A COMPARATIVE STUDY OF STIGMA AND DISCRIMINATION RELATED TO LEPROSY AND HIV/AIDS

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A comparative study of stigma and discrimination related to leprosy and HIV/AIDS

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Master of Public Health

by

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Declaration:
Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.
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List of Acronyms

ACORD	Agency for Cooperation and Research Development
AIDS	Acquired Immunodeficiency Syndrome
ART	Anti Retroviral Treatment
ARV	Anti Retroviral
CADRE	Centre for AIDS, Development, Research and Evaluation
CBR	Community Based Rehabilitation
CHW	Community Health Worker
CPA	The Centre for Policy Alternatives
FBO	Faith Based Organization
HE	Health Education
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research on Women
ICF	International Classification of Functioning, Disability and Health
IDEA	International Association for Integration, Dignity, and Economic Advancement
ILEP	International Federation of Anti-Leprosy Associations
MANET	Malawi Network of People living with HIV/AIDS
MB	Multi Basilar
MDT	Multi Drug Therapy
MTCT	Mother-to-child transmission
NAPWA	National Association of PLWHA
NGO	Non Governmental Organization
NLCP	National Leprosy Control Programme
OHCHR	Office of the High Commissioner of Human Rights
PB	Pauci Basilar
PEP	Post-exposure prophylaxis
PHR	Physicians for Human Rights
PLWH	People living with HIV
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
POD	Prevention of Disability
POID	Prevention of Impairments and Disability
S&D	Stigma & Discrimination
SER	Socio-economic Rehabilitation
SHG	Self-Help Group
SSA	Sub-Saharan Africa
STD	Sexual transmitted disease
STEP	Stigma Elimination Programme
STI	Sexual transmitted infection
TASO	The AIDS Support Organization
TBA	Traditional birth attendant
TB	Tuberculosis
TLMI	The Leprosy Mission International
VCT	Voluntary counselling and testing
VT	Vocational Training

UNAIDS	United Nations Programme on HIV/AIDS
USA	United States of America
USAID	United States Agency for International Development
WER	Weekly Epidemiological Record
WHO	World Health Organization

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Dedication

I like to dedicate this thesis to my late aunt
Marina Frijlink, who made it possible
for me to do this course.

Miller quoted by Heijnders
"It is not so important what people think about each other, but what people say about each other; it is words that give weight to attitudes"

Reckless words pierce like a sword,
But the tongue of the wise brings healing.
Proverbs 12:18

Abstract

Stigma is called the hidden burden of disease. It is a phenomenon which is added on to the burden of disease that can be measured. Stigma and its consequences have a negative impact on individuals, families and public health programmes.

A literature review was conducted with the aim to review and compare the determinants, manifestations and consequences of stigma and discrimination in leprosy and in HIV/AIDS and to make recommendations for interventions.

While many endemic countries may have reached the elimination target of less than one case per 10.000 people, the major concerns for a person affected by leprosy are disability and stigma. Fear and misconceptions still prevail and still leprosy-affected people are insulted, isolated and rejected. Stigma and discrimination (S&D) causes psychosocial problems resulting in great suffering for those affected by leprosy.

HIV/AIDS is feared because of disease and death. S&D is fuelled by lack of knowledge and sexual norms. HIV/AIDS has reinforced stigmatization of already socially rejected groups like homosexuals, injecting drug users, and sex workers. People can be unfairly and unjustly treated because of their actual or presumed HIV status or because of their association with a certain group.

The following **findings** are relevant in leprosy and HIV/AIDS (a) stigma is not a static attribute but a dynamic process (b) the ways to creating S&D, self-stigma and self-discrimination are similar; (c) the response of the individual to a negative stereotype will play an important part in determining the severity of self stigma; (d) deterioration of physical condition increases the severity of stigma in society; (e) improvement of condition can reverse S&D and the one affected can regain his/her social position in the community; (f) the consequences of stigma are surprisingly similar in leprosy and HIV/AIDS, in different cultures and public health programmes.

The following **interventions** are suggested for addressing S&D in leprosy:
(a) <u>focus on the individual</u>: in order to empower leprosy-affected people, provide individual counselling and/or peer counselling; establish self care groups and/or self help groups with socio-economic assistance; strengthen and empower leprosy affected persons organization(s)
(b) <u>focus on the community</u>: design and use cultural sensitive messages about leprosy and involve religious leaders, community and/or tribal leaders for dissemination of information about leprosy in order to ensure better impact and acceptance of the health messages
(c) <u>focus on institutions:</u> health services: ensure to have skilled health care workers in dealing with the management of leprosy complications and POID; to have greater participation of leprosy-affected people in all activities; involve the media
<u>In relation to policies</u>: advice MOH on National strategy for POID and rehabilitation; use of indicators for measuring S&D and self stigma and for monitoring S&D and self stigma reduction interventions
(d) <u>Research:</u> Cross cultural study on concealment cycle; feasibility study on adapting the 'Toolkit for action'; feasibility study on developing 'Health-related S&D' as subject on the curriculum for health professionals at Universities and Nursing Academies.

Keywords: Discrimination, HIV/AIDS, leprosy, stigma

Introduction

I am a nurse and I am working with The Leprosy Mission International (TLMI). First, I worked in Thailand in a leprosy hospital for five years. From there, I moved to Indonesia and worked with TLMI in the National Leprosy Control Programme (NLCP) in different parts of the country for more than 17 years. I started working as a district supervisor and worked closely with my national counter part. Later, I became provincial coordinator of a project. Training and Health Education (HE) were the main part of the project.
By choosing Stigma and Discrimination (S&D) as subject for my thesis I had the opportunity to look more in depth at this phenomenon. It has given me a better understanding of S&D and it will be helpful in my work.

Stigma and discrimination is a public health problem. It is sometimes called 'the Hidden Killer' or 'the Hidden Burden of Disease' or 'the Enemy Within'. The 'hidden killer' can be seen in relation to the results of attitudes, responses and behaviour of society towards diseases such as leprosy and HIV and those who are affected by leprosy and HIV/AIDS. The 'hidden burden of disease' can be seen in relation to public health because stigma and discrimination has an adverse effect on prevention and control. The 'enemy within', self-stigma can be seen in relation to the perception and experience of the individual having leprosy or HIV/AIDS which can lead to psycho-social problems causing great suffering.

The main objective of this study is to review and compare the determinants, manifestations and consequences of stigma and discrimination in relation to leprosy and HIV/AIDS and to make recommendations for interventions.

Chapter I describes briefly stigma and discrimination as burden of disease followed by explaining the history of leprosy and HIV/AIDS.
Chapter II will start with describing stigma and discrimination in leprosy and HIV/AIDS and the similarities between the diseases. It continues with the study questions, the thesis objectives and finally the methodology of the research done.
Chapter III gives an overview of different concepts and definitions related to stigma and discrimination. It will address the study questions: "How does S&D arise? Why does one person seem to be more stigmatised and discriminated than others? What are the similarities and differences of S&D in relation to leprosy and HIV/AIDS?"
Chapter IV reviews and compares the determinants, manifestations and consequences of S&D in relation to leprosy and HIV/AIDS. It continues to look at the similarities and differences of S&D in relation to leprosy and HIV/AIDS. It also addresses the questions: "How are people affected?" Who are the actual stigmatizers?
Chapter V will describe good practices in reducing S&D in leprosy and HIV/AIDS. It addresses the study questions: "Is there common ground for interventions? What can be learned from the recent good practices in HIV/AIDS for the leprosy programme?"
Chapter VI will discuss the findings of Chapter III and IV.
Finally, in chapter VII appropriate recommendations based on the findings and good practices are suggested for intervention strategies in reducing S&D in leprosy.

Chapter 1: Background

Stigma and discrimination (S&D) is referred to as the hidden burden of disease. This burden is difficult to quantify. It is added on the burden of disease which can be measured (WHO fs218, 2001). S&D is a phenomenon associated with many chronic health conditions, amongst them are leprosy and HIV/AIDS (van Brakel, 2006).

In this chapter the history of leprosy and HIV/AIDS will be explained.

1.1 Leprosy

Leprosy is a chronic infectious disease caused by Mycobacterium leprae, an acid-fast bacillus. It affects the skin, peripheral nerves, the mucosa of the upper respiratory tract and the eyes.
The mode of transmission is still not exactly known but most likely it happens via droplets, from the nose and the mouth, during close contact with untreated cases especially multi bacillary (MB) cases (Davey at al, as cited by WHO, undated; WHO, fs101, 2005). Man is the most important host. There is no effective vaccine developed yet against leprosy. If the disease is left untreated it will progress and permanent damage to skin, nerves, eyes and extremities can occur. There are an estimated two million people with visible, irreversible disabilities in the world due to the consequences of leprosy. Throughout history the disease has been feared because people thought it was highly infectious, and incurable. In addition to that people greatly feared leprosy because of the mutilation of the body resulting in rejection, and exclusion from society (Bainson et al, 1998; Lockwood et al, 2005; WHO fact sheet undated) The cumulative number of people over the centuries who suffered this dreaded disease is unknown.

In the 1940s the sulfone group of drugs was introduced. The first trial took place in 1941 and by 1950 dapsone was regarded as the most effective drug used. It was a cheap drug that was taken orally (WHO,WER no 27, 2004).
Multidrug therapy (MDT) was introduced by WHO in 1982. Under this programme. patients classified as ‘paucibacillary’ (PB) are treated for 6 months with a combination of the drugs rifampicin and dapsone, while those classified as ‘multibacillary’ (MB) are treated for 12 months with a combination of the drugs rifampicin, clofazimine and dapsone. The medication for one month is packed in ‘blister packs’, which the patient takes home. Once a month the patient should come to the clinic for a supervised dose of rifampicin and a physical check up to see if there are any changes in nerve function. MDT for leprosy is highly effective in curing the mycobacterial infection, but treating nerve damage is much more difficult (Lockwood et al, 2005; White, 2007)

In 1991, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000 using the prevalence as measurement. The definition of the elimination of leprosy as a public health problem was a prevalence rate of less than one case per 10,000 population. Because of the widespread use of MDT the burden of disease has been reduced dramatically. More than 14 million cases were detected and treated with MDT between 1982 and 2005 (WHO, fs101, 2005). In 1985, 122 countries in the world had a leprosy prevalence of > 1 case per 10.000 population. This number fell to 24 countries in 2000 and to 4 countries by 2007 (Lockwood et al, 2005, WHO, 2007). The global registered cases of leprosy at the beginning of 2007 was 224.717 cases while the number of new cases reported during 2006 was 259.017. The latter does not include the small number of new cases in Europe (WHO, WER no 25, 2007).

Elimination campaigns have been successful because of the political involvement and collaboration of many partners. However the concept of elimination to a prevalence of < 1 case per 10,000 population has been misunderstood and is often thought of as the absence of cases.' (Lockwood et al, 2005).

1.2 HIV/AIDS

The UNAIDS/WHO report showed that in 2007 there were globally an estimated 33.2 million adults and children living with HIV/AIDS, 2.5 million adults and children newly infected with HIV and 2.1 million AIDS deaths. The low and middle income countries are mostly affected by the epidemic. The devastation and suffering caused by HIV/AIDS to individuals, families, communities and entire nations are beyond words (ACORD, 2004). This is especially seen in Sub-Saharan Africa (SSA) which has the highest burden of HIV/AIDS with 22.5 million adults and children living with HIV/AIDS, 1.7 million adults and children newly infected with HIV and 1.6 million AIDS deaths. In addition to that this region has an estimated 11.4 million orphans due to AIDS. South and South East Asia follows SSA with 4.0 million people living with HIV/AIDS, 340.000 people newly infected with HIV and 270.000 AIDS deaths. In this part of the world the epidemic is more concentrated (UNAIDS/WHO, 2007).

HIV/AIDS has a high mortality rate. In the beginning there was no treatment and PLWHA would suffer severe weight loss. HIV/AIDS has reinforced stigmatization of already socially rejected groups like e.g., homosexuals, injecting drug users, men having sex with men and sex workers (Aggleton, 2000). Lack of knowledge, fears of disease and death and sexual norms are causing stigma and discrimination (Nyblade et al, 2003).

The virus can be transmitted in three ways: (1) By sexual transmission, (2) Through blood and blood products, (3) From mother to child during pregnancy, delivery and breastfeeding (WHO, fact sheet 1 HIV, undated). Prevention is mainly done through safety precautions and dissemination of information (WHO, fact sheet 1 HIV, undated).

The communicability of HIV is most likely a lifetime. It is high during the first months after infection and increases with viral load, with worsening of clinical status and with the presence of other sexual transmitted infections (STIs) (Heymann, 2004).

HIV testing was done in the past to confirm the diagnosis. Nowadays there is the voluntary counselling and testing (VCT) service where people can come voluntarily to find out their HIV status. The service includes pre-and post test counselling (WHO, fs1 HIV, undated).

Anti retroviral treatment (ART) is a combination of drugs that slows down the HIV replication and immune deterioration in the body. Because of that life can be prolonged and the quality of life can be improved. ART has brought hope for those living with HIV/AIDS as they can attain a so good possible health (WHO, fact sheet 1 HIV, undated).

In 2003, WHO and UNAIDS launched the '3 x 5'initiative with the goal to reach 3 million people living with HIV/AIDS with ART by 2005. This target was achieved by the end of 2007. But ART coverage remains still low, only 31% of the estimated 9,7 million people in need of treatment in low- and middle-income countries were receiving it (WHO, 2008).

Chapter 2: Problem Statement, Objectives and Methodology

This chapter will start with explaining stigma and discrimination in leprosy and HIV/AIDS followed by the similarities between the two conditions. It continues with the study questions, the thesis objectives and finally the methodology of the research and finished with the set-up of the thesis.

2.1 Stigma and discrimination in leprosy

Stigma and its consequences have an negative affect on individuals, families and leprosy control programmes. Some patients diagnosed with leprosy may conceal their illness out of fear of rejection and exclusion from society. Others may stop their treatment prematurely out of fear for stigmatisation because they experience drastic appearance changes due to side effects of treatment e.g. uneven darkening of skin due to clofazimine and facial swelling and weight gain because of prednisone (Bainson et al 1998; White, 2007). There are times when people report late due to stigma and because of that the opportunity for the transmission of the disease increases. This has consequences for control efforts and not only that it will have financial consequences as well because the condition of the person affected may worsen and therefore people will need prolonged treatment and special care. Late reporting can have adverse consequences for the patients as they may suffer physical impairments and disabilities, which could have been prevented if they had come earlier (Bainson et al, 1998). Physical impairments cause difficulties for a leprosy affected person in carrying out activities s/he could do well before. If these impairments have become permanent the person may experience greater disadvantages for example losing his/her job, not able to work well and because of that unable to earn enough for a living, denied to go to school, loss of social status. Through participation restriction the person affected will become more and more isolated and excluded from society as s/he cannot fulfil the role which was expected of him or her (Kaur & van Brakel 2002). Psychological changes occur in the patient due to impairments and disabilities that are perceived as negative by the patient resulting in negative expectations of himself with respect to life. A variety of emotions like fear, grief, confusion and anxiety may develop and could lead to depression, loss of self-esteem, withdrawal and mental problems (Tsutsumi et al, 2004). As a result of the disabilities, people affected by leprosy are more prone to be stigmatized. Visibility of wounds and ulcers can aggravate the fear of contagion (Jopling, 1991; Seddon et al, 2006).

People affected by leprosy have experienced isolation and discrimination as they were rejected by their families and pressurised by community members to leave their villages (Shieh et al, 2006).

Stigma is not only associated with fear of catching the disease or a result of a person's strong feelings of dislike towards disabilities. Some traditional and religious beliefs also play a major role. For example, in many Hindu societies, persons affected by leprosy are blamed for their condition, which is thought to be a punishment for something they have done wrong in a previous life. In this case, stigma involves a moral judgement (Seddon et al, 2006).

As much as disabilities can be a determinant of stigma, this is not always the case as it is not only the person suffering from leprosy who is affected by stigma, but people associated with the patient as well. These people do not have any signs of leprosy but are still stigmatised and the impact weighs heavily on their lives. The prospect of getting a job or getting married can be at stake (Seddon et al, 2006).

Leprosy is still a stigmatised disease despite the fact that it is curable and that MDT is available. Strong beliefs and fear still persists. It is those beliefs, attitudes and behaviour that need to be taken into account in order to address the struggle against stigma in leprosy (Seddon et al, 2006).

2.2 Stigma and discrimination in HIV/AIDS

Different beliefs and fears regarding HIV/AIDS are persistent and create a negative influence and outcome on the prevention and treatment of the disease. Use of language like metaphors- as death, as horror, as punishment, as shame, as guilt, as otherness, in relation to HIV/AIDS have aggravated this and have reinforced stigmatization and discrimination (Gilmore et al, 1994; Aggleton et al, 2002, Ogden et al, 2005). People are still fearful that HIV is transmitted through simple, daily interactions without the involvement of blood or body fluids. Casual contact like shaking hands, kissing, eating together with a PLWHA or sleeping in the same room as a PLWHA are frightening to people. Due to this fear PLWHA are isolated from the community (Nyblade, 2006). Stigma is also fuelled by moral judgement. People see it as a personal choice of engaging in 'bad' behaviour such as adultery, sex between men and injecting drug use of PLWHA. In other words, they bring it on themselves and should be ashamed of themselves. This shame is not limited to the persons themselves, but affects their families as well. Others may see it as a punishment from God, as something PLWHA deserve for their disobedience or deviant behaviour (as cited by Aggleton, 2000; Nyblade, 2006, ACORD, 2004).

Discrimination is the result of “the enactment of prejudiced ideas which leads to do things (or not to do things) that harm others or deny them services or entitlements” (Aggleton et al, 2003). Health care providers who deny treatment to seriously ill PLWHA because they do not believe treatment is going to work; orphans, who are denied their right to schooling (MANET, 2003); employees, who are sacked overnight once their HIV status become known (CPA, 2005). PLWHA are often not allowed to participate in community gatherings and feasts. Children of PLWHA may be teased at school and excluded from games and social interaction with their peers (ACORD, 2004).

Because of fear for discrimination people do not acknowledge that they are HIV positive. Those who are HIV positive or suspect they are HIV positive may not use preventive measures in order not to create suspicion about their condition (O'Neil and Samiel, 2004). Concealment of their condition can result in stress and anxiety for the PLWHA. This may lead to further psychological consequences for how PLWHA come to see themselves, resulting in some cases, in depression, lack of self-worth and despair (Aggleton et al, 2002).

HIV- related S&D has an effect on individuals getting tested; people seeking care, support and treatment; increasing social inequalities; hindering access of PLWHA to health, housing, education and employment (Morrison, 2006).

Because of delay in seeking treatment the morbidity and mortality will increase as well the transmission of HIV and opportunistic infections will continue to spread (O'Neil and Samiel, 2004).

2.3 Similarities between leprosy and HIV/AIDS

Both leprosy and HIV/AIDS are public health problems and both are highly stigmatised diseases. AIDS is even referred to as '*the present-day leprosy*' (as cited by Barrett, 2005). Leprosy and HIV/AIDS have things in common. Leprosy once an incurable disease with no hope is curable nowadays. Treatment with dapsone was revolutionary but the drug needed to be taken lifelong depending which type of leprosy someone had. Multidrug treatment is now available and the duration of treatment is short in comparison before, 6 months for PB cases and 12 months for MB cases. For HIV/AIDS there was no treatment at first, no hope similar with leprosy. At the moment there is HIV Anti Retroviral Treatment. The treatment is not a cure, but it can stop people from becoming ill for many years. It consists of drugs that have to be taken every day for the rest of someone's life. Counselling has been an important aspect in HIV programmes and is of similar importance in leprosy. However in leprosy it has not been so explicitly stressed as with HIV/AIDS. The difference between leprosy and HIV/AIDS is that leprosy is regarded a neglected disease whereas HIV/AIDS has a lot of attention and a lot of money available.

2.4 Study questions

- How does stigma and discrimination arise?
- Why is it that one person seems to be more stigmatised and discriminated than others?
- What are the similarities and what are the differences of stigma and discrimination in leprosy and HIV/AIDS
- How are people affected?
- Who are the actual stigmatizers?
- What good practices have been done in order to reduce stigma and discrimination in leprosy and HIV/AIDS and what can be learned from it?
- Is there common ground in these interventions?

2.5 Thesis objectives

2.5.1 General objective

To review and compare the determinants, manifestations and consequences of stigma and discrimination (S&D) in leprosy and in HIV/AIDS and to make recommendations for interventions.

2.5.2 Special objectives

- To describe and compare S&D related to leprosy and HIV/AIDS
- To review and compare the determinants, manifestations and consequences of S&D related to leprosy and HIV/AIDS
- To describe briefly best practices that have been/are used to address S&D in leprosy and describe best practices that are used to address S&D in HIV/AIDS from selected countries
- To make recommendations for intervention strategies in leprosy

2.6 Methodology

2.6.1 Literature review

The thesis is based on a literature review – KIT (Royal Tropical Institute) library, NLR (Netherlands Leprosy Relief) library, UBVU (Free University) library and Internet have been used to search published literature relevant to the topic.

2.6.2 Search method

Websites PUBMED, Google scholar, UNAIDS, USAID, WHO, Population council, ICRW, CSA, CADRE and Lepra have been used to search literature. **Keywords** to searching literature include: leprosy, HIV/AIDS, stigma, discrimination, denial, prejudice, human rights, gender, media, health care, behaviour change, health workers, disability, deviance, impairment, scapegoating, metaphor, poverty, intervention, best practices, PLWHA, advocacy, prevention

Manual search: **Keywords** stigma and leprosy were used to get a reference list with relevant articles from Leprosy Review, Indian Journal of Leprosy and available articles in the NLR library.

2.6.3 Focus of the study

The review focused on leprosy and HIV/AIDS in low income countries like India, Nepal, Bangladesh, Indonesia, Nigeria, Uganda, Zambia, Ethiopia and Vietnam.

2.6.4 Years covered

The articles were chosen from 1980 onwards. Only one book was from 1963.

2.6.5 Set-up of the thesis

The set-up of the thesis is as follows:

The *introductory part* is in chapters I&II as we have already seen with in chapter I describing briefly S&D as burden of disease followed by the history of leprosy and HIV/AIDS. Chapter II describes S&D as problem in leprosy and HIV/AIDS, continuing with describing the similarities between the two conditions and followed by study questions, objectives and methodology of study.

The *second part* describes the research done on stigma and discrimination; and determinants, manifestations and consequences; and best practices which can be found in chapters III, IV&V. Chapter III will cover special objective: " To describe and compare S&D related to leprosy and HIV/AIDS". Chapter IV will cover special objective: "To review and compare the determinants, manifestations and consequences of S&D related to leprosy and HIV/AIDS. Chapter V will cover special objective: "To describe briefly best practices that have been/ are used to address S&D in leprosy and describe best practices that are used to address S&D in HIV/AIDS in selected countries".

The *final part* can be found in chapters VI&VII. Chapter VI will contain the discussion on the findings with conclusion. Chapter VII with the recommendations will cover special objective: "To make recommendations for intervention strategies in leprosy".

Chapter 3: Stigma and Discrimination

This chapter gives an overview of different concepts and definitions related to stigma and discrimination (S&D). It starts with research done since 1960s and continues looking at more recent research on leprosy-related and HIV/AIDS-related S&D, followed by a proposed definition of health-related stigma for research purposes.

3.1 Concepts of Stigma and Discrimination

Stigma is as old as history. The Greeks used the term stigma to signify a person's moral status by a cut or burn into the skin. Goffman (1963) defines stigma as an attribute that is deeply discrediting. The one, who possesses an attribute of undesired 'difference' is as a result tainted and devaluated in the eyes of society. He mentioned in his discussion the categorizing of people as 'normals' and 'deviant' individuals. In continuation of that discussion he referred to "the attitudes we normals have towards a person with a stigma and the actions we take in regard to him" (p.15). Discriminatory actions were seen as the end result of the stigma process with as result the reduction of life chances for those stigmatised (Nyblade et al, 2006)
Goffman (1963) gave an example of two people attending a meeting, one in a wheelchair and the other had no visible attribute to show there was a difference. However, the latter had a speech problem what at the time of speaking was revealed and the person in the wheelchair could contribute to the discussion without any problem. "Handicap is not an inevitable consequence of disability. It is dependent on interactions between a whole range of social, cultural and behavioural variables" (Dalal et al, 2000 p.18). The International Classification of Functioning, Disability and Health (ICF) focuses on the level of health and functioning, rather than on people's disability. "It acknowledges that every human being can experience a decrement in health and thereby experience some disability" (WHO, 2002).
Goffman (1963) proposed three different types of stigma: 1) physical deformity, 2) blemishes of character and 3) tribal stigma of race, nation, religion and social class. All these different types of stigma are found in leprosy and HIV/AIDS.

The focus of Goffman (1963) was on the individual and being different. Parker and Aggleton (2003) expand on that and discuss stigma as a social process based on an already existing social hierarchy and inequalities. They turn from difference to pre-existing stigmatised groups based on gender, race, sexuality, class and age. These groups can be devalued by others in society. "Stigma as a social process produces and reproduces relations of power and control" (Ogden et al, 2005).
Discrimination follows stigma and is unfair and unjust treatment of people (Ogden, 2005). Groups with a dominant status seem to legitimize inequalities of power and exercise control over marginalised and stigmatized individuals and groups. The disadvantage of those stigmatized is more often than not mixed in with exploitation and oppression (Scambler, 2006). Stigmatization has a disabling effect on the mind and body. It is difficult for those affected to resist stigma and discrimination (S&D). They often seem to accept and even internalize it (Parker & Aggleton, 2003).
Parker and Aggleton (2002) have linked HIV/AIDS-related stigma and discrimination to pre-existing sources of S&D. The framework is shown in Annex 1.
The framework may not be applicable for leprosy. However, like HIV/AIDS, leprosy is seen as a disease of the poor, so poverty-related features may apply to both conditions. E.g., the poor are often of a low social class, which is a pre-existing stigmatised condition.

3.2 Stigmatization process – concealment cycle

Heijnders (2004) described stigma as a dynamic process, based on former studies by Alonzo & Reynolds and Hyland. She elaborates on the concealment cycle which was introduced by Hyland. The concealment cycle shows that the person affected by leprosy goes through different phases using different coping strategies in order to manage stigma and discrimination and to maintain his/her social integrity as a person in the community. The model of this process she proposed is shown in Annex 2.

Many people with leprosy are affected by stigmatization. They may be labelled as 'lepers'. This can have consequences for the individual as well as the family. Visible impairments of a person affected by leprosy may lead to a negative response from those he or she meets. Sometimes people cringe when they see a person with leprosy-related deformities. In this dynamic process of stigmatization the affected person will go through different phases using different coping strategies. Other people may respond different in each phase. These phases are related to the interactions between people affected and other people, as well as to the development of the disease e.g. development of visible symptoms. In addition, the condition of the person affected and the direct environment can have an influence on the process and impact of stigma. The concealment cycle is a recurrent process used by the person affected to keep his or her place or position in the community. The person affected may try to conceal his or her condition as long as possible in order to manage stigma. It may be through "story telling" at the time of curious questioning by others about symptoms or visits to the health clinic. If these questions become more frequent and disturbing making the person affected feel threatened, he or she may 'withdraw' in order to preserve his or her social integrity. The withdrawal may result in stopping treatment, or leaving the village with their families, or leaving alone in order to work in another community (Heijnders, 2004).

There are different levels of exposure to stigma. They vary from private exposure to public exposure. Private exposure means the person affected knows others know about his or her condition and are talking about it. Heijnders continues to say that "this talking about him or her can change from private curiosity, via suspicion and gossip to 'public silence and private slander'". The private slander is the talking about the disease of the affected person by others at home. The public silence is shown through the politeness and respect in the street. Other people in the community may "wait and see" what is going to happen next. "This stage of mutual concealment in a social interaction is showing that actual stigmatization only happens after an action or a response is triggered" (Heijnders, 2004). If during this period the person affected takes treatment and the condition is good, the process of stigma can be reversed. The person affected will regain his or her social integrity. If, on the other hand, a person affected stops treatment or continues but gets reaction and his or her condition gets worse, this will result in public discrimination. A person can move from a later phase to an earlier one within the concealment cycle. This emphasises the dynamic nature of stigma and means he or she can regain his or her social position in the community. Reactions in the last phase may differ. A person affected can be asked to eat separate and use separate utensils within the family or to move outside the village or be sent away. People who were asked to eat separately or live outside the village can also regain their social integrity. The people who had been sent away could not. The reason for this was not clear (Heijnders, 2004). This kind of issue needs to be seen in cultural context, but the above shows that stigmatization is a dynamic, ongoing process, shaped and re-shaped by social interaction. The severity of stigma in society is related to the progress of the disease. Heijnders' study shows the importance of recognizing the different phases and coping strategies of the person affected by leprosy during the

stigmatization process.
HIV infection is invisible and, in the early stages, the PLWH is able to conceal it. The secondary markers like the onset of e.g. TB or wasting – 'called slim in Uganda' (Monico et al, 2001) – identify the person, who has AIDS (Deacon et al, 2005 p.12). The Castro & Farmer (2005) paper showed a similar kind of process in relation to a PLWH, who owned a small shop. He lost his customers when he started to lose weight and developed visible skin infections. After he started treatment his condition improved. He reopened the shop and the customers came back.

3.3 Different definitions of stigma

3.3.1 Felt and enacted stigma

There is a distinction between felt or perceived stigma and enacted stigma. Felt stigma refers to the imagined or real fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease, or association with a particular group (Jacoby, 1994). For instance: women may delay seeking treatment if they suspect they have leprosy out of fear of being abandoned, anticipating less chances of getting married or that it may affect their role in the household. In the case of HIV, an individual may not disclose HIV-positive status for fear of being rejected by family and friends or out of fear of losing a job. Jacoby (1994) cited Scambler and Hopkin in saying that felt stigma was more prevalent than enacted stigma. She continued discussing about people with epilepsy that "they did not experience discrimination but felt stigma as a product of stigma coaching by key individuals such as parents". Most likely the response of the parents with care and protection to deviance is high and stigmatizing and harmful effects of responding are often unintended (Dijker and Koomen, 2006). Acceptance of the disease leprosy or the HIV status by family and friends is important for the person affected. Acceptance will help the person affected to accept his or her condition and continue to live a positive life (Siyam'kele, 2003).

Enacted stigma is the real experience of discrimination that means unjust and unfair actions of people in society towards people affected by a certain condition or associated with a particular group (Jacoby, 1994). Examples include rejection by the family/community, restrictions in participation in religious activities and loss of a job because of one's HIV-positive status or because of leprosy.

3.3.2 Public and self stigma – psycho-social model

There is a distinction between public and self-stigma. Public stigma refers to the attitudes of the community concerning a certain illness or condition, e.g. leprosy, HIV/AIDS and mental illness. It encompasses three parts, stereotypes, prejudice and discrimination. Social psychologists view "stereotypes as knowledge structures that are learned by most members of a social group" (Corrigan & Kleinlein, 2002 p.16). Stereotypes give information about social groups, which are categorized and agreed upon by society. They give quick impressions and expectations of individuals belonging to the stereotyped group. People become prejudiced if they endorse a negative stereotype ("That's right; people with mental illness are violent!") and it may lead to negative emotional reaction as a result ("They scare me!"). Prejudice is a cognitive and is an affective response, whereas discrimination is the behavioural response. Anger may lead to withholding help, whereas fear may lead to avoidance (Corrigan & Kleinlein, 2002 p.17). The impact of public stigma affects many people; not only the person with the condition, but also family, friends and even caregivers.

Self-stigma results from internalisation of negative stereotypes and agreement with these. Self-prejudice can lead to emotional reactions resulting in low self-esteem and low self-efficacy. In addition to that, self-prejudice may lead to behavioural responses. Low self-esteem and demoralization may stop a person from pursuing work or going to school. Self-stereotyping, self-prejudice and self-discrimination will have an impact on a person's purpose in life and on the quality of life. Self-stigma has often been presented as an automatic result of being a member of a stigmatised group. However, not everyone looses self-esteem, as studies have revealed. There are different ways to respond to stigma. In part, this depends on the person's level of identification with the stigmatized group. A person can comply with the perceived threat of stigma and view oneself poorly, or s/he can oppose the negative evaluation, which may result in a positive self-perception (Corrigan & Kleinlein, 2002).

Personally, I have seen people affected by leprosy with different levels of self- esteem. John*, a young adolescent, dropped out of high school because he had a visible impairment of his left hand. He felt he could not go to school anymore. Five years passed before the rehab worker of the leprosy programme came in contact with him. With encouragement he went back to school. On a special occasion he was asked to raise the flag at school, which is an honour in Indonesia. He was so proud to be chosen, it was a boost for his morale. Peter*, also a young adolescent with very deformed hands, could not write normally because the pinch function of his thumb was gone. He had to hold a pen with the thumb web of his hand. He went through high school, went to the youth club without any problems. He sold newspapers or fish. People bought it from him. The way he carried himself made a world of difference.
(* fictive names)

Internalised or self-stigma in relation to HIV and leprosy

"Self-stigma is the enemy within. It renders a person complicit with the injustice of externally imposed discrimination and stereotyping". It leads a person to adopt attitudes of self-loathing and self-blame (Everett, 2006). It is not surprising that this is happening, as the PLWH and people affected by leprosy are members of the same community as their stigmatizers. They have the same cultural, social and moral background with the same norms and values attributed to it. Many individuals living with HIV or leprosy are going through a process, from initial shock, despair, shame, guilt and grief and sometimes a period of denial before eventually reaching a point of acceptance. In the early stages of their condition PLWH often experience less acceptance by their family and have no contact yet with other HIV positive people or HIV positive support groups. However this position of isolation may remain throughout their lives. It can contribute to feelings of hopelessness, worthlessness and believing there is no future (Ogden et al, 2005; Brouard et al, 2006).

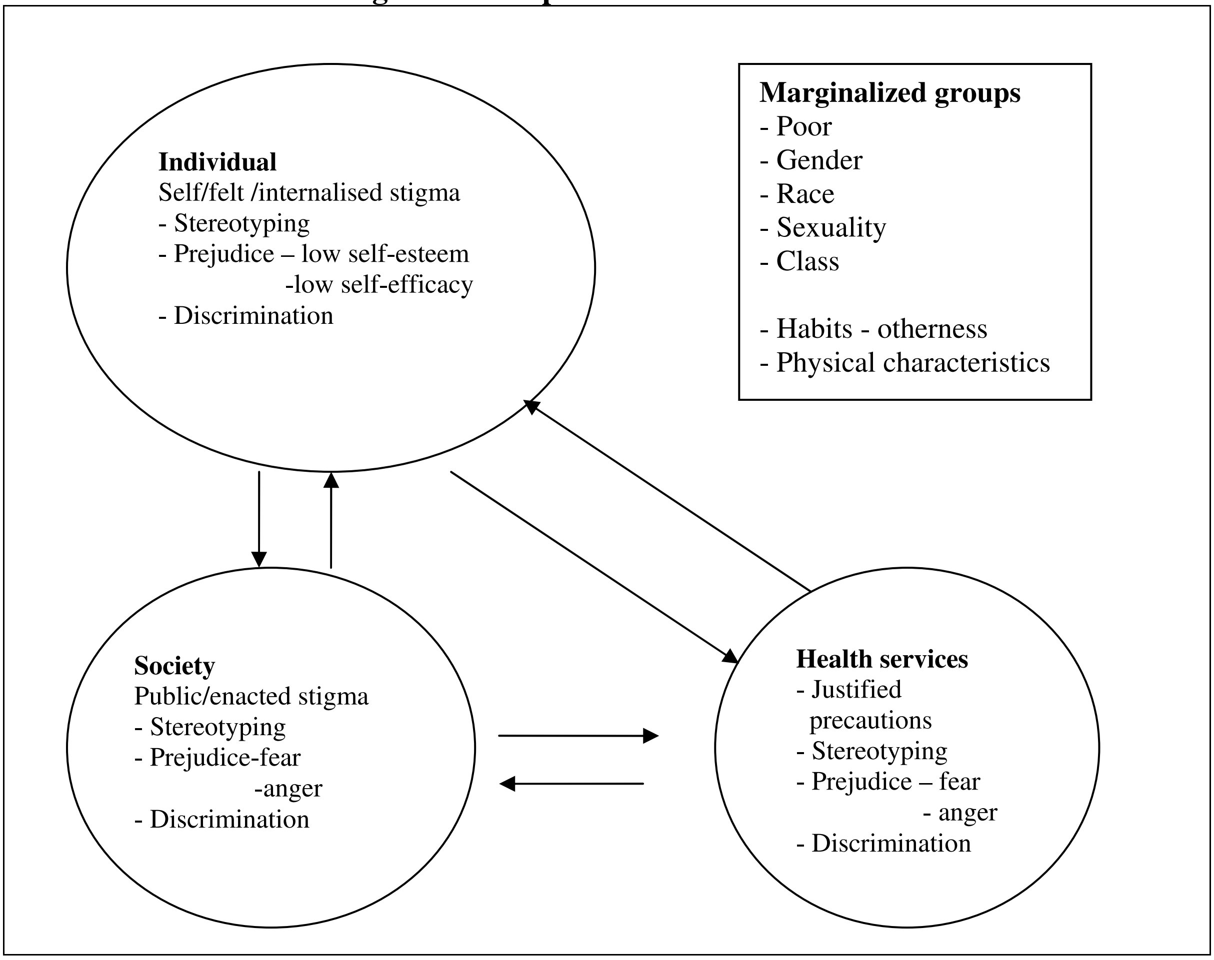
I have observed that, despite being accepted by the family and living with the family, a person can be affected deeply due to internalised stigma. Paul*, a young man in his late twenties with severely deformed hands, was visited at home by the rehab worker of the leprosy programme. Paul was sitting head down, hands covered and he did not say a word. The rehab worker spoke to the mother, who was present at the time. When the rehab worker left, Paul said goodbye and that had been the only word he said. He did not go to church or social gatherings in the village. In the past he had done some work, but he had stopped. He owned a small plot of land, which had his interest. The rehab worker visited him regularly and one time he suggested to Paul to be part of a self-help group. However, he did not feel ready yet. (*fictive name)

From the discussion of public and self-stigma we can learn that the ways to creating stigma, discrimination, self-stigma and self-discrimination are similar. However, we may draw the conclusion that the ways to combating stigma, discrimination , self-stigma and self-discrimination will be different. For the public we will focus on addressing fear and anger whereas in relation to the individual it will be more on the level of the internalisation of the negative stereotypes and the agreement of these.

As mentioned under felt stigma, acceptance of the person affected by leprosy or HIV/AIDS by the family and community will be important as it will help the person affected to accept his/her condition as well. However, feeling included by family and society will not be enough in addition to that self-acceptance is necessary as well.

Box 1 gives a quick overview of what has been discussed. Existing institutions in society like e.g., the health services can be stigmatising as well. The box in the right top shows the pre-existing stigmatised person or groups.

Box 1: Overview of the stigmatization process



3.3.3 Health-related stigma

The below definition refers to health-related stigma. Researchers in the area of health-related stigma have proposed this formulation for research purposes:
"Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or a group. This judgement is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted. In addition to its application to persons or group, the discriminatory social judgement may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgements about enduring features of identity apart from health-related conditions (e.g., race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma" (Weiss and Ramakrishna, 2004).

The definition of health-related stigma is a comprehensive definition with the implication of an action focused application. With this definition in mind we will continue to address S&D.

Chapter 4: Determinants, Manifestations and Consequences of Stigma and Discrimination

The main focus of this chapter is on the determinants and only briefly mentions the manifestations and consequences of S&D in leprosy and HIV/AIDS. The determinants that are focused on are social cultural beliefs and misconceptions, socio-economic factors, health services, gender, legislation and human rights and the role of the media.

There are circumstances in which it does not seem to be clear what leads to S&D the determinants or the consequences.

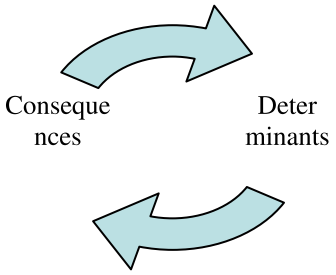


Figure 1: Vicious circle of multidirectional Stigmatization and Discrimination (S&D)

4.1 Social cultural beliefs and misconceptions

4.1.1 Leprosy

In order to understand more of the social-cultural aspects related to leprosy we need to look at the concepts of disease, illness and sickness. The disease of leprosy is the biomedical perception. The illness of leprosy is self perception. The sickness of leprosy is the social perception. The health professional will perceive the disease by its physical symptoms. Illness is experienced by the patient and shaped by the social cultural influences. Sickness is perceived by society and may be expressed as social stigma (Stigter et al, 2000). Jopling (1991) stated it nicely: “The problem with leprosy is not what the disease ***is*****,** but what the people believe it to be”. The stigma against leprosy is partly due to traditional beliefs and misconceptions about the causes and transmissions of leprosy. A common belief is that leprosy is hereditary. Other beliefs and theories among various cultures are bad blood; bad spirits/curses, curse of God, supernatural causes; touch, sweat; water, air, defecation; food/breaking of food taboos; sex with prostitutes and therefore a punishment for moral lapse; sexual contact in the open air, sex with a woman during her monthly period; a spell/witchcraft/evil magic; disturbing the djinn (ghosts); direct punishment by God for one’s sins or evil character; getting the disease as a consequence for one’s own irresponsible actions. (Reddy et al, 1985; Jopling, 1991; Rao et al, 1996; Bekri et al, 1998; Scott, 2000; Stigter et al, 2000; Idawani, undated p.52; Kaur et al, 2002; Nicholls et al, 2003; Wong, 2004; Barkataki et al, 2006; Try, 2006) Other misconceptions and beliefs are that leprosy is highly contagious, incurable and disabling (Rao et al, 1996; Stigter et al, 2000; Kaur et al, 2002; Wong, 2004; White, 2007). Because of these beliefs, some members of the community feel justified discriminating people affected by leprosy and, as a result, the latter may delay

seeking help. Negative attitudes may also affect adherence to treatment. These attitudes have an effect on the psychological wellbeing of the leprosy-affected person.
Sometimes the translation of the word leprosy in a local language can have a totally different meaning. The meaning of the word for leprosy in Amharic is ‘to cut’ or ‘mutilate’. So the Amharic word has a negative connotation in relation to the early signs of leprosy. People think that deformities are the first signs for leprosy (Bekri et al, 1998). In Nepal, the word ‘khori’ is used for a leprosy-affected person, which means ‘curse’. This implies that it is not only through a curse that the disease is brought on a person, but the person affected by leprosy him or herself ***is*** the curse. Due to the supernatural connotation of curses, people in the community try to avoid contact with people who are believed to be a curse. The community feels it is justified to exclude those affected by leprosy (Cross, 2006).

The way people view their illness and healing process needs to be seen and understood in the context of that culture (Opala & Boillot, 1996).

In many cultures the people will go to the traditional healers before going to a medical doctor, often because they believe witchcraft or other supernatural causes are involved (Opala & Boillot, 1996; Scott, 2000; Idawani et al, undated).

Biblical references regarding leprosy are always taken from the Old Testament, which in some passages refers to leprosy as a punishment for sins (Jopling, 1991; Awofeso, 2005). In Brazil, some of the Catholic churches still preach that Hansen’s disease (leprosy) is a shameful and spiritually polluted condition. Evangelicals in Brazil suggest that complicated diseases be may the result of demon possession and can only be cured through prayer.
“These forms of societal stigma may affect treatment-seeking behaviour, adherence and overall patient experience” (White, 2007).

Leprosy is not mentioned in the Qu’ran. To Muslims, all events including diseases are caused by the will of God. But diseases should not be seen as a punishment by God for sins. Most beliefs, practices and attitudes in Islamic countries originate from indigenous tradition (Haidar, 1984). Hindus often view deformity as divine punishment for sin in a previous life. Parents examine the families of a prospective bride or groom for their children for the presence of conditions like leprosy or mental illness, which makes it very difficult for a person affected by leprosy to get married.

4.1.2 HIV/AIDS

Misconceptions and beliefs about the transmission of HIV still exist, such as getting HIV from kissing; by getting bitten by mosquitoes; from using public toilets; from sharing meals with an HIV positive person and from shaking hands; through the air; spread through women; moral judgement, people who got AIDS did something to deserve it; and HIV associated with witchcraft and curses (Aggleton, 2000; Ogden et al, 2005; PHR report, 2007). These cultural beliefs are determinants for stigmatization, discrimination and denial. People living with HIV who know these beliefs may conceal their status and experience emotional stress as a result. Beliefs in relation to prevention include prayer and use of traditional medicines (Physicians for Human Rights (PHR) report, 2007). A study in Botswana and Swaziland showed that the knowledge of how HIV is transmitted and how infection can be prevented was high. However, the frequency of use of condoms was low in both countries. Misconceptions, negative attitudes and myths about the condom and its use still prevail. For example, men think the condom is not 100% safe, that there are worms in condoms or that condoms have

HIV in it (PHR, 2007 p.55 & p.90). These beliefs will undermine willingness to take precautions and increase the risk of infection and the prevalence of HIV.
In the beginning of the AIDS epidemic the metaphors used in relation to the disease have exacerbated fear and denial and lead to stigmatization and discrimination. HIV was portrayed as death, horror, punishment, guilt, shame, 'otherness', and the fight against HIV/AIDS as war. These metaphors built on pre-existing fears about contagion and disease. In addition to that, these metaphors referred to groups of people who, because of their behaviour or racial background, were already stigmatized, e.g. homosexuals, sex workers, drug users and other marginalised groups (Gilmore et al, 1994; Goldin, 1994; Devine et al, 1999; Aggleton, 2000).
Most of the time, HIV/AIDS reinforces existing types of stigma. However, in the Dai culture in China it does not. The Dai people perceive HIV/AIDS as a "junkies" disease. Drug abuse is a great problem among them and is feared and people who engaged in it are stigmatised. However, the diagnosis of HIV does not seem to increase stigma and discrimination. HIV is perceived by the community as less fearsome than drug abuse. Becoming infected means the end of addiction. Family members and medical staff take care and support the PLWHA and, in doing so, will earn merit and guarantee happiness in the next life (Deng et al, 2007). What we see here seems to be a shift in response to deviance. Dijker and Koomen (2006) have discussed the response to active and passive deviance. Active deviance is seen as intentional and controllable. Drug use is a norm violating act which is an active deviance. Anger and punishing behaviour is aroused. Passive deviance is seen as uncontrollable as in most illnesses and disabilities. It arouses tenderness, protection and pity. The person infected with HIV here is cared for and supported.

In some African countries, the beliefs about the causes of STDs and AIDS are different than what is offered by biomedicine. STDs and AIDS are interpreted as indigenous and supernatural in origin. The power of witches eat the 'soul' out of a PLWA which causes the wasting. Because these conditions are indigenous and the supernatural is involved, only the traditional healer can treat people. Some cultures make a distinction between indigenous and foreign diseases. The former need to be treated by the traditional healer and the latter can be treated by Western medicine (Goldin, 1994). It is clear that this affects public health efforts to control and prevent diseases. It also affects help seeking behaviour.

The way some church leaders have responded to the HIV epidemic has been stigmatizing. PLWHA have been blamed and AIDS has been seen as a divine punishment for promiscuous behaviour. It will undermine help seeking behaviour in relation to VCT and treatment and will worsen the experience for PLWHA themselves (Gilmore, 1994; Monico, 2001).

4.2 Socio-economic factors

4.2.1 Leprosy

Socio-economic status is recognized as a major determinant of exposure to disease risk (Le Grand, 1997). Some other conditions associated with that are poor housing, lack of clean water and lack of sanitation. Also associated is lack of nutrition, which undermines the immune system and cause people to be more vulnerable to get sick. Leprosy is seen as a disease of the poor. Many leprosy-affected people have no formal or limited education and that limits them in their choice of jobs (Withington et al, 2003). Kaur and van Brakel (2002) described the way leprosy-affected people ended up in beggary. Leprosy and the social stigma attached to the disease had changed their lives completely. They had a job before, lost it because they got leprosy and were discriminated by the community. Verbal abuse and being forbidden to use common places in the community made life unbearable, causing them to leave their villages. Sometimes a person left home him/herself in order not to be in the way so his/her siblings had a chance to get married. This kind of situation gave a lot of emotional stress and anxiety. Others were rejected by their families. Their physical impairments had often worsened, which restricted them in earning a living. Some beggars live in slum areas. Many of their children do not go to school, but get involved in beggary (Barrett, 2005). The effects of poverty can be more severe on women. The stigma of leprosy is often compounded by gender inequalities and lack of protection. Women may experience physical and sexual abuse and at times they are forced into prostitution (Barrett, 2005).

Employers may dismiss an employee affected by leprosy out of fear of getting the disease and of losing customers in their businesses. Another reason for dismissing is that people with impairments due to leprosy may not be able to perform well on the job (Calcraft, 2006; Scott, 2000). However, there have been occasions where the employers could be persuaded to let the leprosy-affected persons continue to work despite their impairments. However, their income was reduced (Reddy et al, 1985).

For a leprosy-affected person not being able to work will mean to become more dependent on the family and if resources are scarce this will give a lot of tension. The feeling of uselessness because of not being able to contribute to the income of the family will lead to loss of identity and self-worth.

4.2.2 HIV/AIDS

In countries which are poor, HIV/AIDS is an extra burden. To have a PLWHA in the family is a burden. Most of the time income is already scarce and the PLWHA will need care and treatment for a long time, often supplemented with special food. This is very difficult as there is hardly enough food for the family. The caregiver is unable to work when the PLWHA is very sick, because the caring takes up a lot of time and that means loss of income. The burden on a caregiver or family is not only financial but emotional as well. This can lead to scolding of the PLWHA, which is very hurtful and discriminatory. Sometimes the women engage in sex work in order to pay for the treatment of their husbands. If they are not already infected, it will put them at risk of becoming infected. In certain cultures it is the custom that if a husband dies, the family of the husband may take what ever property is there, leaving the wife and children to take care of themselves (Bond, 2003). The access to services may be limited due to high transport costs that will affect the adherence to treatment Other people living with HIV/AIDS, like street kids and sex workers, are worse off. Being marginalised, powerless and vulnerable, they do not have anything and are overlooked. If you are poor, nobody will take care. (Bond, 2003). Being poor is already a stigmatising condition, but with HIV/AIDS added, it is worse. It becomes a vicious circle from where it is difficult to escape.

Many people lost their job because of their HIV-positive status. For those who were selling food the number of customers would drop especially after symptoms of HIV-related diseases became visible (Ogden et al, 2005). For a person living with HIV job opportunities may often be reduced because of his/her condition resulting in no income, which can lead to poverty.

4.3 Health Services

Under the health services we will have a look at the accessibility of services, delivery of services by health professionals and the attitude of health professionals towards people affected by leprosy and HIV/AIDS.

4.3.1 Leprosy

Reports reveal different situations in which the people affected by leprosy are stigmatised and discriminated by the health care system. In Guyana, a study was conducted in two hospitals with the aim to assess attitude, knowledge and ideas of the disease amongst health care workers. A self-completing questionnaire was distributed and 185 questionnaires returned. It was found that half of the health care workers did not know leprosy is curable and many still thought it could be transmitted through touch (Briden and Maguire, 2003). A study amongst nursing students in Nigeria revealed that they thought leprosy is a highly contagious disease and that deformities are inevitable in leprosy (Awofeso, 1992). Scott (2000) documented that fear of leprosy still exists among many health workers in general hospitals in South Africa. These misconceptions often lead to negative attitudes towards people affected by leprosy.

The organization of the health services will affect the accessibility and the utilisation of the services. In eastern Nepal a qualitative study was conducted to explore the quality of services. Heijnders (2004) found that privacy during examination was a problem especially for the women. Distribution of medication could only happen on a certain day before a certain time. Sometimes people were blamed for not being motivated to take their treatment. If leprosy-affected people would come late, the health worker would refuse to give the medication. The attitude of the health worker was very different to a rich leprosy-affected person than to a poor person. Some people continued their medication despite the negative treatment they received, while others defaulted (Heijnders, 2004).

4.3.2 HIV/AIDS

Health professionals are a key resource in the care, treatment and support for PLWHAs. However PLWHAs and their families have experienced negative attitudes and practices towards them by health professionals. A study in four districts hospitals and eight rural health units in Kenya showed that lack of knowledge and lack of universal precautions to protect health workers from HIV, such as gloves, adequate needle disposal and post-exposure prophylaxis (PEP), lead to stigmatising attitudes among health workers, because they were afraid to get infected (Nyblade et al, 2003; Ogden et al, 2005; Mukasa, 2006). In some other countries, nursing staff still made inappropriate comments like ‘wasting medicines giving it to those who are HIV-positive’ (Musaka, 2006; Nyblade et al, 2003).

Every patient has the right to treatment and care, however examples of discrimination have been reported from many countries, e.g. Ethiopia, where a PLWH was denied dental care and asked to leave the clinic (Ogden et al, 2005) and India, where a patient was transferred from a private hospital to a government hospital after the blood results showed HIV- positive. Patients who are HIV-positive may receive different treatment in stead off injections they will receive tablets (Aggleton, 2000). Some default because of health professionals attitude (Morrison, 2006), others still continue despite discriminating attitudes (Pinyajeerapat, 2006).

Every patient has a right to be respected whatever his condition. However, it does occur in some countries that at times patients with HIV-positive status are left waiting for a long time before they receive the care they need (Ogden et al, 2005; CPA, 2005). Bond et al (2003) reported that the quality of care given to a PLWHA was influenced by the status of that person within the community.

Testing without consent and revealing a patients medical condition to a relative or others is unethical. Disclosure of results of HIV test is common among health workers as was reported at the International AIDS Conference in 2006 (Aggleton, 2000; Mukasa, 2006).

The way services are organised will affect the accessibility to care and utilisation of the services. Results of a survey in Burundi showed that people thought the programmes targeting PLWHAs contributed to stigma. People did not feel comfortable to access the services as other people who saw them going for VCT assumed they were HIV positive and stigmatised them (ACORD, 2004 p.34). TB patients in South Africa felt they were pressured to take the HIV test (Daftary et al, 2007; PHR report, 2007). In Malawi, long waiting time before the HIV-test results were given caused a lot of worry and anxiety for the clients (MANET p.4, 2003).

From the above, it is evident that the different experiences of discrimination and stigmatisation will lead to undermining the uptake of care, adherence to treatment and the access to and utilisation of services (e.g. VCT). Even the anticipation of such stigma and discrimination may lead to concealment.

4.4 Gender

4.4.1 Leprosy

Gender inequalities in health have a significant impact on women's health (le Grand, 1997; Shieh et al, 2006). Gender is not only related to sex but encompasses the social, cultural and economical aspects designated to men and women by social structures (le Grand, 1997). In many developing countries the women bear the responsibilities for the family.
Women are often already disadvantaged because of illiteracy, less education and no power to make decisions. It is the husband or the mother in law (India), who make the decisions.
Their actual situation is characterised by dependency and often discrimination. In India, in most situations both men and women are negatively affected by leprosy in the area of cooking, eating together, touching others, sleeping together in one room, using common articles, mixing with other members (Rao et al, 1996; Zodpey et al, 2000). It is especially hard on the women not being allowed to touch their children or to be touched by them. They feel rejected. Another matter, which is strongly felt by women is the fact that they are often not allowed to participate in domestic work. That makes them feel useless. The social impact on women is worse than for men. Women are more isolated (Rao et al, 1996; Zodpey et al, 2000). These restrictions result in greater morbidity, depression and anxiety and affect their treatment. Women may delay seeking treatment if they suspect they have leprosy out of fear of being abandoned, anticipating less chances of getting married or that it may affect their role in the household. Other factors like lack of money, time, mobility and traditional customs are contributing to the delay in health seeking and adherence to treatment. In many communities the women already have a low status and they will be treated differently by the members in the family and the wider society. Several investigators reported that women were insulted by family members. Men received more support of their spouses and family than women (Rao et al, 1996; Le Grand, 1997; Zodpey et al, 2000).

In Eastern Nepal, a similar difference in social status was expected between men and women, however this was not the case. Attitudes and behaviour towards people affected by leprosy was associated with the visibility of the disease only and not with gender. The place women had in society was not affected (Stigter et al, 2000). In Aceh, Western Indonesia, men and women affected by leprosy are treated equally. Men have the same problems as women in getting married (Idawani et al, undated). In South East Nepal, men also have problems with getting married. A man was abandoned by his wife because her and even his family put so much pressure on her to divorce him. Some women experienced the same; the influence from others was so strong that their husbands left them because they were pressured to do so (Try, 2006).

4.4.2 HIV/AIDS

Gender roles and relations influence the course and impact of the HIV/AIDS epidemic. The roles for men and women are assigned by society. Men are supposed to be masculine and women feminine. Both are at risk of becoming HIV infected. For the men the risk of HIV infection is primarily determined by their own proactive behaviour, whereas women's vulnerability to HIV infection can be beyond their control (Anderson et al, 2002). In Latin America men can have multiple partners which is regarded as 'macho', whereas in Uganda it gives social status. The peer pressure in some cultures is high on men as they are expected to be seen around with girls. They have to prove they are men. However, young women are expected to be virgins and when married they should be faithful to one partner. Women should keep up the moral (Aggleton, 2000; Monico et al, 2001; Anderson et al, 2002; PHR report 2007). In many developing countries, women are in a disadvantaged position due to lack of education and social, economic and legal rights within their culture. They have less access to information about HIV prevention and to HIV treatment once infected. They have no power to negotiate safe sex. Even when at risk of becoming infected by the spouse, they cannot refuse to have sex. Domestic violence seem to be more common in cultures where women are regarded to be property. Rape is seen as a moral offence rather than an offence against a person (PHR report, 2007). Economic dependence may lead women to get engaged in unprotected sex in order to get financial support. The lack of power in negotiating sexual relations and the fear of losing their income drives women to continue in high risk behaviour. Once infected, they often experience stigmatisation and discrimination more severely than men and have to endure a lot of abuse (Ogden et al, 2005). Relatives strongly discourage HIV-positive women to have children. If they get pregnant they may be penalised by the family (Ogden et al, 2005). Men living with HIV/AIDS are more accepted by the family and the community than women (Aggleton, 2000). Sometimes the women are blamed by their in-laws to have infected their spouse. In some cases, wives were deserted by their spouses after they disclosed their HIV-positive status. For single HIV-positive people it is difficult to get married and sometimes they make a decision not to get married (Ogden et al, 2005). Women, who are HIV positive are considered to have failed morally. They are supposed to be healthy, caring for others and sexually pure. In case both husbands and wives are infected, family resources will be spent on the husbands' treatment (Anderson et al, 2002). Women are most likely the caregivers at home and carry most of the psychosocial and physical burden of care of PLWHA (Anderson et al, 2002). The women are double stigmatised and carry a double burden.

4.5 Legislation and human rights

4.5.1 Leprosy

There are still laws in India that are stigmatising and discriminating to leprosy affected people. The Hindu Marriage Act of 1955 allows separation and divorce on grounds of a spouse suffering from leprosy. Similar provision can be found in the Muslim Marriage Act 1939, the Christian Marriage Act and the Special Marriage Act 1954 (Jopling, 1991; Kaur et al, 1994). In December 2005, people affected by leprosy presented the Delhi Declaration during the National Conference on "Integration & Empowerment of Persons Affected by Leprosy". As participants, they stated their dignity and their right to be involved in making decisions related to their daily lives and future. Through these recommendations they wanted to counter the effects of stigma and discrimination they and their families had experienced, in order to promote quality of life. One of the recommendations was that "all discriminatory laws, including the law that facilitates divorce due to leprosy should be repealed". This refers to the above mentioned laws (Leprosy-affected people, 2005) The conference was good for all the people affected by leprosy to realize they are not alone and that together they can demand respect and claim equal treatment which is a right for everyone.

In August 2005, the United Nations Sub-Commission on Promotion and Protection of Human Rights passed a resolution titled "Discrimination against leprosy victims and their families". Some of the aspects of the resolution are as follows: the request that the Governments forbid discrimination of any type against people affected by leprosy and their families and that the Governments provide appropriate remedies to people affected by leprosy who had been forced to live in colonies or leprosaria in the past. In the beginning of this year, the residents of Lo Sheng, a former leprosarium in Taiwan, were told by the government to move out by April as the land belonging to Lo Sheng was going to be used for a station. One of the residents spoke up about the unreasonableness of this decision. The people had been segregated for public health reasons and now again they had to move because of a public construction. Sympathisers in Taiwan were demonstrating against the government ruling, and in the USA, people affected by leprosy marched the streets of New York in support of the people affected by leprosy in Taiwan. Many leprosy-affected people have become members of IDEA. IDEA stands for 'International Association for Integration, Dignity and Economic Advancement' and represents the interests of persons affected by leprosy around the world (ILEP, 2007). The people of Lo Sheng made their voices heard with the support of the members of IDEA, as well as the members of society in Taiwan in presenting their case.

4.5.2 HIV/AIDS

In South Asia, because of discrimination, PLWHA are unfairly and unjustly treated (Shelhore and Rana, 2001). It does not only affect them but their families and communities as well. Discrimination of PLWHA has also consequences for public health programmes and effect the prevention and control of the HIV/AIDS epidemic. International Guidelines on HIV/AIDS and Human Rights have been issued by the Office of the High Commissioner of Human Rights (OHCHR) (UNAIDS, 2006). Some countries like China and Malawi still do not have specific legislation prohibiting discrimination against PLWHA in institutions like schools, place of employment and health services (HRW, 2005 p.53; Manet, 2003 p.38).

The participation and involvement of PLWHA at international and national level has success stories. An advocacy campaign took place with the involvement of PLWHA, in order to influence the contents of the Declaration of Commitment on HIV/AIDS adopted by the United Nations General Assembly in 2001 (Garmaise, 2003). In Australia, the National Association of PLWHA (NAPWA) submitted recommendations to the government to reform HIV-related laws, so that the laws would be more consistent in all the States and Territories. They also recommended reform of the migration law, which is still discriminating towards PLWHA (NAPWA, 2002). In Mexico, successful advocacy took place by PLWHA with as a result the reform of 17 laws including the State Law on Human Rights in the Yacatán State (POLICY project, 2001). Partnership of Policy Project Kenya and Kenya National

Commission on Human Rights in addressing the problem of widows inheritance of property resulted in the reinstatement of many women to their property through interventions by elders (Nyong'o & Ongalo, 2005). "In India, lawyers, activists and NGOs are working towards securing social justice and taking legal action against offenders" (Selhore and Rana, 2001). A government hospital in Delhi refused the surgical treatment of a PLWHA. Public Interest Litigation (PIL) was filed in the Supreme Court with the help of an NGO. Before the court hearing could take place the PLWHA was admitted and treated (Shelhore and Rana, 2001).
In Costa Rica, in the late nineties, a small group of PLWHA had been negotiating with the government about provision of ART for PLWHA. The government's excuse had been that it was too expensive to provide. The cause was taken to the Supreme Court and won its support with as result PLWHA receiving combination therapy (Aggleton et al, 2003).

4.6 Role of the media

Over the past 30 years, it has been demonstrated through research that the mass media are of great influence on belief systems. People seem to form their attitudes on what they see through news reports, television programmes and films (WHO, 2004). With this in mind we look at the role of the media in disseminating messages about leprosy and HIV/AIDS.

4.6.1 Leprosy

Linguistic terms describe not only the disease but a deeper meaning attached by socio-cultural perceptions. For example, "Tai Ge", which is the Taiwanese term for leprosy, describes the open and ulcerative wounds as unclean, filthy, and foul. The person affected by the disease is stereotyped as lowly, untouchable, unwelcome, unclean and contagious (Shieh et al, 2006)
In India derogatory words like leper, maharogi and kori are still used which is inappropriate and stigmatising (Nippon foundation, 2006). In Brazil, the use of "lepra" which means dog mange is discouraged by law (Wong, 2004). For decades the words leprosy, leper and leprous have been used by writers, journalists and even politicians to imply something evil, degrading or immoral (Jopling, 1991; Frist, 2000; Awofeso, 2005; Sasakawa, 2006). In the past leprosy was often depicted in a negative way through pictures of people with severe deformities. This is changing and different countries have been using mass media to change the image of leprosy by showing pictures of leprosy patients without visible impairments and by doing this stressing the result of early detection and treatment (Wong, 2004; van Brakel & Gopal, 1999)

4.6.2 HIV/AIDS

Language is a powerful means to communicate. In many countries, derogatory words and phrases have been used or are still used to describe HIV infection and AIDS and the people living with HIV/AIDS. Words with negative connotations are used in daily conversations and in gossip, as well in the media. However, people are often not aware of doing so and that those words can be stigmatising and have a damaging impact. People's perception about PLWHA as useless, unproductive and a burden to those around them is reinforced through the use of metaphors and euphemisms for death and physical appearance and phrases that highlight the deviant behaviour in connection with HIV-infected people (Aggleton et al, 2000 p.10; Aggleton et al, 2003 p.4; Nyblade et al, 2003 p.30, Tessa, HIV/AIDS and African Languages, undated).

Sometimes journalists ask PLWHA inappropriate questions, like: "Who infected you?" or "Since when have you been positive?" The PLWHAs felt as well that in order to have a newsworthy report the journalists wrote only certain aspects of the stories told by PLWHA (Siyam'kela, 2003).

The International Federation for journalists conducted research in three Asian countries, India, Cambodia and Philippines and three African countries Nigeria, Zambia and South Africa. The research took place between November 2005 and March 2006. Among the different aspects researched were quality of articles and appropriateness of language. In almost all countries it was felt that there was an improvement of the quality of the articles. However, there was still derogatory language used and words like "aids sufferer", "aids patient" and "aids scare". Further, the report showed that in Africa PLWHA were more likely to be used as sources than in Asia (Pollard and Walters, 2006). This is probably due to the fact that the HIV/AIDS epidemic in Africa is general and in Asia more concentrated and among groups with higher risk of HIV exposure. Especially in Sub Saharan Africa, many people have lost a family member or a friend or a colleague because of AIDS, so directly or indirectly, people have been affected. It has not reached that stage yet in Asia.

In this chapter the determinants, manifestations and consequences of stigma have been described. Table 1 p.23 shows the comparison of the determinants of stigma in leprosy and HIV/AIDS. Amongst the determinants we find beliefs, misconceptions, religious teaching, moral judgement, supernatural involvement, progressing of the disease, gender inequalities, knowledge, attitudes and practices of health workers, organization of programmes, discriminatory laws and use of inappropriate information and images by the media. The comparison of the consequences on the individual and/or community and on the public health programme is shown in Table 2 p.24. In that table we see the consequences of stigma on interpersonal relationships, marriage, education, employment, mobility, participation, access to treatment and care, increased morbidity and increased burden on health services.

The different forms of stigma show in what ways leprosy-affected people and PLWHA are effected. The forms of stigma have been *physical* - isolation and violence; *social* - isolation and loss of identity/role; language/verbal - taunting, expression of blame, labelling and use of derogatory words; *institutional* – loss of livelihood, differential treatment in health care settings, legislation and media.

From the review we see that the stigmatizers of leprosy affected people and PLWHA are the community, religious leaders, employers, other workers, health workers, in-laws and especially in HIV/AIDS the caregiver. The stigmatising attitude of the caregiver was compounded by poverty (4.2.2. HIV/AIDS p.16).

Table 1: Comparison of the determinants of stigma in leprosy and HIV/AIDS

Determinants of stigma	**Leprosy**	**HIV/AIDS**
Socio-cultural: Traditional beliefs & misconceptions		
Common cause: touch, water,	X	X
Witchcraft and curses, supernatural	X	X
Sexually-transmitted disease		X
(Assumed) promiscuity and other risk behaviour		X
Moral judgement on sin	X	X
Punishment from God	X	X
Condoms cause disease		X
Disease related to drug abuse		X
Disease: highly contagious, incurable, disabling	X	X
Negative words/terms used to describe disease or person affected	X	X
Religious teaching	X	X
Socio-economic:		
Progressing of the disease	X	X
Gender:		
Less education, illiteracy	X	X
No power to make decisions	X	X
Lack of resources like money/dependency	X	X
Social, economic & legal rights	X	X
Health services:		
Knowledge of health workers	X	X
Attitude of health workers	X	X
Inappropriate comments	X	X
Preventive measures are necessary		X
Lack of confidentiality when disseminating information about disease/test result	X	X
Inadequate counselling		X
Testing without consent/breaching confidentiality		X
Non-attendance of hospital staff to bed patient		X
Denial treatment/referral to other hospital	X	X
Inequity of care	X	X
Organization of services: opening time/waiting time	X	X
Vertical programme/special services	X	X
Law, legislation		
Existence of discriminatory laws	X	X
Media		
Use of derogatory words	X	X
Lack of appropriate information	X	X

Table 2: Comparison of the consequences of stigma on individuals, community and public health programmes and interventions

Consequences on the individual and/or community	**Leprosy**	**HIV/AIDS**
Anxiety and emotional stress	X	X
Problems in getting married	X	X
Problems for sibling to get married	X	
Problem with employment or in getting a job or loss of property	X	X
Reduced educational opportunities for the children	X	X
Problems in social relationships	X	X
Concealment of disease	X	X
Poorer prognosis	X	X
Lack of motivation to continue treatment	X	X
Motivation to continue treatment	X	X
Loss of childbearing opportunity		X
Increased gender inequalities	X	X
Isolation	X	X
Increased disability	X	X
Psychological and psychiatric morbidity	X	X
Increased inequities between those affected and those who are not	X	X
Participation restriction e.g. economic dependency	X	X
Empowerment e.g. positive self image and confidence developed in resistance to discrimination	X	X
Consequences on public health programmes and interventions		
Delay in presentation for treatment	X	X
Poorer treatment prognosis	X	X
Continued transmission	X	X
Failure of prevention		X
Poor adherence and default	X	X
Risk of drug resistance	X	X
Increased burden on the health services	X	X
Poor image of the public health programme	X	X

Chapter 5: Examples of good practices

This chapter will briefly describe examples of best practices used in addressing S&D in leprosy and HIV/AIDS from selected countries.

5.1 Examples of good practices

5.1.1 Leprosy

Community Health Education has the aim to inform the community about the facts about leprosy in order to increase awareness and reduce stigma. However, the results may differ on the impact regarding attitudes. Some authors considered HE successful in reducing leprosy-related stigma (Arole et al, 2002; Croft & Croft, 1999) whereas others felt the impact on the attitude towards leprosy-affected people had not changed much (Opala & Boillot, 1996).

In Malaysia, a culture-specific health education programme showed increased acceptance of the leprosy messages and improved knowledge and attitude towards leprosy. The message had incorporated the local cultural beliefs and taken peoples sensitivities, values and beliefs into consideration. (Wong and Subramaniam, 2002).

Arole et al (2002) did a comparative study of an integrated versus vertical leprosy programme in Maharashtra, India. It showed clearly the better awareness about leprosy by the family and the community members of the integrated approach. The grassroots workers and other community members disseminated the facts about leprosy to the wider community. In the vertical programme the family and community members still had various ideas about leprosy. Stigma among community members and self-stigma among people affected by leprosy was high in the vertical approach.

Group counselling – empowerment of leprosy-affected people - was proposed as being a way to reduce leprosy-related stigma. A pilot study was conducted in Nepal. The counselling had a positive effect on the leprosy-affected people. However, the authors felt that counselling alone would not eradicate stigma and that additional interventions like economic rehabilitation and health education was necessary (Floyd-Richard and Gurung, 2000).

Stigma Elimination Programme (STEP) in Nepal – empowerment of leprosy-affected people - 10 leprosy-affected persons were selected to facilitate Self-Care Groups. They got training in self-care and applied it themselves. A facilitators training followed and they were encouraged to start Self-Care Groups in their villages. The establishment of the groups went well and they developed into Self-Help Groups (SHGs). The SHGs included other marginalised and disadvantaged people. The SHGs have taken on different projects benefiting the communities. Another aspect is that the SHGs have a close relationship with local Health Post staff. Some of the groups have been involved in tracing defaulters and case detection activities. Many local people have consulted them first if leprosy was suspected. The SHGs have a positive impact on the development in their communities. Through the STEP, the participation restriction of leprosy-affected people in the target villages has been greatly reduced. The self-esteem and confidence of the leprosy-affected people has increased considerable (Cross et al, 2005).

Bangladesh: Socio-economic rehabilitation (SER) project – through vocational training courses e.g., in sewing, tailoring water-pump maintenance and bicycle repairs or loans. Men and women, who had followed the courses felt confident in going back to their villages. They would be able to work and that would give them an improved status in the community. For the women it would mean more chances in getting married (Plagerson, 2005).

Participation scale - the participation scale is a tool to measure the level of participation in the community of people affected by leprosy, disability or other stigmatised conditions and measure the impact of stigma on social life. It is relevant to use for monitoring the impact of stigma reduction interventions (PSDT, 2005)

5.1.2 HIV/AIDS

Information-based approaches: Information was provided through peer education, pamphlets, lectures or workshops resulting in increased positive attitude towards PLWHA in Jamaica and Israel (Brown et al, 2001 p.10)

The Aids Support Organization (TASO) had conducted a study among 730 HIV-positive clients in different hospitals in order to evaluate the counselling services during 1993 till 1994. Counselling was given to clients and families to help them cope with HIV and AIDS. The results showed high disclosure of HIV status to another person (90%) by the PLWHA and high acceptance of the family (79%) and community (76%) of the PLWHA. As a result the hospital managers provided more space for them and encouraged doctors to refer clients to them (Kaleeba et al, 1997)

In Zambia, anti-AIDS clubs are established as an intervention to reduce stigma and discrimination among young people. The young people learn about their sexuality, their risk perception as well as their attitudes towards PLWHA. Out of the 785 young people involved in the programme 524 felt comfortable to care for a PLWHA. The regular visits of the young caregivers to the PLWHA and their families did not only make them understand better the needs of the PLWHA but it increased the support of the community as well and the PLWHA felt the difference in attitude towards them and their families (Population Council, 2002).

ACORD – In Uganda - conducted awareness workshops for politicians, civil servants, NGOs and FBO in nine sub-districts and two districts headquarters. The workshops addressed different topics including the rights of the PLWHA and a review of the government's policies on HIV/AIDS related issues. Through the sessions the participants became aware of their own stigmatising and discriminating attitudes and behaviours. It made them realize that the rights of PLWHA had been overlooked. Policies and laws protecting PLWHA needed to be put into place and enforced by the right authorities (ACORD, 2006 p.33)

In India – In order to provide PLWHA friendly services, a participatory approach was used by involving hospital managers in developing policies on matters such as pre- and post test counselling, confidentiality and the importance of informed consent. Training of health care workers (HCWs) took place in order to improve understanding of HIV/AIDS transmission and procedures for infection control and to introduce concepts of confidentiality, patients rights, VCT, and support. There was an improvement in knowledge, attitude and practices by HCWs however, there were still misconceptions on the transmission of HIV amongst them (Mahendra et al, 2006).

Uganda- Mbuya outreach – Holistic approach of HIV management. The mission of the

Mbuya parish is to provide medical, social, emotional and spiritual support to PLWHA in order to improve the quality of life of those affected and to prevent further spread of HIV/AIDS to the community. The parish serves a catchment area of 60,000 people and cares for 1,500 PLWHA by a team of 230 volunteers of whom 77% are clients themselves. There are 11 different health and social programmes e.g., VCT, ART, food programme, vocational school and micro finance. By their actions, the organization has demonstrated that they do not ostracize members of the parish because of there HIV/AIDS status. PLWHA are given new hope, skills and can live an independent life (Eric, 2005).

Influential people- Dr. Kaunda, former president of Zambia publicly announced that his son died of AIDS in the 1980s. Ever since that time he promoted openness about HIV/AIDS and abstinence, mutual fidelity, condom use, voluntary testing and counselling and compassion for PLWHA. He has been campaigning in TV and radio spots against stigma towards HIV/AIDS involving other key leaders in Zambian society like the Ministry of Health, traditional Chiefs, PLWHA and music stars. March 2002 at the time of the opening of the New Start Centre in Lusaka, a place for VCT, Dr. Kaunda took a public HIV test. By October 2003, 11,000 people had come for counselling and testing at the centre (USAID, 2003).

The Toolkit for action consists of modules in 'Understanding and challenging HIV stigma' There are twelve modules and each module addresses a specific topic like: Moving to action; Naming the problem; More understanding, less fear; Sex, morality, shame and blame; Family and stigma; Home-based care and stigma; Coping with stigma; Treatment and stigma; MSM and stigma; Children and stigma; Young people and stigma and a Picture booklet containing general- and rights pictures. This educational material was written by HIV trainers for the use of educating community leaders or organised groups. The purpose is to raise awareness and promote practical action to challenge HIV S&D (IHAA, 2007).

HIV/AIDS stigma indicators - set of indicators focussing on internal and external stigma (Siyam'kela, 2003; Nyblade & MacQuarrie, 2006) in order to evaluate stigma reduction interventions.

5.2 What can be learned from the HIV approaches that can be used for leprosy?

The examples of best practices show that leprosy approaches have been focusing on community health education (HE) programmes with sometimes the use of cultural sensitive health messages, group counselling and Self-Care groups through empowerment of leprosy affected people, SER and integrated leprosy programme as stigma reduction interventions. Counselling and empowerment of leprosy-affected people has started quite late. What is seen in the HIV approaches is that the counselling has been proposed from the early stages of the epidemic. Another aspect is that the PLWHA have been active and involved in the prevention of HIV/AIDS such as TASO. A strong point is that through the different approaches mentioned above many people have been reached at different levels in society from the community to political leaders, from formal to informal health care providers including FBO and NGOs. We see also a strong involvement of the community including FBO in taking care and giving support to the PLWHA.

In suggesting additional interventions for reducing stigma in leprosy it will be good to provide individual counselling, to have greater participation of leprosy-affected people in all activities, to have a stronger involvement of the community and civil society and look into the feasibility of adapting the 'Toolkit for action' for educating community leaders about S&D in leprosy. The aim should be a combination of institutional and community based approaches.

Chapter 6: Discussion and Conclusion

The review reveals that the development of the stigmatising process (see 3.3.2 p.9&10) and the impact of stigma is similar in leprosy and HIV/AIDS, in different countries, despite cultural differences and condition specifics. Stigma affects interpersonal relationships, marriage, education, employment, mobility, participation in social gatherings and access to treatment and care and public health programmes (see Table 2 p.24). The importance of knowing that there are similarities is to see if there is common ground in using appropriate interventions in order to reduce S&D.

Stigma is not a static attribute but a **dynamic process**. We can see from the research done that it can start with an individual approach, defining stigma as an undesirable or discrediting attribute. The person who possesses the attribute is labelled, which can change the way the person views him or herself and the way s/he is viewed by society. The attitudes and responses by society lead to discrimination, and in the one affected, it can lead to internalized stigma. We tend to identify and categorize different people. That in itself is not wrong. But it is the decision of which difference is more valuable and that linked to stereotyping is what creates the way to stigmatising and discrimination. We see that the ways to creating stigma, discrimination, self stigma and self-discrimination are similar (see 3.3.2 Public and self stigma p.9&10). However, the ways to combating stigma, discrimination, self stigma and self-discrimination will be different. In addressing **S&D**, the focus will be on making people aware of their feelings of fear and anger. Why do they feel like that? Are these emotions based on reality and are they justified? By **self stigma and self discrimination** we see how important the emotional response of the individual is. Does s/he agree with the negative stereotypes and comply to the perceived threat of stigma and view oneself poorly or does s/he oppose the negative evaluation that may result in a positive self-perception? Acceptance by the family and community of the condition of the leprosy affected person or the PLWHA can be a help to the affected person in the process of overcoming stigma. However, from personal experience it does not seem to be enough. Acceptance by the individual of his or her condition is necessary as well (see under Internalised stigma p.10). The mind seems to be a powerful tool and negative thoughts dwelt on can have a destructive affect on the outlook of life of that person.

Jacoby (1994) mentioned that **felt stigma** was a product of **stigma couching** by key individuals such as parents. What can we think of this 'stigma couching'? Most likely, it is the **overprotection** of parents towards their children with a certain condition.

According to social psychologist **stereotypes are learned**. If something is learned it must be possible to unlearn it. However, stigma is entrenched in society. It seems rather difficult to change negative attitudes and negative behaviour of people.

We look back at an **attribute of undesired difference** making those who possess it tainted and devaluated by society. From the examples Goffman mentioned (see pg. 9), we see that the impairment does not have to be visible and that it depends on the circumstances before it is revealed. As Dalal pointed out, it depends on interactions between a whole range of social, cultural and behavioural variables. The ICF acknowledges that every person at some point in time can experience some disability. If we take that to the extreme we can ask ourselves: "Who is normal?" and "Who defines what is normal?"

From the **concealment process** we can learn what triggers the onset of stigmatisation and discrimination and how the person affected tries to cope with it. Worsening of condition increases severity of S&D but improvement of condition reverses S&D and the person affected can regain his/her social position in the community. The concealment cycle gives an insight in what kind of interventions and resources are needed in order to deal with S&D appropriately.

We have seen S&D highlighted from **different perspectives** and each one contributes to a part of the overall picture of this dynamic phenomenon. The process is ongoing, shaped and re-shaped by societal interaction. In the context of social inequalities, dominant groups use stigma to gain power and exercise control over marginalised and stigmatised individuals and groups which can lead to unfair and unjust treatment of those individuals and groups. The comparison shows that these different processes take place in relation to both leprosy and HIV/AIDS and that these processes are similar even at different continents. However, there are some disease specific features as we see from the frame work of HIV/AIDS-related S&D to pre-existing sources of S&D by Parker and Aggleton. The only aspect of the framework applicable to leprosy is the low social class as a pre-existing stigmatised condition. Leprosy like HIV/AIDS is seen as a disease of the poor.

The **findings of the comparison of the determinants, manifestations and consequences** of stigma related to leprosy and HIV/AIDS show more similarities than differences.
The beliefs of common causes, the involvement of the supernatural, judgement, misconceptions and religious teachings still prevail in both diseases. With reference to religious teaching, in relation to leprosy Biblical references are always taken from the Old Testament speaking about punishment and never taken from the New Testament where healing and restoration to normal life takes place (Luke 17, v 14). Why is this? It looks like that people in holding on to a negative aspect, use it to make vulnerable people feel bad and in doing so, have power and control over someone. In relation to HIV/AIDS, there is the challenge to show compassion instead of condemnation to those who will need care for being sick with AIDS.

The **differences under socio-culture** that stand out are the once related to the nature of HIV infection e.g., sexually-transmitted disease, assumed promiscuity and other risk behaviour, disease related to drug abuse and condom as cause of the disease. This is not relevant in leprosy. Drug abuse is usually seen as a pre-existing stigmatised condition in relation to HIV/AIDS. However, a shift in response to deviance can be cultural influenced as we can see under 4.1.2 HIV/AIDS at p.15. The people who got AIDS as result of drug abuse were not double stigmatised and discriminated but taken care off by their families. Beliefs like condoms causing HIV will have as a result continuous risk behaviour with adverse affects on the prevention of HIV-infection and the promotion of condom use will have no effect. In leprosy, the assumption has been that the problem of stigma could be diminished through health education about leprosy. However, the cultural and traditional beliefs still prevail not only in leprosy but in HIV/AIDS as well. It seems that it is not enough to address the diseases from a biomedicine perspective alone.

The effect of S&D on **getting married** is a problem for the individual affected by leprosy and the PLWHA. But in leprosy we see that it can be a problem for siblings as well. This does occur in certain cultures like India and Nepal. However, I have never it come across in West Papua or the small Sunda Islands in Indonesia.

It is a **right to have children**. But S&D creates loss of childbearing opportunity for PLWHA. The fact is that the HIV virus can be transmitted from mother-to-child during pregnancy, delivery and breastfeeding. The risk of MTCT may be reduced through ARV treatment. However, the prevention of mother-to-child transmission (PMTCT) is not available everywhere. Counselling is necessary to look at the risks of getting pregnant when a woman is found HIV positive.

Deterioration of the conditions of the leprosy-affected person and PLWHA will lead to problems **socio-economically**. It also aggravates the social stigma. Prevention of disabilities (POD) for leprosy-affected people can be offered to prevent worsening of visible impairments. For PLWHA treatment can be given.

We see **increased gender inequalities** in both conditions. Most of the time the women seem to be double burdened and double stigmatised.

Health professionals are a key resource in the care, treatment and support for leprosy-affected people and PLWHA. Insufficient knowledge still prevails in both conditions and leads to misconceptions and fear. For leprosy, it is fear for disfigurement and deformities. Fear for AIDS as it is a life threatening condition.
Inappropriate attitudes and practices of health professionals contribute to S&D. However, S&D in health settings is not only caused by the individuals but can be due to institutional factors as well. In relation to HIV, underlining factors can be that the health workers are not well informed about infection control measures, have not had enough training about HIV and supplies like gloves are limited.
Professional attitude with regards to confidentiality and provision of care is important. Whatever a person's background and/or condition is a sick person who needs care and treatment need to be taken care off. This can not depend on the personal believes and/or values of the health professional.

The review has shown that certain **laws and legislation** reinforced S&D towards leprosy affected people and PLWHA. Especially PLWHA have booked remarkable successes in changing laws and legislation through advocacy. To have the right laws and legislation in place will give the people affected by leprosy and PLWHA the ability to stand up for their rights.

The **media** is a powerful tool in disseminating information quickly over a vast area. Many people get their information from the media. The dissemination of incomplete messages and the use of inappropriate images in relation to leprosy and HIV/AIDS still occur and perpetuate stigmatising attitudes. Most likely, media workers have not been trained in addressing stigma-related issues of diseases such as leprosy and HIV.

From the results of the review we see that stigma and discrimination may occur at home, in the community, in the workplace, in the health and social services, in legislation and in the media. S&D occurring in the health services are particularly harmful for the leprosy and HIV/AIDS health programmes.

As we have seen the stigmatizers of people affected by leprosy and HIV/AIDS are the community, religious leaders, employers, other workers, health workers, in-laws and especially in HIV/AIDS the caregiver. The question may arise "Why ask who are the real stigmatizers?" as it is already known. The choice for this question was made after reading that people with epilepsy had ‘felt stigma’ as a product of stigma couching by key individuals. Does this happen in leprosy and HIV/AIDS as well? However, I did not it come across in the literature. What I did find was that there were spouses pressured by family and others to leave their wives and husbands because they had leprosy or HIV/AIDS. The spouses did not seem to have a stigmatising attitude but they were influenced through the discrimination of others.

It is unrealistic to say that stigma can be eliminated as labelling, stereotyping is so ingrained in society. But it is possible to make a start and do something about it to minimize the effects of stigma and discrimination in order to improve the quality of life for those who are affected by leprosy and HIV/AIDS.

Conclusion

The following findings are relevant in leprosy and HIV/AIDS (a) stigma is not a static attribute but a dynamic process (b) the ways to creating S&D, self-stigma and self-discrimination are similar; (c) the response of the individual to a negative stereotype will play an important part in determining the severity of self stigma; (d) deterioration of physical condition increases the severity of stigma in society; (e) improvement of condition can reverse S&D and the one affected can regain his/her social position in the community; (f) the consequences of stigma are surprisingly similar in leprosy and HIV/AIDS, in different cultures and public health programmes.

Chapter 7: Recommendations

From the results of the findings of the study and the good practices the following recommendations are proposed for leprosy NGOs.

Interventions focused on people affected by leprosy:

- Counselling: This may be individual or peer counselling. Sometimes the leprosy affected person is not yet ready to share his/her feelings and experiences in a group. For them individual counselling is more appropriate. The purpose of the counselling is to help the leprosy affected person cope with the disease and avoid self-stigmatisation and empower him/her to face discrimination.

- Establish Self Care Groups and/or Self Help Groups with socio-economic assistance. The establishing of groups is with the purpose of empowering people that leads to enablement , leads to success and independence and leads to equal life compared with others. Through this method self-stigmatisation and discrimination will be addressed.

- Strengthen and empower organizations of people affected by leprosy. Through advocacy they can campaign against stigma and discrimination and stand up for their rights.

Interventions focused on the community:

- Design cultural sensitive messages that incorporate traditional beliefs on leprosy. It will be a challenge to find the right mix to incorporate the traditional beliefs with the modern medical facts about leprosy. Traditional beliefs are difficult to change. The purpose is to reach optimal effectiveness of the health message with as result increased acceptance of the leprosy message and change of attitude.

- Involve religious leaders, community and/or tribal leaders in dissemination of information about leprosy in order to ensure a better impact, continuity and wider acceptance of the health messages.

Interventions focused on institutions

- Health services: Keep the knowledge and skills of the health workers up to date through training on complication management in leprosy and POID. The treatment of leprosy with MDT is quit easy but dealing with reaction type I and II is more complex and treating it correctly is a crucial part in POID.

- Health services: Have greater participation of leprosy-affected people in all activities like TASO

- Involve the media and conduct a workshop for media personnel about leprosy-related S&D in order to ensure right information will be disseminated about leprosy to the wider public.

Advice on policies

- Advice the MOH on a National strategy for POID and Rehabilitation for leprosy-affected people in order to prevent and /or reduce impairments getting worse. It will reduce the possibilities of stigmatization and discrimination of leprosy affected people.

- Use indicators in order to measure S&D and self stigma. It will be also relevant to use them for monitoring S&D and self stigma reduction interventions.

Research

- Conduct cross cultural research on psycho-social impacts of leprosy e.g., look at the concealment cycle in different cultures. The aim is to compare factors that lead to different attitudes and behaviour towards leprosy affected people. What can we learn from it and can results of positive attitudes and behaviour in one area be adapted and applied to an area with less positive attitudes and behaviour?

- Study the possibility of adapting "The Toolkit for action" to be able to use as educational materials for community leaders or organized groups in addressing S&D in leprosy. The purpose is to raise awareness and promote practical action to challenge S&D in leprosy.

- Conduct a feasibility study on developing 'Health-related S&D' as subject on the curriculum for health professionals at Universities and Nursing Academies. This effort could be a collaboration between members of ILEP, WHO and UNAIDS.
  The aim is to make health professionals aware of health-related stigma and discrimination and its consequences in relation to the individual, their families and public health programmes. Also to understand how does S&D arises? Are feelings of fear and anger based on reality.

References

ACORD, 2004 Unravelling the dynamics of HIV/AIDS related stigma and discrimination: The role of community based research. Case studies of Northern Uganda and Burundi

ACORD, 2006 Good practices for challenging Stigma and Discrimination & Rights Promotion of PLWHA, A case of Tanzania and Uganda

Aggleton, P., 2000 HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants Research studies from Uganda and India, UNAIDS

Aggleton, P., Parker, R., Maluwa, M., 2002 World Aids Campaign 2002-2003, A conceptual framework and basis for action, HIV/AIDS, Stigma and Discrimination, UNAIDS Nov.

Aggleton, P., Parker, R., Maluwa, M., 2003 Stigma, Discrimination and HIV/AIDS in Latin America and the Caribbean, Inter-American Development Bank, Washington, D.C.; Sustainable Development Department, Technical Papers Series

Anderson, H., Marcovici, K., Taylor, K., 2002 The UNGASS, Gender, and Women's Vulnerability to HIV/AIDS in Latin America and the Caribbean, Women, Health and Development Programme, Pan-American Health Organization, Washington D.C. December

Arole, S., Premkumar, R., Arole, R., Maury, M., Saunderson, P., 2002 Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy, Leprosy Review 73, 186-196

Awofeso, N., 1992 Appraisal of the knowledge and attitude of Nigerian nurses toward leprosy, Leprosy Review 63, 169-172

Awofeso, N., 2005 Concept and impact of stigma on discrimination against leprosy sufferers – minimizing the harm, Leprosy Review 76, 101-102

Bainson, K.A., Van Den Borne, B., 1998 Dimensions and process of stigmatization in leprosy, Leprosy Review 69, 341-350

Barkataki, P., Kumar, S., Rao, P.S.S., 2006 Knowledge of and attitudes to leprosy among patients and community members: a comparative study in Uttar Pradesh, India, Leprosy Review 77, 62-68

Barrett, R., 2005 Self-Mortification and the Stigma of Leprosy in Northern India, Medical Anthropology Quarterly, Vol.19, Issue 2, pp. 216-230

Bekri, W., Gebre, S., Mengiste, A., Saunderson, P.R., Zewge, S., 1998 Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia, International Journal of Leprosy Vol. 66, No 1

Bond, V., 2003 Stigma when there is no other option: understanding how poverty fuels discrimination toward people living with HIV in Zambia, Chapter 10, based on qualitative fieldwork in urban and rural Zambia

Briden, A., Maguire, E., 2003 An assessment of knowledge and attitudes towards leprosy/ Hansen's disease amongst healthcare workers in Guyana, Leprosy Review 74, 154-162

Brouard, P., Wills, C., 2006 The Internalization of Stigma Related to HIV, January USAID

Brown, L., Trujillo, L., Macintyre, K., 2001 Interventions to Reduce HIV/AIDS Stigma: What have we learned? Horizons Program , Tulane University

Calcraft, J.H., 2006 The effects of the stigma of leprosy on the income generation of leprosy Affected people in the Terrai area of South East Nepal, Asia Pacific Disability Rehabilitation Journal Vol.17 No.2

Castro, A., Farmer, P., 2005 Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti, American Journal of Public Health January Vol. 95, No. 1

Corrigan, P.W., 2005 On the Stigma of Mental Illness, Practical Strategies for Research and Social Change, Ch 1 The impact of mental illness stigma by Corrigan, P.W. and Kleinlein, P. Published by American Psychological Association, Washington, DC

CPA, 2005 A Profile of the Stigma and Discrimination faced by People living with HIV/AIDS, study conducted by The Centre for Policy Alternatives (CPA) for The Asia Pacific Leadership Forum (APLF)

Croft, R.P., Croft, R.A., 1999 Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh, Leprosy Review 70, 34-42

Cross, H., Choudhary, R., 2005 STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal Lepr Rev 76, 316-324

Cross, H., 2006 Interventions to address the stigma associated with leprosy: A perspective on the issues, Psychology, Health & Medicine, August 11 (3): 367-373

Daftary, A., Padayatchi, N., Padilla, M., 2007 HIV testing and disclosure: a qualitative anlysis of TB patients in South Africa, AIDS Care, April, 19(4): 572-577

Dalal, A.K., Pande, N., Dhawan, N., Dwijendra, D., Berry, J.W. 2000 The Mind Matters Disability Attitudes and Community Based Rehabilitation; Published by Centre of Advanced Study, Department of Psychology, University of Allahabad, India

Deacon, H., Stephney, I., Prosalendis, S., 2005 Understanding HIV/AIDS Stigma, A theoretical and methodological analysis, HSRC Research Monograph

Deng, R., Li, J., Sringernyuang, L., Zhang, K., 2007 Drug abuse, HIV/AIDS and stigmatization in a Dai community in Yunnan, China, Soc Sci & Med, Published by Elsevier

Devine, P., Plant, E.A., Harrison, K., 1999 The Problem of "Us" Versus "Them" and AIDS Stigma, American Behavioural Scientist 42; 1212

Eric, K., 2005 REACH OUT – MBUYA PARISH HIV/AIDS INITIATIVE, Reach out – Mbuya Parish HIV/AIDS Initiative; 3 (1) 312-320 UMU Press

Everett, B., 2006 Stigma: The Hidden Killer, Background paper and literature review, Mood Disorders Society of Canada

Floyd-Richard, M., Gurung, S., 2000 Stigma reduction through group counselling of persons affected by leprosy – a pilot study Leprosy Review 71, 499-504

Frist, T.F., 2000 Stigma and Societal Response to Leprosy: Experience of the Last Half Century, Indian Journal Leprosy, Vol. 72(1) 3-5

Garmaise, D., 2003 - 1 Involving People Living With HIV/AIDS: the key to success, Sexual Health Exchange

Gilmore, N., Somerville, M.A., 1994 Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming “Them” and “Us”, Soc. Sci. Med. Vol. 39, No. 9, pp. 1339-1358

Goffman, E., 1963 Stigma Notes on the Management of Spoiled Identity, Penguin Psychology Penguin Books Ltd, London, England

Goldin, C.S., 1994 Stigmatization and AIDS: Critical Issues in Public Health, Soc. Sci. Med. Vol. 39, No. 9, pp. 1359-1366

Haidar, A.A.M., 1985 Leprosy – the Moslem attitude, Leprosy Review 56, 17-21

Heijnders, M.L., 2004 The Dynamics of Stigma in Leprosy, International Journal of Leprosy 72, No.4 437-446

Heijnders, M.L., 2004 An exploration of the views of people with leprosy in Nepal concerning the quality of leprosy services and their impact on adherence behaviour, Leprosy Review 75, 338-347

Heymann, D.L., 2004 Control of Communicable Disease Manual, An official report of the American Public Health Association, APHA WHO

Human Rights Watch, 2005 Restrictions on AIDS activists in China, Human Rights Watch Vol. 17, No. 5 C p. 53

Idawani, C., Yulizar, M., Lever, P., Varkevisser, C.M., undated Gender, Leprosy and Leprosy Control, A case study in Aceh, Indonesia, KIT Publishers

ILEP, 2007 Leprosy patients’ case for referral to UN Human Rights Commission, International Federation of Anti-Leprosy Associations (ILEP)

International HIV/AIDS Alliance (IHAA), Academy for Educational Development (AED), International Centre for Research on Women (ICRW), 2007 Understanding and Challenging HIV Stigma, Toolkit for action

Jacoby, A., 1994 Felt Versus Enacted Stigma: A Concept Revisited, Evidence from a study of people with epilepsy in remission, Soc. Sci. Med. Vol. 38, No. 2, pp. 269-274

Jopling, 1991 Leprosy stigma, Leprosy Review 62, 1-12

Kaleeba, N., Kalibala, S., Kaseje, M., Ssebbanja, P., Anderson, S., Van Praag, E., Tembo, G., & Katabira, E., 1997 Participatory evaluation of couselling, medical and social services of The AIDS Support Organization (TASO) Uganda, AIDS CARE 9(1) pp13-26

Kaur, H., Ramesh, V., 1994 Social problems of women leprosy patients – a study conducted at 2 urban leprosy centres in Delhi, Leprosy Review 65, 361-375

Kaur, H., van Brakel, W., 2002 Dehabilitation of leprosy-affected people – a study on leprosy-affected beggars Leprosy Review 73, 346-355

Le Grand, A., 1997 Women and leprosy: a review Leprosy Review 68, 203-211

Lockwood, D.N.J., Suneetha, S., 2005 Leprosy: too complex a disease for a simple elimination paradigm, Public Health Review Bulletin of the World Health Organization March 83 (3)

Mahendra, V.S., Gilborn, L., George, B., Samson, L., Mudoi, R., Jadav, S., Gupta, I., Bharat, S., Daly, C., 2006 Reducing AIDS-related Stigma and Discrimination in Indian Hospitals, Horizon Programme Sharan, Institute of Economic Growth

Mukasa, D.S., 2006 Unveiling the truth, Shedding light on HIV stigma and discrimination, A report from the XVI International AIDS Conference, Toronto, Canada –August p.11-13

Malawi Network of People living with HIV/AIDS (MANET) 2003 Voices for Equality & Dignity, Qualitative Research on Stigma & Discrimination issues as they affect PLWHA in Malawi, Report, July Lilongwe, Malawi

Monico, S.M., Tanga, E.O., Nuwagaba, A., Aggleton, P., Tyrer, P., 2001 Uganda: HIV and AIDS-related Discrimination, Stigmatization, and Denial, UNAIDS, Geneva

Morrison, K., 2006 Breaking the Cycle: Stigma, Discrimination, Internal Stigma, and HIV, USAID, Jan

NAPWA, 2002 Submission to the review of the 4th National HIV/AIDS strategy, National Association of people living with HIV/AIDS, Australia

Nicholls, P.C., Wiens, C., Smith, W.C.S., 2003 Delay in Presentation in the Context of Local Knowledge and Attitude Towards Leprosy – The Results of Qualitative Fieldwork in Paraguay, International Journal of Leprosy 71, no. 3 198-209

Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H., Kidanu, A., Kilonzo, G., Mbwambo, J., Bond, V., 2003 Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia. International Centre for Research on Women (ICRW), Washington, D.C., U.S.A.

Nyblade, L., 2006 HIV/AIDS Stigma Finding solutions to strengthen HIV/AIDS Programs, International Centre on Research for Women (ICRW), Washington, D.C., U.S.A.

Nyblade, L., MacQuarrie, K., 2006 Can we measure HIV/AIDS-Related Stigma and Discrimination? Current knowledge about quantifying stigma in developing countries, ICRW on behalf of the POLICY Project, USAID January

Nyong'o, D., Ongalo, O., 2005 From Despair to Hope, Women's right to own and inherit property, POLICY Project Kenya and Kenya National Commission on Human Rights

Ogden, J., Nyblade, L., 2005 Common at its core: HIV-Related Stigma, Across Contexts International Centre for Research on Women (ICRW), Washington, D.C., U.S.A.

OHCHR, 2005 U.N. Human Rights Sub-Commission Passes Leprosy Resolution 11-8, The Nippon Foundation
http://www.nippon-foundation.or.jp/eng/leprosy/2005721/20057211.html accessed1-8-2007

OHCHR, UNAIDS, 2006 International Guidelines on HIV/AIDS and Human Rights

O'Neil, C., Samiel, S., 2004 A Health Promotion Approach to Reducing Stigma and Discrimination: A Framework for Action, Caribbean Epidemiology Centre (CAREC) PAHO/WHO

Opala, J., Boillot, F., 1996 Leprosy among the Limba: Illness and Healing in the context of World View, Soc. Sci. Med. Vol. 42, No. 1, pp. 3-19

PAHO, undated Basic Information on TB/HIV Co-Infection, fact sheet Pan American Health Organization

Parker, R., Aggleton, P., 2003 HIV and AIDS-related stigma and discrimination: a conceptual frameworkand implications for action, Social Science & Medicine 57, 13-24

Parker, R., Aggleton, P., Attawell, K., Pulerwitz, J., Brown, L., 2002 HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action, Horizons Program

Participation Scale Development Team (PCDT), 2005 Participation Scale, Users Manual Version 4.5 final, February.

Persons affected by leprosy, 2005 The Delhi Declaration, December 19, The Nippon Foundation
http://www.nippon-foundation.or.jp/eng/leprosy/2006737/20067372.html accessed 1-8-2007

Physicians for Human Rights (PHR) 2007 Report: Epidemic of Inequality; Women's Rights and HIV/AIDS in Botswana & Swaziland, An evidence based report on the Effects of Gender Inequity, Stigma & Discrimination. A report by physicians for human rights

Pinyajeerapat, N., 2006 Unveiling the truth, Shedding light on HIV stigma and discrimination, A report from the XVI International AIDS Conference, Toronto, Canada –August p. 48-49

Plagerson, S., 2005 Attacking social exclusion: combining rehabilitative and preventive approaches to leprosy in Bangladesh, Development in Practice, Vol. 15, Number 5 August

POLICY Project, 2001 POLICY Project's Approach to HIV/AIDS, Answering the Call, Human Rights, Stigma and Discrimination

Pollard, R., Walters, E., 2006 HIV/AIDS Media Guide, IFJ media guide and research report on media's reporting of HIV/AIDS

Population Council 2002 Youth and HIV and AIDS Stigma and Discrimination http://www.popcouncil.org/hivaids/stigma.html accessed on 8-5-2007

Rao, S., Garole, V., Walawalkar, S., Khot, S., Karandikar, N., 1996 Gender differentials in the social impact of leprosy, Leprosy Review 67, 190-199

Reddy, N.B.B., Satpathy, S.K., Krishnan, S.A.R., Srinivasan, T., 1985 Social aspects of leprosy: a case study in Zaria, Northern Nigeria, Leprosy Review 56, 23-25

Sasakawa, Y., 2006 Media perception of leprosy, Leprosy Review Vol. 77 No. 1

Scott, J., 2000 The psychological needs of leprosy patients, Leprosy Review 71, 486-491

Seddon, D., Seeley, J., 2006 Leprosy and stigma, Asia Pacific Disability Rehabilitation Journal Vol. 17 No. 2

Shelhore, N., Rana, S.Y., 2001 Snapshots of GIPA: the Greater Involvement of People Living with HIV/AIDS in South Asia, An Interim Report, UNDP HIV and Development Report, South and Southwest Asia

Shieh, C., Wang, H.H., Lin, C.F., 2006 From contagious to chronic: a life course experience with leprosy in Taiwanese women, Leprosy Review 77, 99-113

Siyam'kela 2003 Tackling HIV/AIDS stigma: Guidelines for people living with HIV/AIDS who interact with the media, Policy Project, South Africa; The Centre for the Study of AIDS, University of Pretoria, Pretoria

Siyam'kela 2003 HIV/AIDS stigma indicators, A tool for measuring the progress of HIV/AIDS stigma mitigation, Cape Town: Policy Project, South Africa

Stigter de, D.H., Geus de, L., Heijnders, M.L., 2000 Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal, Leprosy Review 71, 492-498

Susman, J., 1994 Disability, Stigma and Deviance, Soc. Sci. Med. Vol. 38, No. 1, pp. 15-22

Tessa, undated HIV/AIDS and South African Languages http://www.africanvoices.coza/research/aidsresearch.htm accessed 12-08-07

Try, L., 2006 Gendered experiences: Marriage and the stigma of leprosy, Asian Pacific Disability Rehabilitation Journal Vol. 17 No. 2

Tsutsumi, A., Izutsu, T., Akul Islam, M.D., Amed, J.U., Nakahara, S., Takagi, F., Wakai, S., 2004 Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma Leprosy Review 75, 57-66

UNAIDS, 2007 AIDS epidemic update, UNAIDS WHO, December

USAID, 2003 Kaunda Campaigns against HIV/AIDS in TV, Radio spots Zambia Oct. http://www.usaid.gov/our_work/global_health/aids/News/succespdfs/zambiastory4.pdf accessed 8-09-07

Van Brakel, W.H., Gopal, P.K., 1999 Portraying a positive image of persons (previously) affected by leprosy, International Journal of Leprosy Vol. 67 No. 4 p.477-479

Van Brakel, W.H., 2006 Measuring health-related stigma – a literature review Psychology, Health & Medicine Vol. 11 No. 3 p. 307-334

Weiss, M.G., Ramakrishna, J., 2004 Health-Related Stigma: Rethinking Concepts and Interventions, Research Workshop on Health-Related Stigma and Discrimination

White, C., 2007 Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil, Health Education Research, Theory & Practice Health Education Research Advance Access published January 17

Withington, S.G., Joha, S., Baird, D., Brink, M., Brink, J., 2003 Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: a 1 year cohort of new leprosy cases in north Bangladesh, Leprosy Review 74, 120-132

WHO, 2001 Mental health problems: the undefined and hidden burden, WHO fact sheet no 218, Revised November
http://www.who.int/mediacentre/factsheets/fs218/en/ accessed 25/05/2007

WHO, undated Leprosy: the disease, WHO fact sheet
http://www.who.int/lep/leprosy/en/print.html accessed 04/07/2007

WHO, undated Transmission of leprosy, WHO fact sheet
http://www.who.int/lep/transmission/en/print.html accessed 04/07/2007

WHO, 2005 Leprosy, WHO fact sheet no 101, Revised October
http://www.who.int/mediacentre/factsheet/fs101/en/print.html accessed 24/05/2007

WHO, undated The leprosy burden at the end of 2005
http://www.who.int/lep/situation/se_asia/en/index.html accessed 24/05/2007

WHO, 2004 Twenty five years of multi drug therapy for leprosy, Weekly Epidemiological Record, NO. 27, 2 July

WHO, 2007 Global Leprosy Situation, Weekly Epidemiological Record, NO 25, 22 June

WHO, undated Fact Sheet 1 HIV/AIDS: the infection, WHO
http://www.who.int/hiv/abouthiv/en/fact_sheet_hiv.htm accessed 05/07/2007

WHO, 2005 Stigma and discrimination against mentally ill in Europe, WHO European Ministerial Conference on Mental Health; Facing the Challenges, Building Solutions Helsinki, Finland 12-15 Januari

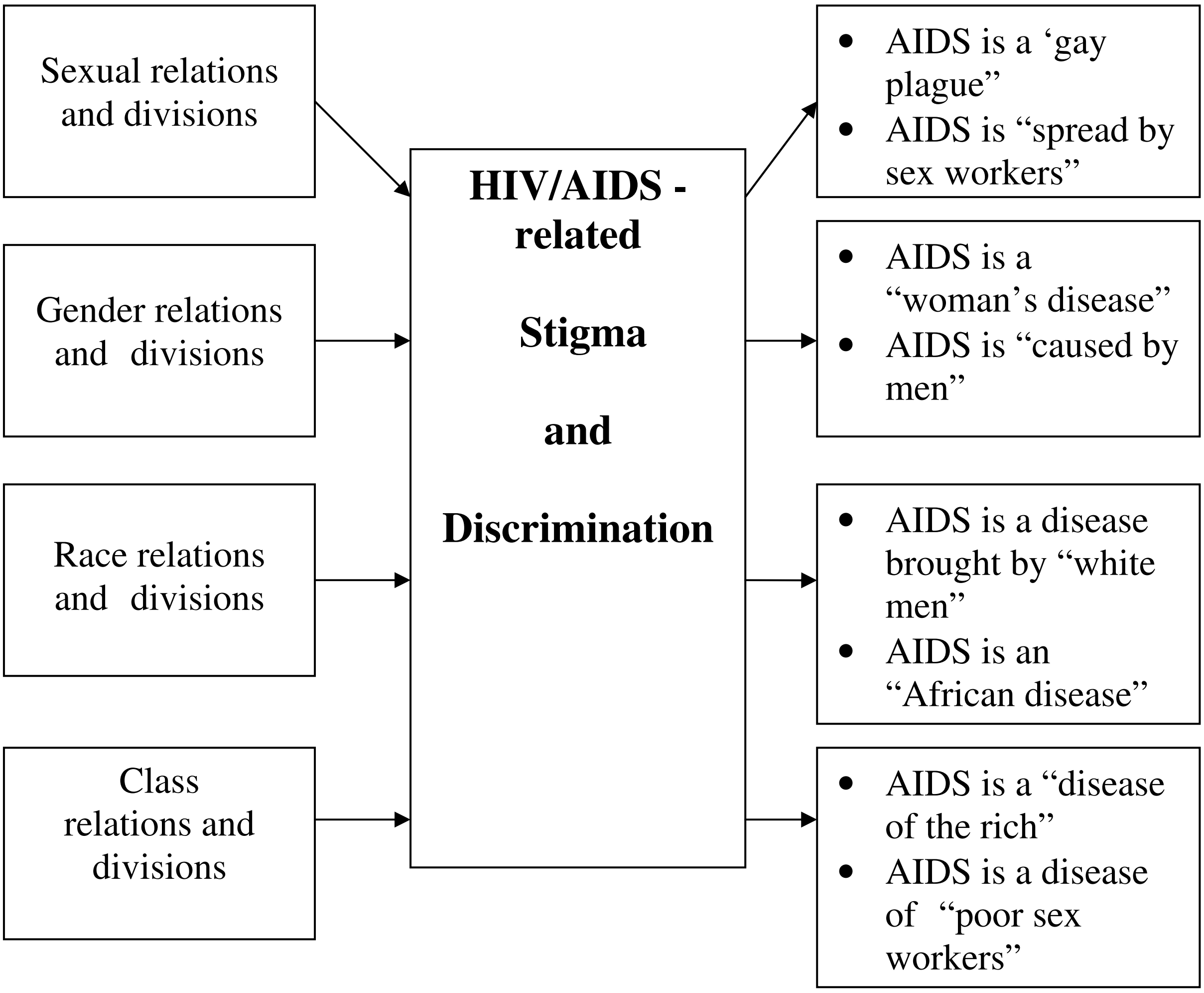
Wong, M.L., Subramaniam, P., 2002 Socio-cultural issues in leprosy control and management, Asia Pacific Disability Rehabilitation Journal Vol. 13, No.2

Wong, M.L., 2004 Designing programmes to address stigma in leprosy , issues and challenges Asia Pacific Disability Rehabilitation Journal Vol. 15 No.2

Zodpey, S.P., Rajnarayan, R., Tiwari, R.R., Salodkar, A.D., 2000 Gender differentials in the social and family life of leprosy patients, Leprosy Review 71, 505-510

Annexes

Annex 1: HIV/AIDS related stigma and discrimination based on pre-existing stigmatized groups



Annex 2: Stigmatization Process - Concealment Cycle