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Dimensions and process of stigmatization in leprosy

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Summary Leprosy is a disease which has struck fear into human beings for thousands of years. This is partly because it causes considerable deformities and disabilities. In 1991, the 44th World Health Assembly adopted a resolution to eliminate the disease as a public health problem by the year 2000. However, one of the major obstacles to achieving this objective is the stigma associated with the disease. Stigma against leprosy patients affects all aspects of leprosy control. This paper describes a model of the stigmatization process in leprosy. The process of stigmatization can be divided into two stages. The first stage describes how certain cognitive dimensions of leprosy lead to a variety of affective responses towards the disease. The second stage involves how these affective responses contribute to social devaluation of the leprosy patient and, consequently, the adoption of negative behaviours towards them.

Introduction

Leprosy has been described as a disease that destroys not only the body but the soul; it is a disease that slowly turns a person into a ‘thing’.[1] The disease has afflicted humanity for a long time. It once affected every continent and it has left behind a terrifying image in history and human memory of multilation, rejection and exclusion from society.[2] Since ancient times leprosy has been regarded by many communities as contagious, mutilating and incurable.[2]

Following the successes achieved after the introduction of multi-drug therapy (MDT) in leprosy control, the 44th World Health Assembly adopted a resolution in 1991 to eliminate leprosy as a public health problem by the year 2000. One of the constraints to achieving this objective is the stigma associated with the disease. Stigma is a word that was originally used by the Greeks to refer to bodily signs used to expose something unusual and bad about the moral status of the signifier. Today, the term is widely used similarly to the original literal sense. The meaning of stigma has been extended to embrace any mark or sign of

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perceived or inferred conditions of deviation from a prototype or norm.[3] Furthermore, stigma might be considered as representing a negative outcome or unwanted effect.[4] Goffman[5] describes three types of stigma: physical abomination, blemishes of individual character, and tribal stigma.

Stigma has adverse consequences for leprosy control. The degree of stigma against leprosy in a given community influences many aspects of leprosy control. Some patients would rather conceal their illness than suffer the social rejection which may accompany revelation of the diagnosis. In addition, for fear of being stigmatized, some patients may discontinue chemotherapy prematurely. Further, where patients present late, sometimes because of stigma, transmission of the disease in a community increases, and consequently, hinders control efforts. Finally, patients who report late may suffer deformities and disabilities, which could have been prevented if they had reported earlier.

The objectives of this paper are:

1. To describe the cognitive and affective dimensions of leprosy.
2. To use socio–psychological theories to explain the process of stigmatization in leprosy.

The approach that has been used for this paper is first, to describe the dimensions in leprosy in relation to certain characteristics of the disease, and secondly, to explain the process of stigmatization in leprosy using socio–psychological theories. This approach has been adopted because interventions aimed at solving the problem of stigma in leprosy are unlikely to be effective unless one understands how the various dimensions of the disease influence the process of stigmatization.

The biomedical course of leprosy

The bio-medical course of leprosy describes the illness experience as based solely in pathology. Figure 1 describes the bio-medical and social courses of leprosy from the stages of impairment, through disabilities, handicaps and dehabilitation to destitution. It also describes the psychological changes leprosy patients experience following the appearance of these bio-medical changes. This is a modified version of the WHO model on the bio-medical and social course of leprosy.[6] The WHO version does not clearly illustrate the psychological changes which occur in the leprosy patient: this model describes how the cognitive perceptions in the patient eventually cause loss of self-esteem. Another drawback of the WHO model is that it categorizes personality disorders as an impairment due to leprosy. This creates the impression that leprosy affects one's mental function, a fact which is not supported by scientific evidence.

Leprosy damages nerves. The function of nerves is to provide sensation to the skin, control mobility of the body and to stimulate glands in the skin to keep the skin moist and supple. Consequently, damage to nerves results in loss of feeling, dryness of the skin and paralysis. Without adequate care, secondary changes may occur including ulcers, contractures, shortening of the fingers and toes, as well as bone destruction. In addition, the disease may cause damage to the eyes, leading to blindness.

It may also cause infiltrations in the face, which may result in facial disfigurement. These changes in the structure and function of certain parts of the body are referred to as impairments. Impairments are loss or abnormality of psychological or anatomical structure or function.[7] Impairment may be primary or secondary. Primary impairment results from

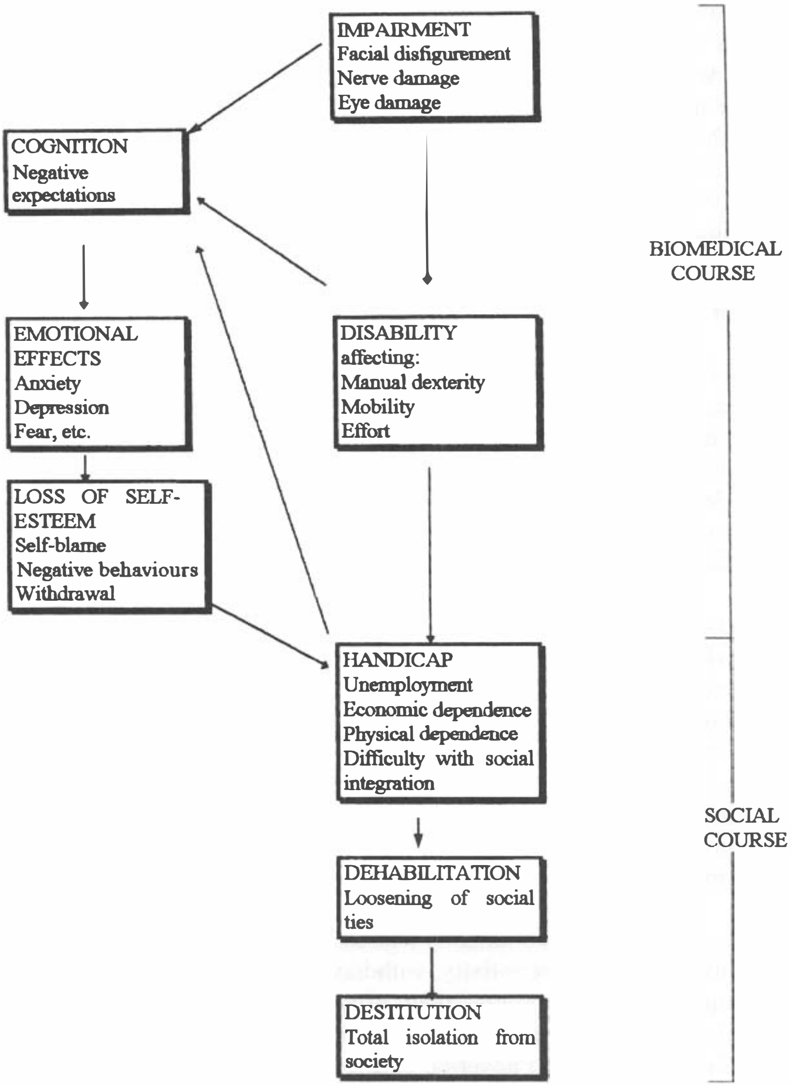

Figure 1. Diagram of the bio-social course of leprosy (modified version of WHO model on bio-social course of leprosy, 1993[6]).

direct damage by the bacterium, whereas secondary impairment results from neglect of primary impairment. A deformity is a visible impairment or a visible consequence of an impairment inside the body.[7] When there is an impairment (primary or secondary), the affected person may find it difficult or impossible to carry out certain activities. This is referred to as a disability, that is, any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.[7] Leprosy patients often suffer from a variety of disabilities. For example, manual dexterity (skilful use of the hand) may be affected because of insensitivity and muscle paralysis. Walking may become difficult because of ulcers or disintegration of bones of the foot. Orientation of space, mobility and many other aspects of living may become difficult or impossible, if the eyesight becomes poor.

The impairments and disabilities lead to psychological changes in the leprosy patient, which influence the social course of the disease. Impairments are interpreted as negative perceptions by the patient. As a result, the patient develops negative expectations of himself with respect to life. This is likely to generate a variety of emotions, including anxiety, fear and depression. Eventually the patient loses self-esteem and may become withdrawn or adopt negative behaviours.

Social course of leprosy

The social course of leprosy indicates that the disease develops in a local context where economic, moral, cultural and social factors powerfully affect the lived experiences of leprosy patients. According to Kleinman,[8] the social course varies according to the different local worlds, social networks and social histories. Thus the social dimensions of leprosy are closely interwoven with the cultural traditions of a society. Every society considers health and disease, life and death in different ways and this influences the attitudes taken by a community towards leprosy patients as a consequence of their illness.

A persistently disabled person may experience many disadvantages that limit or prevent that person from fulfilling his or her normal role in society. These disadvantages are known as handicaps (Figure 1). Leprosy patients with disabilities experience and suffer from a variety of handicaps. For example, they may lose their jobs, and consequently their economic independence. This means that they cannot support their families. In addition, those who are severely disabled may lose their physical independence, since they need others to care for them. Other consequences of stigma include loss of self-esteem, difficulty in finding a marriage partner, and generally a lower quality of life. Indeed, in some cases the mere diagnosis of leprosy is sufficient handicap for the affected person, even when there is no disability.

The adverse reactions of the community tend to devalue the status of the leprosy sufferer. This manifests itself by fear, insensitivity, withdrawal, etc. Eventually, the leprosy sufferer loses social status and becomes progressively isolated from the society, family and friends. Frustrations with employment, crippling deformities and social ostracism may finally force him into alcoholism, begging and adoption of a hostile attitude towards society. This stage is known as dehabilitation.

Eventually, a leprosy patient may be forced to leave his or her home and settle in a rehabilitation home or in a leprosy colony with other leprosy patients. This final stage is known as destitution.

Dimensions of stigma

Cognitive dimensions describe how much influence a mark has in interpersonal interactions.[3] They are also useful in understanding the stigmatization process, including how a condition emerges as a socially degrading mark, as well as how a stigmatized individual develops a negative self-concept. Indeed, it is the perceptions people have about leprosy rather than the disease itself which significantly influences their attitude towards leprosy and leprosy

Table 1. Cognitive dimensions in relation to characteristics of leprosy

Cognitive dimensions	Characteristics of leprosy
Concealability	High visibility of stigmatizing 'marks': on head, hands or feet
Course	Curable but generally perceived to be incurable; chronic course
Disruptiveness	No specific characteristic relevant to this dimension
Aesthetic qualities	Deformities
Origin	Depends on culture, religion, etc. For example, punishment by god, inherited, physical causes, witchcraft
Peril	Mildly contagious but generally perceived to be very contagious

patients. Jones *et al.*[3] describe six cognitive dimensions of stigma. These are concealability, course, disruptiveness, aesthetic quality, origin, and peril. Table 1 describes the various cognitive dimensions as well as the characteristics of leprosy under each dimension.

Cognitive dimensions

CONCEALABILITY DIMENSION

According to Jones *et al.*,[3] concealability describes the extent to which certain characteristics of marks make themselves obvious or can be made obvious to all who are involved in a relationship. It may depend on the visibility of the mark, what the afflicted individual says or does, on the characteristics of those interacting with the victim or on the circumstances of the interaction. At one extreme, stigmatized persons can be in a position where no one knows about the problem. At the other extreme, they always have to be conscious of the social effects of their affliction. In general, among stigmatizing conditions leprosy fares poorly on the concealability scale, because most of the deformities occur on the head, the hands or the feet. Consequently, they are very visible. A patient with severe deformities of the hands, feet or head continually bears the mark of the disease and, consequently, stands in perpetual danger of being stigmatized. It must, however, be added that even a patient who bears no external mark of the disease may suffer some stigma if he discloses his history.

COURSE DIMENSION

The course of a mark focuses on the pattern of change over time and its ultimate outcome. Gussow and Tracy[9] described eight criteria that ultimately influence social rejection. Three of these are related to the course of a disease. These are, that the condition should be progressively crippling and deforming, that it should be non-fatal and chronic, and that it should appear to be incurable. Leprosy meets all three criteria. However, so does a condition like rheumatoid arthritis. And yet the former is very stigmatizing whilst the latter is less so. This implies that even though the course dimension may be significant in the stigmatization process, there are other dimensions which make leprosy more amenable to stigmatization. As noted by Jones *et al.*,[3] the course dimension appears to be bound to other dimensions of stigma. Further, it is also important to distinguish between actual changes in the course in contrast to beliefs held by the labeller involved about the pattern the mark will follow in time to come. Indeed, it appears that it is the cognitive perceptions held by the labeller about the course rather than the actual course which is more important in the process of stigmatization.

For example, an air hostess in Ghana had early signs of leprosy without any disabilities or deformities, received adequate treatment and was cured. Yet she continued to suffer social rejection from her colleagues at work and eventually had to quit her job. The patient noted actual changes in her condition, and yet her colleagues continued to hold the belief that the course (or perhaps other dimensions of the disease) had not changed.

DISRUPTIVENESS DIMENSION

The third dimension of stigma is disruptiveness, which means the property of a mark that hinders, strains and adds to the difficulty of interpersonal relationship.[3] The authors refer to any condition that makes appropriate interaction patterns uncertain and unpredictable, and that blocks or distorts the communication process. How relevant is this dimension in stigmatization of leprosy patients?

Leprosy does not affect mental functioning. Arguably, the mark in leprosy that is likely to draw attention to itself and perhaps affect communication is the disabilities and deformities. In leprosy, this dimension is inextricably linked with other dimensions, for example, concealability, perceived threat and aesthetics. It is the opinion of the authors that this dimension is unlikely to play a significant role in the stigmatization of leprosy patients. Indeed as noted by Jones *et al.*,[3] this dimension must be viewed as tentative and its usefulness more in doubt, because it is inherent in various dimensions of blemishing conditions.

AESTHETIC DIMENSION

The fourth dimension according to Jones *et al.* is aesthetics. This refers to what is beautiful. Though scholars have long discussed the nature and determinants of aesthetic appeal, we are a long way from understanding why one object is beautiful and another generally considered ugly.[3] In spite of the cliché that ‘beauty is in the eye of the beholder’, some people seem ugly to most observers. A leprosy patient with numerous large nodules on the face or one who has lost all her fingers would hardly be described by most people as beautiful. But to what extent does aesthetics contribute to stigmatization in leprosy? Is it culturally determined?

English[10] argues that a number of studies suggest that the aesthetic factor strongly influences social and personal preferences of non-disabled for disabled persons. People generally respond to others as though they agree with the statement that physical beauty is a sign of interior, spiritual and moral beauty. This is perhaps why people on first sight are attracted to others with well-proportioned features and not to those with less well proportioned features. The aesthetic dimension appears to engender a primitive affective response which is in sharp contrast to the cognitive, attributional, stigmatizing processes elicited by other conditions.[3] Indeed, it is doubtful whether leprosy would be associated with such stigma were it not for the distortions it causes to personal beauty.

But familiarity as determined by cultural standards of beauty also appears to influence our concept of beauty. Society’s concept of beauty is not static and, indeed, is inherent in prevailing cultural values. In occidental societies, great value is placed on physical beauty, so there is a tendency for anyone with physical deformity to be socially devalued.[12]

ORIGIN DIMENSION

The fifth dimension of stigma, according to Jones *et al.*[3] is origin. This dimension refers to how a mark came to be, including when the mark originated during the course of life, the rapidity or slowness of its onset and the afflicted individual's role in engendering his own mark. In leprosy, this dimension covers areas such as the perceived cause of the disease and the interpretations made of the perceived cause. How significant is this dimension in the entire stigmatization process in leprosy? Does it matter whether leprosy is perceived to be caused by a witch or a punishment for a transgression against a deity? It would appear to the authors that the significance of the perceived origin is related to the cultural environment of the leprosy patient as well as the perceived role the individual has in bringing about his affliction.

A few issues need to be raised in reaction to Jones's categorization. Will a child with leprosy suffer the same level of stigma as an adult? If not, are there other factors that determine such evaluations? Does rapidity of onset of the mark influence the degree of stigma in leprosy? Research on these issues with respect to leprosy is scant.

PERIL DIMENSION

The last dimension, peril, focuses on the threat posed by the stigmatized individual. Threat may be perceived when the disease is believed to be contagious, or where leprosy patients are considered to be ritually unclean, or where, as in certain cultures leprosy patients are believed to be witches. Indeed, even a weak and deformed hand may be perceived as a threat. For example, one of the authors personally observed a 10-year-old enter a bus. Unknown to the boy, he sat next to a leprosy patient with severe deformities of the hand. As soon as he saw the deformed hand, he quickly moved away from the patient. When the author asked him later about his behaviour he replied, 'I feared he would knock me on the head with his hand'. Unknown to him, that hand was too weak to even give a knock.

Affective dimensions

The emotional reactions that individuals, groups or communities develop towards leprosy patients may include pity, anger and fear. Figure 2 describes the affective responses that

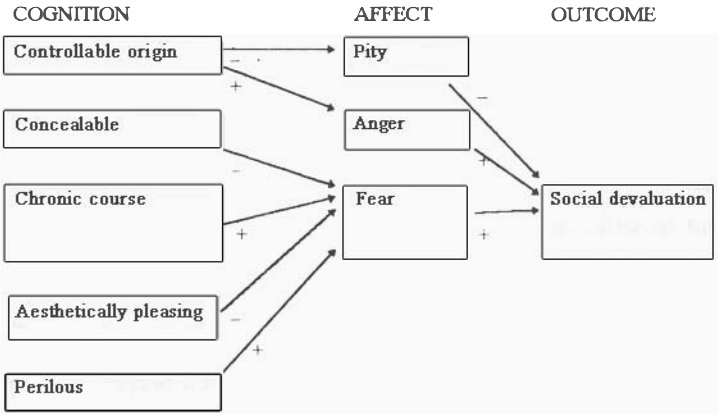

Figure 2. Schema of stigmatization in leprosy.

mediate between the cognitive dimensions and the outcome (stigma). The cognitive dimension which will be most relevant antecedents to these affective responses will depend on the knowledge, beliefs and values of individuals, groups or communities.

FEAR AS MAJOR AFFECTIVE DIMENSION

It appears that in leprosy, the element of fear is more likely to lead to rejection than any other affective dimension. It is the perceived risk of physical harm and pain that serves as the stimulus for fear. Jones *et al.*[3] remarked that leprosy is surely the most striking of the afflictions prompting fears of contagion. What are the reasons for this assertion? First, there are a number of neurological diseases which present similarly to leprosy, but which do not attract the same degree of stigma that leprosy does. For example, a patient was admitted for 3 months in a Teaching Hospital in Ghana with deformities of both hands. He received considerable sympathy and support from the nurses. At the time, leprosy was not suspected, and a non-contagious neurological condition was diagnosed. After several investigations it became clear that the condition was leprosy. As soon as the nurses became aware that the patient had leprosy, their attitudes became negative and they demanded that he should be transferred to the Contagious Diseases Centre. Second, normal people acceptable to others when alone may, by association with a leprosy patient, suffer similar negative social reactions. This may explain why close relations and sometimes health workers attending to leprosy patients also suffer some stigma. Goffman[5] has recognized this phenomenon and labelled it ‘courtesy stigma’.

A leprosy patient may be treated with pity where the perceived cause of the disease is presumed to be beyond the volitional control of the patient. However, where the cause of leprosy is perceived to be under the patient’s volitional control, it is likely to generate anger towards the patient.

Process of stigmatization

Diseases are feared, but it is people who are stigmatized. Katz[13] observed that the reaction of the majority group observer to the stigmatized individual would seem to have two basic components: first, the perception of a negative attribute, and second, the global devaluation of the possessor. This would suggest that stigmatization of the leprosy patient has two basic components: perception of a negative attribute(s) to leprosy and devaluation of the leprosy patient.

ATTRIBUTIONS TO LEPROSY

Individuals and societies make attributions to phenomena in order to make sense of their world. Attributions describe the processes of explaining events and the behavioural and emotional consequences of those explanations. To be stigmatized is in many ways similar to being a ‘failure’.[4] As ‘failures,’ leprosy patients elicit causal search and attributions from others and themselves. According to Attribution Theory,[4] the perceived cause of a stigma should determine affective reactions towards the stigmatized person (e.g. anger, pity, and fear), future expectations regarding that individual (e.g. the likelihood of recovery), and a variety of behavioural responses. Thus the attributions a given society, group or individuals make on leprosy influence significantly the emotions they develop towards the disease and, consequently, their behaviour towards leprosy patients. Why then do some societies adopt different affective responses towards the disease?

First, it may be that in some societies, physical abnormality is associated with moral bankruptcy. This is probably likely to hold true in societies that explain diseases as resulting from a transgression against a divinity. Second, among certain cultures and religions, ethical norms do not demand explanations of the type that are called for in the majority of societies For example, Moslems believe that every outcome (success or failure) is ordained by God. Consequently, it should not be surprising if ardent followers of this religion do not display resentment towards leprosy patients. This may, perhaps, explain why Shiloh[15] observed little stigma among the Hausa in Northern Nigeria, who are predominantly Moslem. Third, social psychologists[3] have proposed that this derives from the norm of social responsibility, which requires that we help those who are dependent.

Weiner[4] described three major dimensions of attributions: locus of causality, controllability and stability. Locus of causality is the perception that the location of the source is either due to factors internal or external to the person. Controllability is the extent to which causes are believed to be under volitional control. Stability is a person's location of cause(s) on a continuum according to how stable or unstable that cause is perceived. According to the theory, if society, groups or individuals perceive the cause of leprosy as controllable by the leprosy sufferer, it is likely that anger will be directed towards the leprosy patient (Figure 2) and, as a consequence, the patient will suffer social rejection. On the other hand where the cause is perceived to be uncontrollable, this is likely to generate pity and help-giving (Figure 2). For example, if the cause of leprosy is attributable to uncontrollable factors such as physical causes in the environment, this is likely to generate sympathy or pity for the sufferer. On the other hand, where the disease is attributable to controllable factors such as religious transgression or sexual indiscretion, this elicits anger, revulsion, and social rejection.

In leprosy, the locus of causality may be perceived as internal where it is believed that the source of the disease is infectious or contagious. This attribution is likely to generate fear. However, where the source of the disease is perceived to be external to the patient, for example, due to physical factors such as the weather, this is likely to generate pity.[4]

CONTEXTUAL FACTORS

Does the affective response exhibited by individuals, groups or communities remain static? Do other factors such as situational or individual characteristics influence this? A study by Gussow and Tracy[14] found that leprosy is not salient in the minds of Westerners. In this study, even though people ranked the disease among the top 10 serious diseases, they generally viewed it with less apprehension than diseases like cancer or mental illness. This finding was unanticipated in view of the prevailing presumption of strong stigma against leprosy. The authors concluded that leprosy was not salient, because the disease was relatively rare, and therefore people did not see it as an imminent threat. Does this mean that familiarity and direct experience with the disease is the basis for the observed Western attitude? Other studies do not, however, support this viewpoint. In a study of leprosy among the Hausa of Northern Nigeria, Shiloh[15] observed little or no stigma against leprosy patients even though the prevalence of the disease was high in those communities.

Conclusion

Stigma may be a hindrance to leprosy control. An understanding of the determinants of stigma and the process of stigmatization is, therefore, an essential step towards developing interventions to address the problem. Sadly, Stigma in leprosy is one area where there is a paucity of empirical data. Research is required into the relative importance of the various cognitive dimensions in engendering stigma in specific communities or cultures. Research would also be required into how the characteristics of the patient or the disease influence the degree of stigma. For example, would a child with similar disease characteristics as an adult suffer the same degree of stigma? Would a leprosy patient who is influential or assertive in his community be less stigmatized than one who withdraws from society? Would a patient with multiple nodules on the face be less stigmatized than one with claw hands?

Further, in the search for interventions that address the issue, research would also be required. For example, to what extent does modelling by care providers to leprosy patients influence stigma against leprosy patients? What informational or instrumental supports need to be given to close relations of leprosy patients to assist them to cope effectively with stigma and, in addition, assist the patient to cope with it? Are integrated leprosy control programmes more successful at addressing the issue of stigma than vertical programmes?

It is when studies have been conducted into stigma in leprosy that we can develop interventions through a planned and systematic approach and application of socio–behavioural and cultural theories.

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