comfortable. Some of the patients told that they were happy to stay in the Netherlands with their ailment. The reason for this was the fact that they thought that in the country of origin facilities are not that sophisticated as they are in the Netherlands. In Surinam, Indonesia, Bonaire, Venezuela and Mauretania, life would have been very different for them.

I have observed that seven out of nine Surinamese persons were diagnosed with leprosy in Surinam. They came to the Netherlands thereafter. One man immigrated 40 years ago because he did not want to remain in Surinam any longer with his disease. He experienced it as a kind of escape. The eldest patient (85yrs) together with his wife, also a leprosy patient, came to the Netherlands 12 years ago at the invitation of his two children, who lived here. The children thought life would be more comfortable here for their parents. The remaining five immigrants mentioned economical reasons and family reunion for their immigration to the Netherlands.

All patients have lives that seem to be rather normal, taking into account that some of them live rather restricted lives due to psychological reasons. Some patients have adapted to live with disabilities, and seem to cope well.

5.6 Patients’ ideas about their medical treatment and about the attitude of medical staff

I introduced myself to all interviewees as a medical doctor, and explained to them the reason why I wanted to conduct the research. I also informed them that I had worked with leprosy patients in Nigeria. This introduction could have led to a bias in two ways. On the one hand, I am used to talking to patients in a clinical setting. The patient is also used to the doctor-patient contact in this way. During consultation, many confidential items can be discussed between doctor and patient. An atmosphere of confidentiality is necessary to obtain useful information during an interview. On the other hand, it could also be a handicap. Talking about colleagues was somehow difficult for me. And the patient could also feel less free to talk about medical staff with a medical doctor.
During my visits to the leprosy treatment centres, I was struck by the fact that both key-informants and the nurses in the AMC and LUMC are very dedicated to the management (4) of the leprosy patients. The patients visit the policlinics together with other dermatological patients. But I got the impression that this group of people are a kind of 'favourites' for the staff involved in their medical care. One of them stated during our conversations: 'Once you have come across leprosy in your medical work, it will never let you go'.

Some of the interviewed immigrants expressed this special relationship in the empathetic way they talked about the medical staff. But, of course, there are different opinions. Dissatisfaction was seldom expressed about the attitude of the staff. One person mentioned that he had the feeling that the doctors do not talk with you but only about you. He stated this after he had complained about his GP. In the past, this doctor had referred him too late. The patient now suffers nerve problems as a result of this delay.

The above-mentioned patient is not the only one who complained about a delay in referral to the leprosy management clinic. GPs, a neurologist and a specialist for internal diseases have been reported by the interviewees as the doctors that did not recognise symptoms of leprosy or leprosy reaction in time. One of the problems I identified during my interviews with GPs was the lack of knowledge about a rare disease like leprosy. I realise that my own knowledge about leprosy was limited during my period as a GP. However, it was in fact unnecessary, because there was no leprosy patient in our practice. There were some immigrant Surinamese patients, but none of them reported with any health problems that could be caused by leprosy.

In this study, most of the patients believe the Dutch medical system is better suited to tackle their physical problems than the medical system in the country of origin. I would like to end this analysis with a quotation: 'Patients may have a complex set of relevant and important beliefs, which influence their opinions on the quality of services' (Williams, 1994). Measurement of this perception is very delicate (note of the researcher).

6. Discussion and conclusions

The main objective of the study is to identify the 'emic' view of immigrant (mostly Surinamese) leprosy patients on the influence of their illness on their position in Dutch society. At the same time, their perception of treatment in the Netherlands is explored.

The group of leprosy patients who are currently under treatment in the Netherlands are immigrants from countries where leprosy still prevails. The patients can be divided into two subgroups; the immigrants from former Dutch colonial areas (Indonesia and Surinam) and the immigrants from other countries where leprosy is still endemic (refugees and economic immigrants).

For this research, fourteen immigrant leprosy patients were interviewed, of which the majority (nine out of fourteen) immigrated from Surinam, a former Dutch colony. The patients arrived in the Netherlands between 1946 and 1999. Some immigrants knew of their ailment at arrival, whereas others were diagnosed in the Netherlands. Most of the interviews were conducted at the leprosy management centres of the LUMC and AMC in the period 14 May to 2 July 2001. Two interviews took place at the home of the patient. The atmosphere was in general confidential.
The fourteen interviewees seem to live normal lives in the Netherlands. Some of them are handicapped. Six patients have visible deformities, such as missing fingers or an artificial leg. They use aids such as a motor scooter, adaptation at their homes, orthopaedic shoes, or aids to control their hand movements. Others have invisible or small deformities such as insensitive feet and hands, or a slightly paralysed finger, for which they have to care very well in order to avoid complications. Only one of the patients has no complications whatsoever. They spend their leisure time according to their interests and abilities. Most of them have a partner. The majority of the group has a regular job, or has undergone normal retirement. But more in-depth information tells more about the hidden side of their social and psychological lives. The majority followed a difficult track to reach the point where they are now. There were many uncertainties about their future. Some of them had to bear humiliations or had to stay in a leprosy colony in the past. Most of the patients keep the diagnosis of their ailment, 'leprosy', secret from their surroundings. Only very close relatives and spouses, or sometimes even nobody, knows about their disease. When analysing their stories it became clear that the reason for the secrecy is the fear of stigmatisation. The Surinamese leprosy patients describe their own community as one that stigmatises leprosy patients in different ways. Further analysis shows that most of the expressed signs of stigmatisation are actually aspects of expected stigmatisation. They are not experienced in reality. According to the interviewees, the autochthonous Dutch community has another approach towards leprosy. This Dutch community seems to be more open towards the disease and is less afraid of infection. But on the dermatological ward of one of the leprosy management centres, the word leprosy is never used. Medical staff uses the term ‘Hansen’s disease’. Stigmatisation of fellow-patients towards the leprosy patients is feared. Patients have their own concept of the infectiousness of leprosy. There is a mixture of traditional, religious and ‘modern’ ideas of causation, but none of them to the point from the biomedical perspective. The interviewees think in terms of multiple causes of their disease. They do not think about ‘the’ cause. I would like to call this phenomenon the multicausality concept (9). I have also conducted interviews with medical staff. I observed that the medical personnel in both the LUMC and AMC, who are involved in the management of the leprosy patients, are very dedicated to their job. This is also confirmed by most of the interviewees. Problems arose with medical doctors working in other medical fields, like GPs and a neurologist. The root of these problems does not seem to be in the attitude of the doctors, but rather in the lack of knowledge about complications of leprosy.

Once you have come across leprosy, it will never let you go (Als je met lepra te maken hebt gehad laat het je nooit meer los).

These are the words of a medical doctor, but I think they are valuable for both immigrant leprosy patients and medical staff.
7. Recommendations

- Immigrant leprosy patients of Surinamese origin express feelings of uneasiness with the stigmatisation that they experience or expect from their own community. It could be worthwhile to explore these findings further. Within the Surinamese community the stigmatisation could perhaps be discussed by recognised spokespersons. Leprosy patients themselves also have an important role in changing the attitude of their fellow immigrants. They could help to bring the stigmatising facts into the open and explain about their own ailment.

- Secrecy about the diagnosis of leprosy can be a burden to the patient and his/her relatives. The medical staff could perhaps motivate the patients to discuss their ailment with others. In this way, stigmatisation within the Surinamese and other communities could be reversed.

- As long as leprosy patients immigrate to the Netherlands, or are diagnosed here after they have immigrated, it is important to keep the medical doctors who could be involved in the management informed about leprosy. Different types of staff need different information by means of refresher courses or medical articles. It is important to inform the medical doctors (especially GPs, neurologists and dermatologists) about the existence of the leprosy management centres in the AMC, LUMC and the Academic Hospital of Groningen.

- My suggestion to the medical doctors who are responsible for the leprosy management would be to develop information material for those GPs who have a leprosy patient in their patient-population. In this way, it could be easy for the GP to remember important facts about the disease; in particular to be reminded which symptoms require referral to a leprosy management centre (leprosy reactions, others).

- The initiative of the AMC to develop a leaflet for the patient about his neuropathic foot could be shared with the other centres.

- Visible deformities are experienced as stigmatising. The fundraising department of the NLR could consider this fact and take it into account when designing their publications/fundraising campaigns.
Epilogue

Apart from the data that can be put on paper, it is obvious that much more happens in the interaction between interviewer and interviewee. This may be described by words, but those words will never be sufficient to cover the deeper feelings and thoughts that are connected with the interaction.

I have experienced it as a privilege to be able to talk to all the interviewees. Some of the interviews with the leprosy patients have left a deep impression on me.

'Once you have come across leprosy, it will never let you go'.

This statement can be valid not only for the persons affected by their illness, but also for the people that are close to them and for the medical staff.

It suits many interviewees and the interviewer in this research.
Annex 1.

Abbreviations:

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMMA</td>
<td>The Amsterdam Master's in Medical Anthropology</td>
</tr>
<tr>
<td>AMC</td>
<td>Academisch Medisch Centrum</td>
</tr>
<tr>
<td>AZR</td>
<td>Academisch Ziekenhuis Dijkzigt</td>
</tr>
<tr>
<td>ENL</td>
<td>Erythema Nodosum Leprsum</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>ICT</td>
<td>Indigenous Contagion Theory</td>
</tr>
<tr>
<td>INFOLEP</td>
<td>(Digital) Library of the NLR</td>
</tr>
<tr>
<td>LUMC</td>
<td>Leids Universitair Medisch Centrum</td>
</tr>
<tr>
<td>NLR</td>
<td>Netherlands Leprosy Relief (Nederlandse Stichting voor Leprabestrijding)</td>
</tr>
<tr>
<td>WAO</td>
<td>Wettelijk Arbeids Ongeschikt</td>
</tr>
</tbody>
</table>
Annex 2.

Notes:

1. A 'leper' is another word for leprosy patient. In Dutch terminology leprosy patient could also be called a 'lepralijder'. Another Dutch term with biblical connotation is the word 'melaatse'.
   In the original text of the bible 'melaatsen' were probably not only leprosy patients but also people with other skin diseases and other 'unclean' diseases like syphilis and gonorrhoea (see also Green page 239).

2. Anthropological descriptions of culture are often characterized as either emic or etic, terms drawn from the study of language. Anthropologists using the emic perspective attempt to provide an insiders's view of culture, which is sometimes called the native's point of view. They use concepts and distinctions that are meaningful to members of the culture they are studying and attempt to acquire a knowledge of how that culture looks from the inside and what one must know in order to think and act as a native of that culture. But anthropology also incorporates an etic, or outsider's, perspective. This perspective allows anthropologists to analyse data in a way that may not be part of the native's cultural awareness or may even be in conflict with it. The aim of emic research is to generate understanding that a native would find meaningful or to help cultural outsiders gain a sense of what it might be like to be member of the culture being described; the aim of etic research is to generate useful scientific theories (Nanda and Warms 1998, page 10).
   In short; The emic view is the insider's view.
   The etic view is the outsider's view.

3. The G. M. Gastmann-Wichers Stichting has been founded in 1950 to care for the leprosy patients in the Netherlands. The founder was prof. Dr. E. H. Hermans, a dermatologist in Rotterdam. After the liberation of Indonesia, a former colony of the Netherlands, ten thousands of Dutch, Indonesian-Dutch and Ambonese people came to the Netherlands in 1949. Because leprosy was (and is still) an endemic disease in Indonesia, many leprosy patients were among this group of people. Some of them were severely mutilated and it was very difficult to accommodate this group of people. After a lot of effort it was possible to establish sanatorium 'Heidebeek', situated on 'the Veluwe' near Heerde, a beautiful wooded part of the Netherlands. At the onset of the programme more than 50 severely mutilated leprosy patients were admitted there. In the course of time all former patients were integrated in Dutch society and those still living nowadays, live their lives as other handicapped people.
   Apart from the severely mutilated people, a group of about 600 less mutilated leprosy patients came to the Netherlands. The Gastmann-Wichers-Foundation established a polyclinic at the dermatological department of the Medical Faculty in Rotterdam for those leprosy patients. The Foundation employed a Medical Doctor/ Leprologist at the department and a social worker. The latter was engaged with the accommodation of the patients and their family, to find schooling and jobs, in short to assist them to build up their lives in the Netherlands. In those days (the 50's-60's) the foundation initiated research on the contagiousness of leprosy in the Netherlands. From this research could be concluded, that leprosy acts as a

fig 3. The former leprosy-sanatorium Heidebeek in Gelderland, the Netherlands, closed in 1971.

Nowadays the Q.M. Gastmann-Wichers-Foundation initiates leprosy research in the Netherlands. This research is carried out in the Academical hospitals, where leprosy patients are managed and at the Royal Tropical Institute (KIT) in Amsterdam.

4. In this thesis treatment of leprosy patients means actually management of the patient/disease. Medical treatment (medication, examination) is only a part of the treatment of the patient. By communication of Prof. Dr. Faber, dermatologist in the AMC, I understood that he preferred to talk about leprosy management instead of leprosy treatment. After the patient has got his/her MDT (see note 5), it is not obvious, that (s)he has finished treatment. The complications of the leprosy (neurological, blindness, physical impairments, psycho-social problems) ask for a multidisciplinary approach, in which process the medical doctor should act as manager. The needs of the patient can be in the field of paramedical treatment (physiotherapy, ergotherapy, nursing at home), different aids (like special shoes, an artificial leg or a scoot-mobil, adaptations at home), extra aid from the medical doctors by achievement of several privileges in various fields (permission for transport by taxi, help to get social welfare or reduction of workload at the workplace). Leprosy patients are kept under control, because they can develop a relapse (return) of the infection. More often they develop, what is called in medical terminology a reaction before, during and even many years after they started MDT (see note 10).

From the above it should be clear, that leprosy treatment is actually leprosy management; medical treatment of the disease and its complications.

In public health programmes in developing countries the term leprosy care is used instead of leprosy management. This term covers also the empathic part of the management (note researcher).

5. The Multiple Drug Therapy (MDT) has to be taken during one year or during six months, depending on the germ load. The WHO has recommended divide the patients in two groups: Multibacillary (MB) with a heavy germ load and Paucibacillary (PB) with a less heavy germ load, both differentiated by the clinical signs and symptoms.
For the MB patients, the treatment lasts 12 blister packs (about one year). They get Rifampicinc(600 mg), Lamprene(300 mg) and Dapsone(100 mg) on the clinic day, which they swallow under supervisions. They take a daily dose of Lamprene (50mg) and Dapsone (100mg) home.

For the PB patients, the treatment lasts 6 blister packs (about half a year). They do not get Lamprene, but they are given Rifampicine and Dapsone like MB patients. Dosages are given differently for children till 14 years old.

6. The Indigenous Contagion Theory (ICT) is a theory extensively discussed by Green in his book Indigenous theories of contagious diseases (1999). In short he states, that many (infectious) diseases, under which leprosy, are usually understood within a framework or a body of health knowledge, that he calls indigenous contagion theory. ICT is not supernatural in character: one becomes ill because one comes into contact with something that anyone could come into contact with. Green thinks that it is very important for the development of public health programmes to give more emphasis on naturalistic understandings of contagious illnesses in ethnomedical research and less on witchcraft beliefs. This will open the way for the development of effective working relationships between biomedical health service providers and indigenous healers for more effective health promotion and disease prevention across the world.

7. Hanseniasis or Hansen's disease is another (biomedical) name for leprosy.

8. The drug, that can cause the side effect of coloration of the skin is Lamprene (Clofazimine), a part of the MDT drugs, mentioned in note 1.

9. Multicausality concept is a term added by the researcher. It can be defined as the fact, that one person can have a perception of more than one cause for his/her illness. This has been described by Green (1998) and also by Varkevisser and Moreira 2000, page 47. The last-mentioned write: “In short: a mixture of traditional, religious and ‘modern’ ideas of causation, but none of them to the point from a biomedical perspective”.


Country of origin of 622 leprosy patients totally registered at the AMC and the Academical Hospital of Rotterdam-Dijkzigt (AZR) in the period of 1970—1991

<table>
<thead>
<tr>
<th>Country</th>
<th>number of pts (%)</th>
</tr>
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<tbody>
<tr>
<td>Suriname</td>
<td>456 (73.3)</td>
</tr>
<tr>
<td>Indonesia</td>
<td>45 (7.2)</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>21 (3.4)</td>
</tr>
<tr>
<td>Dutch Antilles</td>
<td>14 (2.3)</td>
</tr>
<tr>
<td>Africa</td>
<td>13 (2.1)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>23 (3.7)</td>
</tr>
<tr>
<td>Latin-America</td>
<td>2 (0.3)</td>
</tr>
<tr>
<td>Europe</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>47 (7.6)</td>
</tr>
<tr>
<td>Total</td>
<td>622 (100)</td>
</tr>
</tbody>
</table>
Most patients came from Surinam (73.3%) and Indonesia (7.2%).

**Ratio Male: Female**, 371:251, which corresponds with 59.6% Male and 40.4% Female

11. **Leprosy reactions:**
Leprosy reactions are episodes of sudden increase in the activity of the disease. This is thought to be due to an alteration in the immunological status of the patient. *Reactions are the major cause of nerve damage and disability in leprosy.* Therefore, these should be detected early and treated promptly. Reactions commonly occur during the early part of the disease. Occasionally a patient may report for the first time to the centre just with reaction. Sometimes reactions are seen after the completion of treatment. The occurrence of leprosy reactions does not mean that MDT drugs are not being helpful and therefore MDT(S) should not be suspended during reaction. Reactions are part of the natural course of the disease and can occur frequently and be severely damaging in untreated leprosy. Treatment with MDT significantly reduces the frequency and severity of reactions. Possible occurrence of reactions needs to be explained to the patients, since signs and symptoms of reactions could be misunderstood by them as adverse effects due to the drugs, or might persuade them to think that the treatment they are getting is harming them. There are two types of reaction:

**Type 1 or Reversal reaction;**
The patient may present with one or more of the following features:
- skin lesions become reddish and swollen
- painful, tender and swollen peripheral nerves
- signs of nerve damage—loss of sensation and muscle weakness
- fever and malaise
- hands and feet may be swollen
- rarely, new skin lesions may appear

**Type 2 or ENL reaction (Erythema Nodosum Leprosum)**
This type of reaction occurs only with patients with a heavy load of germs. The main features are:
- tender reddish skin nodules
- fever, joint pain and malaise
- occasionally painful and swollen nerves
- eye involvement may occur


12. Nowadays the treatment with biomedical medication of leprosy is very different from 61 years before, when the eldest interviewee was diagnosed with leprosy in Surinam.

Before 1945 leprosy patients were treated with vitamins, recuperative medicines and ointments to treat the skin patches and nodules. From 1945 onwards D.D.S.
(dapsone) has been developed and has been used for treatment of the leprosy infection. The patient should use the drug in principle lifelong. In the beginning the results were very good. But after some period of time it was clear that some of the patients did not get cured from the infection. The bacilli were not sensible to the medication anymore (resistant).

It took until the 1980's onwards before MDT (5) drugs have been introduced on a large scale. Results from research had proven, that when only one type of medicines was used, the 'Mycobacterium leprae' was able to become resistant against that drug. Using more than one drug at the time (two, three or more) avoids resistance and can cure the leprosy patient from his/her bacterial infection. Complications (like insensibility and mutilations) can not be cured by MDT.

It has to be noted, that there are several ways apart from the biomedical approach to treat leprosy. Many traditional healers in Africa, Asia and Latin America have their own way to treat leprosy (with more or less success). I have spoken with a traditional healer, during my working period as control officer in a leprosy- and tuberculosis programme in Bauchi (Nigeria). I met him in 1998 during a meeting at the biochemistry department of the University of Bauchi, where I gave a lecture about tuberculosis. He had very interesting experiences with the treatment of leprosy with local herbs, combined with spiritual healing. But in the course of time he got also experience with the biomedical approach, through leprosy patients that had been treated with MDT. He told, that he referred those patients, whom he suspected of having leprosy to the leprosy clinic. He had observed, that MDT gave good results, although it could not cure the deformities. In the context of this thesis it was not appropriate to study traditional healing-methods for leprosy in depth. Personally I would like to know much more about it.

13. **ULO-a and MULO** were imbedded in the secondary education as it was organised in the Netherlands and the Dutch colonies (Surinam, the Antilles and Indonesia) before. **ULO** means Uitgebreid Lager Onderwijs ('extended primary education'). The -a indicates, that the examination has been done in many "non-science" subjects (languages, etc). **MULO** means Middelbaar Uitgebreid Lager Onderwijs ('secondary extended primary education'). The exams of this type of school could not give access to the University. The Dutch secondary schoolsystem has changed since around the beginning of the '70 and ULO and MULO have been transformed to MAVO (Middelbaar algemeen voortgezet onderwijs; 'medium general secondary education').

14. With 'there' the interviewee means the Japanese concentration camps in Indonesia. Those camps existed there during the second world war (1940-1945). Both he and the other Dutch leprosy patient have been locked up during a longer period. The circumstances in the camps were very bad. Many people had to sleep together in sheds. Those people, who at the end of the war could leave the camps alive were malnourished. Hygiene was very bad, shoes and clothes scarce. Source: personal knowledge from history lessons at secondary school.

15. **Hot** food is the contrary of cold food. The division of all foodstuffs into two main groups, usually called 'hot' and 'cold', is a feature of many cultural groups in the Islamic world, the Indian subcontinent, Latin America and China. In all
these cultures, this binary system of classification includes much more than food; medicines, illnesses, mental and physical state, natural and supernatural forces are grouped into either hot or cold categories. The theory of physiology on which this is based, and which equates health with balance between two categories is called the humoral theory. In Latin American folk medicine, the humoral theory—often called the ‘hot-cold theory of disease’—postulated that health can only be maintained (or lost) by the effect of heat or cold on the body. (source Helman, C. 2000, page 19 and 34)

16. Wisi is defined by Venema (1992) as a intentional attempt to harm another person by means of magic (page 157). It is part of the Winti-religion of the Surinams. ‘Winti is an Afro-American religion in which belief in personified supernatural beings is essential. They can take possession of a person and eliminate his consciousness, after which they can disclose past, to-day and future and after which they can cause and cure diseases of supernatural character (Wooding 1979:251 in Venema 1992: 65).

17. A boslandcreool or boslandneger is a Dutch word for the descendants of the black coloured slaves, who in the past were able to flee the estates of their Dutch masters. They fled to the forest in the inland and build up their lives in their own community. A more official term for boslandcreool is Maroon.

The slaves on the Dutch estates are transported from their first country of origin Ghana (Western Africa) to their second country of origin Surinam (Northern Latin America). I mention Surinam as their second country of origin, because they call themselves Surinam now. Source: Opzij, feministie magazine, July/August 2001, page 87, Barryl Biekman and Landelijk Platform Slavernijverleden, www.platformslavernij.nl
Annex 3.

References:


Patton, M.Q. 1990. 'The content of interviews. The wording of questions.' *Qualitative evaluation and research methods.* California: Sage, 290-316.


Wang, C.H. 1997. Quality of Life and Health for persons living with Leprosy, Nursing Science Quarterly, 10:3, Fall, Perspectives, 144-145


www.platformslavernij.nl
Annex 4

Interview guideline for an interview with a medical key-informant

What are the first words that come to your mind when you think of leprosy?

Own work

1. How did you come into contact with his/her work in the field of leprosy?
2. What kind of professional experiences do you have in the field of leprosy care and leprosy research?
3. What is your opinion about the contemporary leprosy care in the Netherlands? (strong points, weak points, gaps)

Patients

1. Can you tell something about the leprosy patients that are under treatment/management in the Netherlands? What is their cultural background?
2. Where are they treated, by whom and how (medication, other therapies).
3. Do you know anything about the experiences leprosy patients have in the Netherlands with their disease and how it affects their life in Dutch society?

General

Do you have any recommendations concerning the (medical) care for leprosy patients in the Netherlands?
Annex 5

*Interview guideline for an interview with a general practitioner*

What are the first words that come to your mind when you think of leprosy?

**Own work**

1. Do you have any experience with the disease leprosy?
2. Did you come into contact with leprosy patients that live in the Netherlands?
   a. If yes, can you tell something about your (professional) experiences (case management, contact with medical specialist and other medical professionals, contact with the patient)
   b. If no, do you have any idea about the leprosy care in the Netherlands?
3. Can you tell something about the average knowledge of the general practitioner in the Netherlands of the signs and symptoms, treatment, complications and management of leprosy?

**Patients**

1. Do you have an idea about the cultural background of the leprosy patients in the Netherlands?
2. Do you know anything about the experiences leprosy patients have in the Netherlands with their disease and how it affects their life in Dutch society?

**General**

Do you have any questions/remarks after this interview?
Do you have any recommendations concerning the (medical) care for leprosy patients in the Netherlands?
Annex 6

*Interview guideline for an interview with an immigrant leprosy patient in the Netherlands*

<table>
<thead>
<tr>
<th>Interview with leprosy patient</th>
<th>AMC/LUMC</th>
<th>Date:</th>
</tr>
</thead>
</table>

**Personal details**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td>M/F</td>
</tr>
<tr>
<td>Hometown</td>
<td>Country of origin</td>
</tr>
<tr>
<td>Tel nr/ e-mail</td>
<td>Single/Married/ Divorced/Widow/ Widower/Cohabitation</td>
</tr>
<tr>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Income: job/social welfare/other</td>
<td>Children: Y/N number</td>
</tr>
</tbody>
</table>

**Experiences in the timeframe around the diagnosis**

1. Could you tell when your story actually starts? When did you discover something was wrong?
2. Can you tell where, how and by whom leprosy was diagnosed?
3. How did you think about your future at that moment?
4. What did you expect when leprosy was diagnosed? Why? Have your expectations become reality?

**Belief**

1. What do the people in your country of origin think about the cause(s) of leprosy?
2. What do you think about the cause(s) of leprosy?

**Experiences with the reaction of the environment**

3. Did you tell anyone that you were diagnosed with leprosy directly after this message?
   a. If yes to whom did you tell it? How did this person (these persons) react?
   b. If no why not? Did you tell it later to anyone? If yes; To whom? And how did this person (these persons) react? If no; how did/do you keep it secret? Did the fact that you kept/keep it secret cause problems for you?
4. Can you tell anything about how you have been treated by
   - your spouse
   - your blood-relatives
   - your fellow-immigrants
   - your neighbours
   - the people at school/ work
   after they have heard you have (had) leprosy? Were they e.g. afraid for
   contamination? How did they accept the fact that you were diagnosed with
   leprosy?

5. Can you tell if you experience differences in the way the people from your
   culture of origin react and how autochthonous Dutch people react on the fact that
   you have/had leprosy?

Knowledge

1. Can you tell me what you know about leprosy (cause, signs and symptoms,
   complications, treatment, follow-up)?
2. How/ from whom did you get to know this?
3. Do you think leprosy can medically be treated well?

Symptoms and complications

1. What symptoms and complications do you experience and how do you rate them in
   term of seriousness?
2. Do these symptoms and complications affect your social life? If so, how?
3. How do you deal with these symptoms and complications? ( family, school, work)?

Attitude of medical staff

1. Can you tell about your medical treatment? What treatment(s) do you get? Can you
   tell something about your own experiences with it?
2. Can you tell something about the reactions of the medical staff involved in your
   treatment (medical doctors, nurses, other paramedical staff)?
3. Does the medical staff use the word leprosy in your vicinity or is there another
   term?
4. Can you tell something about the differences in medical treatment when you
   compare it in your country of origin and in the Netherlands? Can you imagine/
   describe how it would be/ was to be affected by leprosy in your ‘homecountry’ and
   how it actually in the Netherlands?

Leisure time

1. Do you have hobbies? If yes, which ones?
2. How do you spend your free time?
3. Do you feel hampered by the fact that you have/ had leprosy in spending your free
   time?
Advantage/Disadvantage (only to be asked if applicable)

1. Can you think of circumstances in which having leprosy is not a disadvantage, but
an advantage for you?

Self-perception

1. Is it possible to tell how you feel now?
2. Did this feeling change from the time leprosy was diagnosed with you?
3. If this feeling is different can you describe how it is different?
4. Does one of the terms "I am someone with leprosy, I have leprosy or I had leprosy" count for you?

Wishes/ recommendations

1. Do you have any wishes concerning your (medical) treatment?
2. Do you have any recommendations that would make life easier for you as a leprosy patient?

General

1. Do you have any questions /remarks after this interview?
Interview guideline for an interview with a spouse/blood relative

Knowledge

1. What do you know about leprosy (cause, signs and symptoms, complications, treatment, follow-up)?
2. How/ from whom did you get to know this?

Belief

3. What do the people in your country of origin think about the cause(s) of leprosy?
4. What do you think about the cause(s) of leprosy?

Reaction

1. Can you remember when and from whom you heard that your spouse/blood relative was diagnosed with leprosy?
2. Can you remember how your reaction on this message has been? What did you think, what did you feel, what did you expect? Were you afraid for contamination?
3. Can you describe how you think and feel nowadays about the fact that your spouse/blood relative has/had leprosy?
4. How does it affect your life?
5. Some leprosy patients mention, that they think they burden their relatives and environment. Can you tell how you experience this burden?
6. Do you observe positive/ negative reactions from the environment (school, work, neighbours, fellow-immigrants)?
7. Can you tell anything about the reactions of the medical staff involved in the treatment (medical doctors, nurses, other paramedical staff)?

General

1. Do you have any recommendations (medical and not medical) concerning the care around leprosy patients in the Netherlands?
2. Do you have any questions/remarks after the interview?
Annex 8

Topic list for an interview with a nurse who is directly involved in leprosy management

1. What are the first words that come to your mind when you think of leprosy?
2. What are your experiences with leprosy care/management and leprosy research?
3. How do they perceive your own involvement in the care around an immigrant leprosy patient in the Netherlands?
4. Do they have an idea how leprosy patients view their illness?
5. Do they have an idea how leprosy affects the position of leprosy patients in Dutch society?
4. How do they deal with a leprosy patient on the dermatological ward? (name of the disease, openness to other patients)
5. What is your opinion about the contemporary leprosy care in the Netherlands? (strong points, weak points, gaps)
6. Do they have any questions?
7. Do they have any recommendations concerning leprosy care on your ward/policlinic?
Loneliness

the lance of my desire
the sword of my cross
the hunger for perfection
the nostalgia for my home
pierces and wounds steady
delays consumes my fate
my wandering on earth
my waiting for my God

is that called Messianic desire
does anybody understand that
is there anybody there
who can feel the same
or are you all lunatics
addicted to your job
deadened by the treadmill
of daily life.

does anybody hear me

does anybody hear me

is there anybody

is there anybody

Free translation in English of the Dutch poem by Pieter Baars, published on page 4
Annex 10.

Leprosy and leprosy patient: terms in patients’ native language

<table>
<thead>
<tr>
<th>Language</th>
<th>Term</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch</td>
<td>Melaatsheid (1)</td>
<td>De ziekte van Hansen (2)</td>
</tr>
<tr>
<td>Surinam</td>
<td>Kwasi (3)</td>
<td>Negersiekie (4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Koko be (5)</td>
</tr>
<tr>
<td>Mauretanian</td>
<td>Lepre</td>
<td>Bros</td>
</tr>
</tbody>
</table>

Leprosy patient

<table>
<thead>
<tr>
<th>Dutch</th>
<th>Lepralijder</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Surinam</td>
<td>Lepraman</td>
<td>Kwasiman</td>
</tr>
</tbody>
</table>

**ad 1.** ‘Melaatsheid’ has a biblical connotation. See note 1 about melaatsen.

**ad 2.** ‘De ziekte van Hansen’. See note 7

**ad 3.** ‘Kwasi oedoe’ signifies to beat with a stick. This was told to me by a Surinamese-Creol patient.
The marks you get from beating with a stick look like patches and nodules, which can appear as part of the skin symptoms with leprosy.

**ad 4.** ‘Negersiekie’ means disease of the black man (negro, in Dutch neger). According to one of the Surinam-Hindustan patients black people are more vulnerable to leprosy than people who are less dark skinned. This is the reason why the disease in his community is called negersiekie. He also knew the term ‘kwasi’.
There are many ethnic groups in Surinam with a great variety of skin color (note researcher).

**ad 5** One of the Surinam-Creol female patients told me that ‘koko be’ signifies ‘contraction of the hands’.
Clawing of the hands indeed is one of the complications of leprosy (note researcher).
"A leper is coming" was shouted. From far you could hear him. With a rattle in his hand the ill man walked through the city.

Some intriguing statements:

- One of the central questions of anthropology: how do people explain health and disease and devise cultural mechanism to cure illness. (Green, 1999, last cover page)

- ‘Ritual is surely both a language of argument and a chorus of harmony’ (Harris 1957: 1064) from Venema 1992, page 118.