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LEPROSY: A DISEASE APART
A
HISTORICAL AND CROSS-CULTURAL ANALYSIS
OF
STIGMA

by
Margaret A. Wheatley, M.A.

A thesis submitted to
the Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of
Doctor of Philosophy

Department of Sociology and Anthropology

Carleton University
Ottawa, Ontario

June 1985

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ABSTRACT

Throughout history, individuals and groups have been rejected by other members of their society on the basis of non-acceptable characteristics. They are stigmatised. Some, but only some, health conditions fall into this category in different societies at different periods of time. One disease, however, is unique in the widespread social opprobrium it has attracted. That disease is leprosy.

This study takes leprosy as an extreme example to examine the problem of stigma. A theory of stigma is proposed, which combines the intrinsic characteristics of the disease and socio-religious beliefs about causation. The wide variation in beliefs about disease causation is examined, in order to locate leprosy in historical-cultural perspective. The medical and scientific facts about leprosy are presented and its historical and geographical distribution is reviewed, to provide a picture of leprosy throughout history on all continents.

A detailed historical and cross-cultural analysis is then undertaken. This examination reviews and assesses the religious, medical, legal and social attitudes toward leprosy, which have set the disease apart from others. The findings demonstrate that, almost universally, leprosy and its victims have been, and are, stigmatised. This, despite

the fact that, from a medical point of view, there is no justification for considering leprosy differently from any other disease.

The problem of stigma and disease is then analysed on the basis of the findings in the case study. Suggestions are made on how stigma develops and how it is maintained. Finally, suggestions are made for steps which may be taken to modify the stigma associated with certain diseases and health conditions, including leprosy.

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CHAPTER 1

INTRODUCTION

"Unclean! Unclean!"

Zappa (1933)

Millions of people throughout history have found themselves shunned by society. Throughout the world, various characteristics have been used to identify individuals or groups as being unfit to participate fully in the activities of their society. On the basis of these characteristics individuals have been dehumanised by a process of segregation, ostracism, denigration and deprivation.

In modern complex societies, a wide variety of characteristics has stimulated such a response. Minority ethnic, racial or linguistic groups have frequently found themselves consigned to low or non-status, as have blacks in the southern United States or Japanese Canadians during World War II. Physical handicaps such as paraplegia, deafness or blindness, and physical abnormalities such as dwarfism, albinism or disfigurement, have been grounds for exclusion. Access has also been denied to people with unconventional lifestyles or with occupations which are illegal, such as prostitutes, pimps or drug pushers, or

considered undesirable, such as executioners, morticians and garbage collectors or sewage workers. Individuals with such undesirable habits as alcohol or drug addiction or obsessive gambling, people with mental illness, former prison inmates, the poor and the unemployed can be numbered among those who at times have been subject to a negative social response, which sets them apart from mainstream society. All in some way fail to measure up to societal expectations of conformity, and thus acquire stigmatised status. However, there is probably no stronger image of social stigma than that of the mediaeval "leper" and his bell.

Although some diseases, such as syphilis, have "enjoyed" notoriety at certain times in some areas, only leprosy has been subjected to social opprobrium in so many societies over so long a period of time. Confucius, in the sixth century B.C., is reported to have said of his follower Po Niu: "What a dreadful fate! That such a man should suffer such an illness". The disease from which he was suffering was *q-chi* - "evil disease" - traditionally believed to be leprosy (Lu and Needham, 1967). Indian literature from a similar period depicts *kushtha*, the Sanskrit term translated as "leprosy", as the worst of diseases, carried from one incarnation to the next (Filliozat, 1964; Kutumbiah, 1962; Sigerist, 1951). The Greek

physician Aretaeus in the second century A.D. said of it: "From the disease there is no escape, for it originates in a deadly cause" (Mettler, 1947:245). Throughout Europe in the Middle Ages, leprosy sufferers were flogged, whipped out of town, banished or segregated, with varying degrees of severity (Coudoul, 1943; Feeny, 1964; Roueche, 1953). At the present time, in areas where leprosy is endemic, people who have been treated for leprosy experience marriage breakdown, problems with finding marriage partners, and difficulty in finding accommodation or employment (Kumar & Anbalgan, 1983). Even in North America, victims of leprosy hide their disease for fear of losing or not acquiring jobs (Anon, 1983). The Medical World News of Nov. 23, 1981 carried a headline "Unwanted Import on the Rise: Leprosy", and despite the new Canadian Immigration Act, under which most leprosy patients should not be excluded, Canada still denies entry to all diagnosed cases, thereby contravening the terms of its own act (Leslie, 1984).

The cultural variability of stigmatised status and the number of different characteristics which attract stigma within one society make it difficult to isolate one common element that merits societal disapproval. Goffman (1963) centred his analysis of stigma on the "social information" individuals convey about themselves to others, on the basis of societal expectations. In his preface, Goffman defined

stigma as "the situation of the individual who is disqualified from full social acceptance". He identified three different categories of stigma: the stigma of physical disability; the stigma of abnormality of character; and the "tribal" stigma of race, nation, or religion (1963:4). In each case, a perceived negative trait interferes with the course of social interaction. Goffman examined some of the conditions which cause people to be "discredited" or "discreditable". These included physical disability (blindness, deafness, paralysis), mental illness, and socially unacceptable sexual inclinations. To these conditions I would add certain specific diseases, including cancer, tuberculosis, venereal disease and leprosy. One can then ask why it is that certain human conditions, most of them beyond the individual's control, come to be perceived in such a way. Further, once these conditions are so perceived, why does the social stigma associated with the condition persist, despite the fact that scientific and other evidence suggests that the condition should no longer be "discreditable"?

To date, the study of stigma as it relates to health conditions has focussed either on the attitudes and activities of stigmatised individuals or on the attitudes of the general population toward one or two specific categories of stigmatised people. Goffman's approach analysed the

strategies employed by the "discredited" to cope with society's refusal to accept them. Thus, it was a study in how stigmatised individuals adjust to society's definition of acceptability, with the focus being on contact situations of the stigmatised and non-stigmatised. Gussow and Tracy (1968) made the adaptation of a group of institutionalised, stigmatised individuals (leprosy patients) the focus of their investigation. Society expects that stigmatised individuals will behave differently. Thus, the physically disabled are not expected to behave normally, and the treatment they receive from others reflects that fact (Hunt, 1966). Failure on the part of the disabled to meet these expectations makes the general population uncomfortable (Carling, 1962; Katz, 1981).

While Goffman (1963) directed his attention to the characteristics which result in their bearers being stigmatised, Foucault (1965) saw the act of confinement as the basis for stigmatising the individuals subjected to that treatment. He argued that, in the middle of the eighteenth century, a long-standing fear of confinement was transformed into a fear of contagion by the evil confined. The notion of "rotteness" was both physical and moral, and was compared by Foucault (1965:202) to the spectre of leprosy in the Middle Ages. Leprosy's notoriety, however, preceded the medical theories of contagion of the eighteenth century (see

chapters 6 and 7). Goffman (1961) also argued that the organisation of the institution systematically depersonalises the inmates. Thus, stigma is fostered by some interplay between physical and moral characteristics deemed stigmatising and the institutions which contain stigmatised individuals.

MacGregor *et al* (1953) suggested that the premium on physical attractiveness in North American society leads to the assumption that if someone looks different, he must be different. The person is therefore set apart and consequently treated differently. "Treated differently" tends to mean as inferior, further widening the gap between the deformed and non-deformed (MacGregor *et al*, 1953:67). MacGregor and her colleagues studied the attitudes of facially disfigured people and the general public to facial deformities of varying degrees of severity. They concluded that where deformities were marked or particularly conspicuous, patients anticipated (and frequently received) negative responses, whereas people with less conspicuous deformities, being less certain of the responses of others, were more tense. The predictability of the response was thought to enable those with gross deformities to make greater adjustment than those whose deformities were less severe. This finding confirms Goffman's suggestion (1963:2-6) that observers demand or expect certain

behaviours on the basis of their perceptions acquired from the social information transmitted by the afflicted.

Studies of stigma therefore have examined coping strategies of stigmatised individuals or groups (Goffman, 1963; Gussow & Tracy, 1969), and attitudes toward specific conditions such as alcoholism, mental illness or physical deformity (Barker *et al.*, 1957; Jaffe, 1967; Jellinek, 1960; Katz, 1991; MacInerney *et al.*, 1953). Others have attempted to establish the degree of acceptability of different diseases and conditions (Richardson, 1961, 1971; Shears & Jensen, 1969; Tringo, 1970). Katz (1991) addressed the stigma of disease. In his opinion, diseases viewed as inexplicable, mysterious and relatively uncontrollable or incurable are seen as more stigmatising than those conditions, which although as dangerous, are thought to be better understood medically. The emphasis is on the nature of the disease which is likely to attract stigma. Thus studies of stigma have addressed specific aspects of the phenomenon, rather than undertaking a comprehensive historical and cross-cultural study. Katz suggests a possible factor in the development of stigma associated with disease, but does not suggest why stigma persists and how it is maintained. Foucault (1965:43) links stigma to institutions of confinement, whether establishments of religion and public order, of assistance and punishment, or

of governmental charity and welfare measures. It is suggested here that stigmatised health conditions are those which do not fit neatly into biomedical definitions of disease. Whether or not victims of these stigmatised conditions are confined, social aspects play a larger than normal role and thereby impose a moral connotation on the condition, such that the whole person is stigmatised on the basis of one specific negative trait.

The aim of this study is to obtain a better understanding of the stigmatisation process. This will be done by exploring the socio-historical dimensions of a stigmatised disease and the responses to it. Leprosy will be taken as a case study, to examine why what is now a treatable and mildly infectious disease should still carry so great a stigma, that otherwise rational individuals have an irrational fear and abhorrence of it as a "dread disease" - a disease apart.

In addition to library and other research, this study will draw on personal experience while involved with leprosy work in Tanzania, Nigeria, England and Canada. This experience illustrated the widespread stigma toward leprosy among African, European and North American acquaintances. To be working with leprosy patients was to be tainted by the stigma with which it is associated. Although most people quickly regained their composure when they considered the

matter rationally, the initial reaction was to put distance between themselves and the author. This happened on several occasions, including on a dance floor and in a swimming pool. To know that coasters and table mats used in social gatherings were made by leprosy patients as part of their therapy, creates a similar response today. The study will also bring together references to the subject of stigma from various disciplines, and will attempt to integrate the findings. Thus, it will contribute to the research literature on the sociology of health care and on medical anthropology. Various disabling conditions have been studied by sociologists, but Gussow and Tracy (1968), Boombaum and Gugelyk (1970), and Waxler (1981) provide the only studies of which we are aware in the sociological literature, directed specifically toward leprosy and the stigma associated with it. Meisels (1979a, 1979b) makes contributions to the psychological literature. In each of these cases, the emphasis is on how the stigmatised people - the leprosy sufferers - react to their situation. Although Waxler (1981) recently used leprosy as a case study of the social construction of illness, her cross-cultural study was confined to India, Sri Lanka, Tanzania, Nigeria, Ethiopia and the United States. She concluded that leprosy is not universally stigmatised. This aspect will be examined in the course of this study. Waxler's study again deals with

patient behaviour. In contrast, the focus of this study will be on the societal approach to this stigmatised disease, to examine how the stigma originates, and how it is maintained. Once that has been accomplished, suggestions can be made on what can be done to modify the stigma.

While leprosy is not a priority problem in modern, industrialised societies, it remains a serious medical and social problem in the Third World, affecting as many as 15 to 20 million people. No accurate estimate of the total number is possible at this time because, in many areas, the stigma attached to the disease inhibits sufferers from seeking medical advice and treatment. Even in an area where a good treatment programme was in place, and where the people attached relatively little stigma to the disease, a survey of remote villages revealed that some 40% of people with leprosy were not coming forward for treatment (Wheatley, 1970). A better understanding of attitudes toward leprosy could make a contribution to the mammoth task of controlling this disease. This is especially important for the implementation of the World Health Organisation (WHO) recommendation, to treat leprosy sufferers as out-patients, living in the community and integrated into the primary health care system (WHO, 1966, 1970). The success of this policy is dependent on community acceptance.

The widespread, almost universal, abhorrence of the disease, even in countries where it either does not exist at all, or is certainly not prevalent enough to be considered a problem. Canada, for example, suggests that a study of the stigma associated with leprosy could shed light on the wider problem of the stigma of other diseases and physical and mental disabilities. There have been major modifications in the approaches taken by society to many of these conditions, through the work of voluntary organisations and government legislation. There is ample evidence, however, to indicate that a public, which collectively agrees that discrimination toward these groups is wrong, reacts individually with a mixture of fear and aversion in actual or possible contact situations.

Leprosy provides an extreme example of a stigmatised condition. The disease and the associated stigma have a long history, have occurred in most societies, and both the disease and the stigma have proven difficult to control or eradicate. Despite the fact that a relatively inexpensive and readily available treatment has existed since the 1940s, leprosy control has been hindered in many areas of the world by the stigma associated with the disease. The stigma has caused sufferers to hide early signs because of their fear of ostracism and segregation, as well as for economic considerations. Treatment has only been sought when the

signs could no longer be concealed. At this stage, the disease may be so advanced that irreparable damage has been done, giving support to the notion that the disease is "incurable" and that the body "rots away". The case of leprosy, therefore, provides an excellent opportunity to obtain a better understanding of the stigmatisation process, because it can be studied historically and cross-culturally. Such an understanding may help us to appreciate fully, and hence, eventually to break down, the social and cultural barriers associated with presently stigmatised conditions. This may then allow individuals with these conditions a fuller participation in everyday social and economic life.

The study will begin with an examination of the problem of stigma. The concepts which are deemed to be most relevant to the stigma of disease will be explored and a theory of stigma proposed (Chapter 2). In Chapter 3, the wide variation in beliefs about disease causation will be examined in order to locate leprosy in historical perspective. Chapter 4 will examine the scientific and historical facts about leprosy which show how it has shared with other diseases a slow awakening of scientific knowledge. Chapter 5 will review the historical and geographical distribution of leprosy. Leprosy can then be examined as a stigmatised disease. Chapter 6 will look at the treatment leprosy has been afforded in western

societies, and chapter 7 will look at the approach of non-western societies, to show how religious, medical, legal and social reactions have combined to make it a disease apart. Finally, in chapter 8, the problem of stigma and disease will be analysed on the basis of the findings presented earlier.

The various steps in the literature search and research process are set out in Appendix I.

CHAPTER 2

THE PROBLEM OF STIGMA

"And yet we are human"

Carling (1962)

It is generally assumed that as human groups undergo cultural development, levels of knowledge increase and folk concepts are rejected in favour of rational, scientific explanations. However, in certain health conditions, folk concepts and misconceptions persist, especially in those conditions to which a stigma has become attached, and also in conditions where "scientific medicine" has apparently shown few results. Leprosy provides an example of such a condition. In this study, it will be argued that the development and persistence of stigma associated with disease lie in the complex inter-relationship of a number of factors. In this chapter, the factors regarded as most relevant to this process will be considered. The concepts of stigma, health, disease and illness, abnormality and acceptability, religion, sin and contagion, and the relationships among them will be explored. Following the introduction of these concepts, a theory of stigma will be proposed.

Stigma

Stigma is a complex concept. Originating in the principle of permanently marking and thereby identifying ownership of property, especially slaves and animals, the concept has undergone considerable change. Its use has been extended to conditions where visible marks may not be involved, but inferior status is implied or recognised (Goffman, 1963).

The word "stigma" comes from the Greek *sigma* meaning a mark or tattoo (Webster, 1971). The now out-dated meaning, therefore, was an identifying brand or mark applied by owners to their slaves or animals, both being similarly classified. A stigma, that is a mark, was also used to identify criminals or as evidence of infamy, disgrace or shame (Webster, 1971). It therefore had its origin in the notion of subjection, inferiority, deprecation and disapproval. While the use of "stigmata" to refer to identifying marks or characteristics of a profession, such as the stethoscope of the doctor or wig of the judge, cannot be regarded as derogatory, the notion of singling out and distinguishing remains. Stigma is also used specifically in medical terminology to refer to a symptom of physical or mental disorder, that is, actual manifestations (Webster, 1971). By extension, it has also been used to refer to any deviation from the norm. The stigmata having the most

positive connotations are the marks, resembling those borne by Christ at the crucifixion, which are believed to be supernaturally impressed on the bodies of certain people - the most notable being St. Francis of Assisi. With limited exceptions, therefore, a stigma is undesirable, objectionable, repugnant, unwelcome and above all unacceptable. A stigma can be some observable characteristic, or, more usually, it is something less tangible, often imprecise, yet very real.

Goffman uses the term stigma to refer to an attribute which is deeply discrediting (1963:3) and defines stigma as "the situation of the individual who is disqualified from full social acceptance". That which is stigmatised is, therefore, socially defined. Usually, that which is defined as "normal" or as "deviant" is culture-centric. Physical disability, for example, is considered more of a handicap in some societies than others. Variations in the treatment of deformed people will be discussed in the section on abnormality and acceptability. As indicated above, on the mental plane, the line between psychological disorder and spiritual vision may be blurred. Jeanne d'Arc and Louis Riel provide examples. Heterosexuality is considered the norm in modern societies, but homosexuality was, or is, more tolerated, or even expected, in some societies. In Classical Greece, for

example, the ideal relationship between two human beings was thought to be that between an adult and an adolescent male. It was not only an acceptable practice, but a highly valued relationship, at least among elite males. Female homosexuality was also probably practised, under the influence of the poetess Sappho on the island of Lesbos (Sigerist, 1961:298). Homosexual activity was also said to occur in 76 of 190 pre-literate societies, 48 of these societies considering the practice acceptable and normal (Ford & Beach, 1952).

Although different societies have diverse opinions on what is reprehensible and unacceptable, whenever society stigmatises a state or condition, that view tends to be held by a large proportion of the population. In the case of stigma, a general understanding obtains so that no explanations are necessary. Automatically associated with the condition is a conglomeration of assumed characteristics - usually not based on first hand observations and experience but on hearsay and traditional beliefs which are not substantiated by facts. Klineberg (1964) made a similar statement on racial stereotypes. When scientific facts threaten to interfere with these strongly held ideas, they are often rejected in favour of tradition. Galileo's ideas, for example, were considered heretical in his day. Tradition is used here to refer to the

transmission of knowledge, beliefs and ideas from an earlier period, when such beliefs perhaps had more validity, without being modified by new information which makes the ideas no longer relevant. Tradition, therefore, looks to the past for explanations and answers, and disregards the modified circumstances of the present. This was evident in the adherence to the teachings of the Church Fathers and Greek classical scholars which extended into the Middle Ages. Consequently, it follows that conditions which have been stigmatised in the past are likely to remain so, because these ideas have become ingrained and carry the authority of tradition.

An additional, and important, factor about stigma in the sense used by Goffman, is that the view is shared by both the victim and the general population, for both are socialised together. The victim thus expects to be socially unacceptable and may voluntarily withdraw from social interaction to avoid ostracism, rather than because of it.

Having discussed the concept of stigma in general, the factors contributing to the stigma of health conditions will now be considered.

Health, Illness and Disease

Webster (1971) defines health as "the condition of an organism or one of its parts in which it performs its

vital functions normally or properly". The word "health" originates in the Old English *hal*, still used in Scotland and Northern England in the modern form "hale" meaning whole, as in the common expression "hale and hearty". The verb "to heal" therefore implies to make whole. Thus, health represents the ideal rather than the normal state. A large proportion of the world's population would certainly not be considered healthy by North American standards. The Constitution of the World Health Organisation (WHO) also reflects the concept of wholeness in defining health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1976). Accordingly, health, the ideal state, is socially defined and cannot be equated universally with "normal". The "normal" or usual condition of a given population may well be one of hunger (and recurrent disease). The estimation of health consequently depends largely on who is making the estimate and the parameters used in the estimation. For example, an epidemiologist might determine health status by measuring selected criteria, such as morbidity and mortality rates of the population, or blood pressure, haemoglobin levels, and weight to height ratios in individuals, then placing the results on a scale to determine whether or not the findings are within the normal range for that population.

Illness can be regarded as the opposite of health, for it represents the perceived unhealthy state of the body or mind. "Ill", however, in Mediaeval English and Old Norse, was synonymous with evil, and thus morally reprehensible (Webster, 1971). This notion is retained in certain current words and phrases, such as "ill-fated", "ill-gotten gains" and "ill-natured". The "ill-will" of dialect English, used in curses, reflects earlier beliefs about causation of an unhealthy condition. Illness is "bad health" and as such is a non-ideal state.

Disease differs from illness in several ways, although the terms are frequently used interchangeably. While both represent states of non-health, illness tends to refer to the state of the sufferer - a subjective state of discomfort - whereas disease is the specific occurrence of that state. It is possible for people to feel ill or define their state as illness, without suffering from a disease. Conversely, one may have a disease which has not yet manifested itself and illness has not been identified. Illness denotes a subjective state which cannot be readily confirmed or denied, whereas disease is usually associated with specific causal agents.

In medical opinion, disease is the pathological state which occurs when the body fails to function in the desired way. Disease can occur spontaneously from within

the body (idiopathic) or may be the result of medical intervention (iatrogenic). It may also be caused by an external agent. When inert, this agent affects only the organism where it is located and the disease associated with it is termed non-communicable. On the other hand, an agent which is itself a living organism, capable of multiplying within its host and being transferred to others, introduces the possibility of disease in its new host. Such a disease is termed communicable (Encyclopaedia Britannica, 1975).

Although one can state that a causal agent produces a response in the form of signs and symptoms, which are then identified as a disease, the process is not a simple one. Other intermediary factors influence the development of the disease, the course it takes and its resolution. The causal agent is a necessary but not always sufficient factor. The process may be affected by an individual's genetic background, living conditions, age, sex, previous exposure, and ability to develop resistance (immunity). Dependent on such factors, the degree of severity may vary, or different combinations of symptoms may be present. Also, the impersonal, scientific definition of disease may not coincide with the subjective experience of the victim. For example, blood tests may reveal evidence of a serious health condition, while the patient does not feel "ill". Conversely, when a person considers himself ill, he poses a

medical problem even if the practitioner does not agree with the patient's assessment (Mechanic, 1968). Cultural patterns also influence how individuals and groups perceive, express and respond to illness (Zola, 1962).

Nevertheless, disease or illness is generally considered undesirable and efforts are made to restore health. The condition is considered temporary, and activity surrounding it represents a coping mechanism to make everyday circumstances tolerable and more predictable (Mechanic, 1968). Parsons (1951) suggests that the state of illness legitimates the patient's withdrawal into a dependent relationship. Thus, the state of illness relieves the patient of his normal obligations. Parson's argument, however, also implies that the situation is temporary and that the patient will co-operate in order to recover and again fulfill the obligations. Avoiding such obligations by feigning illness or not co-operating with therapy is considered abnormal. The nature of these obligations and the right to withdraw from them are determined by societal understandings of abnormality and acceptability with regard to health conditions, and these concepts will now be considered.

Abnormality and Acceptability

In considering the concepts health, disease and illness, an implicit acceptance of the notions "normality" and "desirability" is evident in the evaluation. Ideas on "abnormality" and "acceptability" in relation to health status further refine such an evaluation.

By definition, "abnormal" means differing from or deviating from the normal, which originates in the Latin *norma* = a carpenter's square and *normalis* = according to a square. By extension, "normal" is used to describe the state of conforming to the regular pattern or rule (Webster, 1971). Normal, or the norm, thus is the culturally defined, desirable and ideal standard, which is binding on members of a group and serves to guide or control acceptable behaviour.

Deviations above normal tend to be viewed more positively than those below normal. Thus, exceptionally intelligent children are termed "brilliant" while their less gifted counterparts are labelled "subnormal" or "retarded". Yet frequently the former find it equally difficult to fit into a group considered "average" (Austin & Braper, 1981). This situation indicates that abnormality does not necessarily refer only to inferior status. Rather, the difference makes people uncomfortable because they cannot rely on the usual criteria for interaction. The abnormality, whether in behaviour or in physical

characteristics, stands out because it is different, and the individual is afforded different treatment. While an abnormality, being a distinguishing feature, may be interpreted as a supernatural sign of, for example, potential leadership, this response is unusual. Washington (1956) for example, noted that people with emotional or physical abnormalities became shamans. Far more widespread is the association of abnormality with inferior status. Fitzgerald (1941) noted that female slaves were nearly always "cretins", or dwarves among Sino-Tibetan border peoples.

This study is concerned with one particular type of abnormality: disease. It is especially concerned with disease as it affects the physical appearance of the individual afflicted. It can be argued that anything that is different from the usual experience introduces uneasiness into the minds of individuals and groups, for they lack the experience to handle the situation, hence, it makes interaction difficult (Shears & Jensema, 1969). It can be further argued that the greater the difference, the more threatening the situation. In the case of physical abnormality the degree of abnormality considered acceptable varies cross-culturally. Societies which symbolically mutilate the body by various means - scarification, nose piercing, ear boring and ear lobe elongation and the wearing

of lip plugs - obviously have definitions of abnormality and acceptability very different from those in modern western society (Wheatley, 1978). Recently a conflict of cultural values has been evident in Britain, where African and Asian residents have sought to have clitoridectomy operations performed by British surgeons in British hospitals.

The degree of acceptability of any abnormality is reflected by societal responses. A review of the Human Relations Area Files reveals that infanticide was widespread when an infant was considered abnormal. Twins, along with crippled babies, were allowed to die in Formosa (Stanford II, 1956), although Muller (1919) noted that only the second twin was killed among Formosan Aborigines. In that society, the father had the right to have a child killed when it was blind, deaf or physically deformed (Wiedfeldt, 1916). Among the Okinawa, Maretzki (1953) observed mentally defective people but no cases of physical deformity, which suggests that physical deformity was not tolerated. Perhaps the invisibility of mental abnormality at birth is one of the reasons why physical deformity was dealt with but not mental abnormality. In Korea, the blind were considered to have inner vision and were esteemed (Saunderson, 1894) or acted as exorcists, especially against disease (Hulbert, 1906). The Okayawa appeared very tolerant of abnormality, accepting both physical deformity and mental defects, and

even though it was seen as a product of evil, a deformed child was kept alive (Norbeck, 1956). The deformed child could be regarded as a mark (stigma) of the consequence of "sin" and thus served as a deterrent to other members of that society. In Malaya, living "saints" were often marked by some physical peculiarity such as dwarfism. They were seen as having mysterious powers, able to perform miracles and a dwarf held the position of leader of the mosque (Winstedt, 1924). The power to cause storms was associated with physical deformity among the Patani (Annandale, 1903). Physical deformity was therefore obviously feared because of the mysterious power that was thought to be associated with it.

Physical deformities, including hydrocephalus with partial hemiplegia in an adult and congenital club foot, have been found in Egyptian mummies, and depictions of deformity appear on the walls of tombs (Ruffer, 1921) suggesting that at least among the elite, physical deformity was tolerated. This evidence does not inform us whether or not deformity was generally tolerated since only the elite were mummified. In China, however, certain "handicaps", including some eye and skin diseases, lameness and "hunchback" prevented the sufferers from participating in social affairs (Lu & Needham, 1967:226). The emphasis placed on physical fitness and attractiveness led the

Ancient Greeks to kill weak or deformed infants, especially in Sparta, and suicide was accepted as a means of escape from incurable disease or deformity (Sigerist, 1961).

The social response to abnormality, especially physical deformity, is reflected in literature, where "hunchbacks", "dwarves", "cripples" and "bastards" frequently appear as disagreeable characters. Literature, therefore, is one of the vehicles by which the social response is perpetuated. Stereotypes held by society are reinforced by such literary use, are rarely questioned, and, thus, become accepted as "realistic" characterisations. The notion of negative conditions being associated with negative causes is thereby perpetuated. Shakespeare provides several examples. Edmund, the illegitimate son of Gloucester in *King Lear* exhibits the expected evil traits of a "bastard", scheming and plotting, and disposing of people who hinder him. In his play *Richard III*, by describing Richard as "crookback", that is, deformed, Shakespeare creates a character who is accepted by society as capable of committing the atrocity of murdering the princes in the Tower. The Elizabethan public, and others since that time, could identify the deformity and the crime as being related. Whether Richard III did actually have a physical deformity, or was responsible for the deaths of the princes in the Tower, is still a matter of conjecture, but this artistic

licence, given the prevalent beliefs, did provide the author with a "believable" villain.

More recently, the war-disabled, paraplegic Lord Chatterley in Lawrence's Lady Chatterley's Lover receives sympathetic treatment by the author when he is introduced (Lawrence, 1969, orig. 1929). He is "chirpy...[has a] healthy-looking face...challenging bright eyes", but later he is gradually disparaged and denigrated. Negative characteristics emerge to justify Lady Chatterley's rejection of him. His face has "the slight vacancy of the cripple", his manner is "often offensively supercilious", the stories he writes are "curious" and "meaningless", and he is "morbidly sensitive" about them. He is thus reduced from being a bright, intelligent, talented man to being a "hysterical child" and a "squirming monster". Popular literature obviously plays an important role in society's responses to disability. In the first place it reflects the feelings of society about abnormality, and at the same time reinforces stereotypes and fosters the notion of unacceptability.

The response to different physical deformities varies. Richardson (1961) found that among all types of visible deformities, facial disfigurement seemed to provide greatest anxiety and aversion in both children and adults. It could be argued that this reaction occurs because facial

disfigurement interferes with the observer's aesthetic sense, thus making the observer uneasy. The emotions aroused are a complex mixture of fear, pity, sympathy, horror, disgust and revulsion, depending on the degree of abnormality.

Tringo (1970) studied the acceptability of people with chronic illness or disability. Using an amended form of Bogardus' (1925) Social Distance Scale, he devised a Disability Social Distance Scale to rank the acceptability of twenty conditions, with one being the most and twenty the least acceptable. Ulcer and arthritis were found to be most acceptable, while mental illness and alcoholism were at the other extreme. Paraplegia ranked 12th, epilepsy (13th.), cerebral palsy (15th.) and tuberculosis (17th.) were considered acceptable conditions in neighbours but sufferers were not considered acceptable as casual friends. Conditions considered unavoidable (ulcer, arthritis, asthma, diabetes) were more readily tolerated. These conditions are also not visible, except at the time of acute attacks, or where advanced arthritis produces disabilities which could be considered differently. The conditions are regarded as part of the possible repertoire of conditions which any individual may suffer. In the middle ranks were conditions which are typically stigmatised, that is, attract a negative social response (epilepsy, tuberculosis, cerebral palsy).

Least acceptable were the conditions about which it is generally thought that the individual should have some control (alcoholism, mental illness). It seems that the greater the fear occasioned by the mystery of the condition, the lower its position in the hierarchy: that is, the more likely the sufferer was to be an object of stigma.

Shears and Jensema (1969) hypothesised that the acceptance of "anomalous" people by "normals" depends on the combination of perceived differences which make social interaction difficult. The study showed that as the level of intimacy increased, acceptability of the disabled decreased. The authors suggested six dimensions which probably combine and interact to structure the stereotypes of "anomalous" people:

1. visibility of affliction
2. interference in the communication process
3. social stigma associated with disability
4. extent of incapacity
5. reversability prognosis
6. difficulties the anomaly imposes on daily living routine.

The last three dimensions were found to be particularly important at closer levels of intimacy. Shears and Jensema also noted that mental illness or retardation ranked low in acceptability, being underscored only by homosexuality.

Among ten and eleven year old children, it was found that different physical handicaps in a peer group produce social stigma with varying degrees of severity. From most to least liked, the general order of preference was for a non-handicapped white child, a non-handicapped black child, facial disfigurement, use of a wheelchair, crutches and leg braces, obesity and amputations (Richardson (1971)). This finding differs from his 1961 study in which facial disfigurement ranked lowest. Richardson suggests that cues of physical appearance are important, because they provide the only cues from which inferences about personal characteristics can be made when strangers meet. While the present writer believes that children respond to atypical conditions by considering themselves so disabled, they may, as Richardson suggests, also be reflecting the observed responses of adults to people with atypical conditions. Thus, Richardson concludes that educating the young about disability might be a more positive approach to the problem than teaching the handicapped child how to cope with the difficulties which the visible cues of the handicap present. The responses to abnormality found among children indicate that informal education (by taking cues from adults) is another way in which the social response, including stigmatisation, is perpetuated.

Thus it can be seen that while abnormality may be

considered as any deviation from the socially defined norm, the degree of acceptability of any specific physical abnormality appears to be related to the society's perceptions of how the abnormality came about, how aesthetically offensive the condition is to the observer, how incapacitating it is to the sufferer, and whether or not the condition is seen as amenable to improvement. It would appear, in addition, that what is considered acceptable seems to be greatly influenced by the religious beliefs of the group, therefore religion will be the focus of the next section.

Religion

Religion is a universal social institution manifesting itself in many forms. It is a system of communally held beliefs and practices with a strong emphasis on the supernatural sphere. For the purpose of this study, however, the focus is on aspects of religion which provide ways of explaining illness and contribute to the process of stigmatisation.

Fraser (1935), in his work on comparative religious customs (written 1911-1915), denied that early human societies had religion, and argued that religion was born when humans discovered that magic was ineffective. At that time, humans began to be subservient to the supernatural,

using power and supplication, rather than control through spells. Malinowski (1961) agreed with the distinction Fraser made between magic and religion, but found that among the Trobriand Islanders, magic was used to allay anxieties in everyday life, over which they did not have control. Religion, on the other hand, was reserved for life crises.

Durkheim (1954) saw religion as a unifying force with ~~sacred~~ objects symbolising society. Davis (1961) however, argued that religious ritual provides means of renewing ~~common~~ sentiments, with the sacred objects providing a focal point for the community sharing the beliefs. In this way, religion provides an unlimited source of rewards and punishments which exert control over the individuals in the group (Davis, 1961:529).

Whereas Durkheim and Davis saw religion as a unifying force, to Marx (1964) it was the "opium of the people". Marx viewed society as controlled by the religion of the politically dominant class, which used religion to legitimate its own interests and maintain the status quo by diverting the attention of the masses from their real problems. In Marx's view, therefore, religion does not initiate social change but only reflects the ideas of society.

Weber, on the other hand, thought that religious ideas could influence social change. Capitalism, in Weber's

opinion, arose from the Puritan tendency to work hard, abstain from pleasure, and reinvest rather than spend money (Weber, 1958a). Other religions mitigated against such change. Catholicism's emphasis on rewards in Heaven, for example, encourages people to be satisfied with their earthly lot (1963), while Hinduism similarly supports the caste system by threatening a lower caste reincarnation to those who try to move out of their caste status (1958b).

For Berger (1969), religion is rooted in the practical concerns of everyday life with a need for legitimation, but, unlike Marx, Berger views religion as more than a mere reflection of these practical interests. Once religious legitimations become part of a religious tradition, he argues, they attain a certain autonomy distinct from the practical concerns. In so doing religion maintains the reality of the socially constructed world in which men exist. This role is particularly important in "marginal" situations of everyday life, especially the confrontation with disease and death. Thus, religion

maintains the socially defined reality by legitimating marginal situations [disease, death] in terms of an all-encompassing sacred reality.

(Berger, 1969:44)

Religion in this way provides an emotionally satisfying explanation or theodicy, the religious legitimation of these repeated crises. The traditional task of religion,

therefore, was to establish "an integrated set of definitions of reality that could serve as a common universe of meaning for the members of a society" (Berger, 1969:134).

Thus, for the purpose of this study, religion may be seen as a social institution, developed to provide answers to problems of everyday concern to a society, but especially to help cope with life-threatening incidents such as disease or natural disasters, and even death. By placing these answers in the supernatural sphere, they become imbued with divine authority which exerts a moral pressure on maintaining social equilibrium. Once the causal explanation is placed in the supernatural sphere, treatment and cure are seen as subject to divine approval. When this aspect becomes institutionalised, the representatives of divine beings have the responsibility of carrying out the treatment. Initially, these representatives are shamans or priests, but as institutionalisation progresses, buildings, such as houses of prayer, hospitals, asylums and leprosaria, appear where the therapy can be carried out.

In most earlier societies, religion permeated into all aspects of life, and all members accepted these beliefs. With the increasing complexities of modern life, however, religion no longer has this monopolistic position. Not only are many religious options now open to people, to the extent that the total commitment of earlier times seems neither

necessary nor relevant, but other institutions, such as science, have arisen to compete with religious ideas. When man walks in space, magical explanations of the universe lose some of their relevance in the societies concerned. Yet despite the increasing secularisation of society, many elements persist from earlier traditions. Thus people who claim no religious affiliation still seek religious legitimisation in times of crisis such as birth, marriage and death. Many more people, while denying any religious affiliation, have, through the process of socialisation, inculcated and retained former religious ideas.

The adherence to former religious ideas is especially evident in the retention of health practices which do not seem rational in view of scientific knowledge. Davis (1961) argues that in the desire to be well, the patient is ready to believe what seems to offer most hope. The "surest hope and particular kind of confidence" can only be provided by supernatural forces which cannot be disproved. In this way, Davis suggested incomprehension with regard to sickness fosters magic, which in turn fosters ignorance. Scientific medicine challenges highly valued customs and practices, considering them injurious to health, and emphasises individualism which is totally opposed to the integrative force of magico-religious rituals (Davis, 1961:584). With the continued reinforcement of the

normative behaviour, non-conforming activity, frequently called "sins", is afforded special consideration. Sin will be discussed in the next section, and in the section following sin, "contagion", a closely related concept, will be considered.

Sin

The concept of sin is nebulous and has different implications in different periods and cultures, but is widely cited as the cause of undesirable incidents, such as disaster or disease. Bloomfield (1967) however, traces the concept of sin in the western world back to Persia. Zoroaster, in about the sixth century B.C., taught that the world was a battleground where two equal gods (one good, one evil) and their followers struggled. Sin was the wilful non-alignment with the good god, Ahura Mazda (Brandon, 1970). This dualistic concept, however, was not found in early Israelite religion, which was monotheistic and which regarded the whole world as good, or potentially good. This is clearly demonstrated in the Book of Job, whose disease is seen as resulting from sin. Evil, to the Jew was seen as a rebellion against God's law (Bloomfield, 1967:10).

Throughout the Ancient Near East, however, religious or moral actions which offended the deity were regarded as sin. For example, in Egypt, blasphemy and murder were

equally considered sin; the Hebrew concept of Yahweh as a moral God emphasised the moral and ritual aspects of sin; and in Greece and Rome, moral and ritual offences were often attributed to ignorance, the uninitiated being punished in Hades (Brandon, 1970).

Although primitive societies often saw disease as evidence of supernatural displeasure, the notion of sin as the deliberate violation of the legal or moral code seems to be absent. Rather, the emphasis was placed on carelessness, such as the accidental breaking of a taboo, which allowed evil spirits to intrude, or on magic and sorcery. Even in the more highly developed societies "sin" was not considered the predominant cause. This was true in Sumer as early as the third millennium B.C. It was only later that sin came to be considered a primary cause of disease. Apparently the notion was introduced in Assyro-Babylonian times, about the beginning of the first millennium B.C., under the influence of Persia (Sigerist, 1951). The Book of Job dates back to the middle of the first millennium B.C. The pious Job, after many adversities, including disease, seeks the meaning of his suffering. His friends point to personal sin as the root of his suffering. He vehemently protests his righteousness and challenges Yahweh to explain why the innocent suffer. His encounter with Yahweh does not solve the problem of undeserved suffering, but renews Job's trust

in God's purposeful activity, even if His dealings with man remain mysterious.

In ancient India, the worldview centred on the concept of *rita*, the regular order of the universe, with all things harmoniously regulated, including man's moral behaviour. Varuna was the guardian of "the Norm", but did not change it. In this belief, sin was an anomaly, whether the transgression was accidental or deliberate. By extension, disease, which disordered the body, was sin (Filliozat, 1964:91-93). This was not the notion of original sin, for which the individual cannot be held responsible. Rather, it resulted from ignorance. Consequently, sin was not punished, but resulted logically in suffering. The concept of reincarnation considered moral perfection the only route to salvation. Man's status in each incarnation was determined by his combined actions, the ultimate goal being to liberate the soul from the cycle of reincarnation (Sigerist, 1961:169). Thus, all disorders stemmed from violations of the norm, affecting a healthy being as though an impurity had been "wiped off" on him. Treatment often sought ritually to "wipe off" or efface the impurity (Filliozat, 1964:97). Diseases thus marked out those who had violated the norm, lowering the status of the afflicted, who were seen as the source of their own problems.

In China, before Confucius, sin was considered a crime or offence against the cosmic order. As in India, sin was a transgression from the norm. In China, however, delinquency was judged in the "Heavens" and punished. Under Confucius, man's heaven-born nature was considered perfect, and certain acts were considered great sins - theft, murder, mendacity, vindictiveness, weakness and especially unfilial conduct. The same term, *tsui*, was used for both sin and punishment (Smith, 1970). Disease was again seen as a mark or stigma of the transgression.

In Christian belief, the notion of sin becomes diversified. In the New Testament, sin is equated with offences against God or man, focussing on the intention rather than the act (Brandon, 1970). However, in New Testament times there was an obvious connection between sin and disease in popular thought (John 9,1-2). The notion of Original Sin inflicts Adam's guilt on each child, making him prone to sin, but also promoting the possibility of redemption through baptism. Post-baptismal sin, consequently, creates a problem of explanation for commentators, who categorised "sin". "Actual" sin is a willful transgression, and "mortal" sins are the most serious, leading to eternal damnation, whereas "venial" sins are less serious (Brandon, 1970) and pardonable. The seven "deadly" sins (pride, covetousness, lust, anger, gluttony,

envy, sloth), particularly in the Middle Ages, were thought to be the source of other sin. All are deemed to be controllable by the individual.

In the mythologies of many societies, the travels of a living person (or a soul) to an after-world frequently provides a major theme. In some, like the Greek myths, the afterworld was always seen as shady, but later a twofold version of the next world emerged - a pleasant one for the virtuous and an unpleasant one for the evil-doers. The soul on its journey encountered various temptations to be overcome. The mythological reward of virtue and punishment of transgression thus reinforced social norms. By giving names to these "spirits" encountered, it was thought possible to exert more control over them. This notion was incorporated into Christian beliefs, and what probably started out as "vices" gradually came to be considered "sins" and were personified.

Bloomfield sees the origin of this development in Christianity in rules to control the sinful craves (i.e. worldly concerns) of early monks and hermits. Anything bad or worldly was considered a sin, but some sins were more important than others. The notion of sin thus acted as a measure of control for those who had chosen the religious life. Only in the seventh and eighth centuries A.D. did sins move from monastic to general concern, becoming

increasingly important to the lay person (Bloomfield, 1967:72), thereby exerting social control on the population as a whole.

In the Middle Ages, allegory was traditionally used to convey the hidden meaning of Biblical teachings. Virtues were often seen as good influences and sins as diseases (Fletcher, 1964) or as medicine and poisons (Bloomfield, 1967). Although the seven cardinal sins were usually associated with a specific disease, these associations were not consistent. Thus, lechery or lust is associated with dropsy in an early fourteenth century manuscript but with leprosy by Gower at about the same time, with "flux and stinking flesh" in a fifteenth century manuscript, and with venereal disease in Spencer's *Faerie Queene*, where leprosy is linked with envy (Bloomfield, 1967:196-242). In each case, however, the association emphasised the repulsive aspects of disease, providing a basis for rejection or ostracism. Thus certain conditions, linked in this way with sins, became the object of stigma. The cardinal sins continued to receive attention in European Christian societies, but their significance declined with the rise of scientific thought. Old ideas, however, persisted in folk-lore and superstition.

Thus, disease and sin appear to be clearly linked, whether sin is seen as the accidental violation of norms, as

in India, or, as in the New Testament, as the deliberate rebellion against God's known will (a fundamentally theological concept). Sickness was considered the deserved punishment for this wilfull transgression, and singled out and marked the transgressors, on the one hand. On the other hand, it was also seen as atonement for guilt, and therefore a means of redemption (Sigerist, 1943:68). By regarding disease as the manifestation of divine retribution for sin, the afflicted were regarded as sinners, providing grounds for ostracism and rejection, and introducing the related concept of contagion.

Contagion

The word "contagion" is derived from the Latin verb ~~contingere~~ meaning to touch or pollute. It is used in this sense by Frazer (1935) in "contagious magic", whereby the magician casts a spell on any item closely associated with an individual - clothing or nail parings for example - in order to control that individual. A close link is seen between a wound and the weapon responsible for it. Consequently, if the sufferer can gain possession of the bow which shot the arrow, he can keep it cool and thus reduce fever, whereas if the enemy has the bow, he can stimulate inflammation by keeping the bow near the fire. Menstruating women were frequently considered "dangerous" and measures

were taken to avoid association with them. Such a belief is less the idea that the ritual uncleanness will be transmitted in ~~1010~~ to another person, but rather that the impurity will rub off on to those in association (Fillipz, 1962), hence, such women are to be avoided or segregated.

Contagion, therefore, can be regarded as having a magical element - a sort of poison which affects those who are associated. Fear stems from the mystery of the condition. Primitive beliefs accepted "poisoning" through speech, without the necessity of the introduction of a poisonous substance into the body. A look, a touch or even a spell could produce the desired effect. To the person affected, the condition was subjectively real. The individual believed in the condition, the cause and the treatment.

The traditions of the Middle East emphasise the polluting aspect of contagion. The Levitical law specifically sets out activities, foods and conditions which are considered ritually unclean (Leviticus, 11-13). The "uncleanness" results from what are considered abnormal associations. Contagion is thus applied to the handling of a corpse and to a woman following childbirth. These conditions are marked out for special treatment - avoidance - because they are unacceptable. It is quite obvious that the modern notion of infection is not intended here. Rather, these conditions, being considered ritually unclean

or impure, had the ability to contaminate others by association.

In Mesopotamia, contagion was a recognised cause of disease, but it was again the fear of contamination by something which was considered ritually impure. The sick person, having broken some taboo, albeit unwittingly, was seen as ritually unclean and as a consequence could be dangerous.

The Hindu concepts of contagion and sin are almost synonymous. Sin is on a par with concepts such as illness, enmity and distress - all are types of pollution which can be neutralised by the appropriate ritual. The ritually impure state can occur as a result of mistakes in sacrifice, or through contact with a corpse or a ritually impure person, such as someone of a lower caste. Sin does not result from misdeeds which anger the gods, but from the violation of moral principles. The predominant factor is the fear of evil consequences, rather than a consciousness of guilt.

Such a distinction cannot be so readily made in the Christian tradition. Fletcher (1964) points out that the ascetics of the Gnostic religion symbolically purified themselves with rituals, and attacks were made on icons by Tertullian and on stage plays by Augustine, based on the fear that they would contaminate the populace. Contagion,

however, is used in Christian allegorical works to link sin and redemption. The plague, for example, was a symbol of both the cause and effect of sin. Human failing and pollution were linked to spiritual hygiene and divine redemption. Contagion, therefore, begins to take on an aspect of guilt which does not appear to be present in earlier times. Whereas in many avoidance practices no guilt is attributed to the one avoided, the association of contagion and guilt is one of the characteristics of stigma.

The above discussion provides an impression of what stigma is, and the characteristics with which it is associated, but it does not help to determine how stigma develops and persists. What is the process which leads to the attachment of stigma to certain conditions and not to others? This question will be addressed in the proposed theory of stigma which follows.

The Stigmatisation Process: Toward a Theory of Stigma

The process of stigmatisation begins with a socially defined abnormality. Potentially, any abnormality may become stigmatised, but the focus in this study is on one particular type of abnormality - disease. Disease can be regarded as an abnormal state because it deviates from the culturally accepted definition of health, or wholeness. Consequently, that which is defined as disease or

abnormality will vary cross-culturally.

In the normally-functioning society, disease can be seen as a crisis which provides a potential threat to the life of the individual and the survival of the group. It is therefore an undesirable state and attempts are immediately made to resolve the situation and restore the equilibrium. This action involves treating the sufferer, based on the diagnosis of the abnormality. The culturally defined concept of disease incorporates within it the expected willingness of the patient to co-operate with the treatment.

Biomedical definitions of disease associated with specific causal agents such as viruses, bacilli, and parasites, now obtain in modern industrialised societies. Until the development of the science of microbiology in the eighteenth and nineteenth centuries, however, external, environmental, supernatural or magical factors were more usually accepted as causal agents. Many of these ideas persist in "folk" concepts to the present time, as, for example, the attribution of "hare-lip" to the observation of a hare by a pregnant woman, or the transference of warts. A society's religious beliefs develop to explain specific phenomena, including disease, and determine the amount of "diseasedness", and the consequent threat to the group's existence that is acceptable. Measures are taken to restore the equilibrium, based on these beliefs. The more

unacceptable the "disease" the more likely is it to be stigmatised. It is suggested here that certain specific signs and symptoms may be singled out for distinctive treatment, based on the amount of fear generated.

All occurrences of disease in which an individual's life is potentially threatened create fear. Minor ailments, such as the common cold in our present society, cause discomfort, but are not generally considered life threatening. Pneumonia or acute appendicitis, however, are immediately seen as life-threatening, especially in certain groups of people such as the very old or the very young. Similarly, less technologically advanced societies are exposed to situations such as food shortages which are considered acceptable, but a serious injury might kill or maim an individual. There is variation both in the severity of disease, as medically defined and in the response to disease, as socio-culturally defined. Social definitions are closely related to other aspects of culture, especially the propriety of complaining, which leads some ethnic groups to report pain more frequently than others (Zola, 1962). The severity of the condition as medically defined, however, does not appear automatically to be associated with stigma. The association must lie in other socio-cultural factors.

While all diseases present the possibility of becoming stigmatised, only certain diseases and conditions

attract this social reaction. The reaction does not seem to be directly related to the medically determined severity of the disease, but seems to relate to the amount of fear and discomfort engendered in the population by the presence of specific diseases or conditions. A prime requirement for the development of stigma, therefore, is fear, closely linked to disgust. There is an inherent response, which may be termed fear, to abnormality as socio-culturally defined in all societies. Abnormality especially generates the fear response when no apparent cause, such as an accident, is evident. An explanation is sought, in supernatural or magical intervention. Causal factors commonly put forward for conditions which are stigmatised are: social or moral transgression; personal or familial religious transgression; abnormal sexual behaviour; excesses of all kinds, but especially excessive and/or illicit sexual activity. In each case, the "norm" which has been violated is culturally defined, based on the socio-historical development of the given group. This norm is subject to modification over time. Stigma is thus a cultural artefact, along with beliefs about disease, life and death, religion and sin, each of which reinforces the others.

The fear, then, stems from what is seen as a manifestation indicating retribution for a past transgression. Not only is the person "abnormal", he is

also morally impure: the abnormality provides the evidence of the impurity. Being impure, the individual is considered dangerous, capable of contaminating others with the evil, so isolation is necessary. Isolation takes one of two forms: either the "diseased" withdraws from the rest of the community - as do women at the menarche, during menstruation or after childbirth in some societies; or, the individual is isolated by the community as a whole, or by those sanctioned with authority by the community. The imprisonment of Russian dissidents, civil rights activists in southern states of the U.S.A., or mini-skirted women in Iran and some African countries, to prevent them from disseminating their ideas, thereby contaminating the minds of their compatriots, provide modern examples of forcible segregation, and emphasise the "perceived", or "by example" aspect of contagion. Although Goffman (1963) and Foucault (1965) put forward arguments for the stigmatising consequences of confinement, individuals who are singled out and separated or isolated from society are selected on the basis of certain criteria which make them unacceptable to society as a whole, or those sanctioned with authority in that society. It is suggested here that the aspect of contagion outlined above, that is, of tainting by association, underlies the negative social response to abnormality and ultimately leads to stigmatisation.

Diseases, like other naturally occurring situations, is expected to have a temporary occurrence which, after suitable treatment (dietary restrictions, irritations, isolation, penance, personal purification, or magic or surgical intervention in modern times, and the assistance of all other forces) will be resolved and the person readmitted to full and normal participation in social life. In many cases, of course, death removes the "problem". When the desired result is not obtainable, however, as in chronic degenerative diseases, or where marked physical abnormality is present, the "fundamental" and "undesirable" problem/condition remains visible and reinforces the earlier response.

When the abnormality is a physical deformity which is socially unacceptable, many societies dispose of the victims: infanticide of weak or deformed infants was widespread in primitive societies where non-productive members strained the group's resources (Stanford 1946; 1956; Wiedfeldt, 1916; Gigerist, 1961); some deformities such as achondroplasia were "accepted" but the victims were in a position of permanent ridicule as court jesters, as widely described in literature; (in more modern times, deformities are similarly exploited in circuses). In societies where a disabled member survived, he could attain a position of power (Saunders, 1924; Hulbert, 1926;

Windstedt, 1924), perhaps attributable to the fear the population held for the deformity and hence the person, if this condition was seen as a divine sign. In the Middle East, for example, blindness was considered a necessary attribute of a "wise man".

Stigma, as defined by Goffman (1963), thus begins to develop when an unacceptable abnormality remains present in the community, reinforcing the initial fear response. It is suggested here that the more permanent the disability, and the longer the afflicted person remains in evidence, the more likely is the condition to be stigmatised. "In evidence" can apply whether the victim remains in society or is segregated. In the latter case, the basis of the segregation is emphasised and reinforces the stigma. A man on crutches suffering with a broken leg, is more sympathetically viewed than the amputee with crutches. Essentially, therefore, stigma becomes attached to a permanently disabled condition viewed as "incurable". It is further suggested that once the potential for stigma exists - that is, a permanent, irreparable condition - its development is facilitated by religious beliefs which emphasise morality and sin, and thus perpetuate the link between immorality and/or sin and human physical disease. The close historical connection between religious and medical practices served to reinforce traditionally held

concepts. Such close linkage seriously inhibited advancement of scientific knowledge which challenged religious ideas and limited advances in medical knowledge by opposing post mortem dissection in many societies. Such actions fostered the retention of out-dated notions which could not be put to scientific test, by relying on divine intervention to effect a cure.

With the development of written traditions, similar notions can be fostered. In Mediaeval literature, for example, diseases were allegorically linked to sins of the flesh. Conditions which had attracted social opprobrium were repeatedly cited as reminders or as warnings. When used in this way, the characteristics of the condition were selected for their impact. It was indicated above that literature helps to perpetuate the social response to abnormality by the use of stereotypes. Klineberg (1964), referring to stereotypes as "pictures in our heads", notes that they are widely held, unresponsive to objective facts and involve some degree of evaluation. Stereotypes are thus generalisations, based on secondhand, incomplete or inaccurate information, rather than on empirical evidence. Thus, they act as reinforcers and help to maintain the stigma.

Old and out-dated notions are transmitted across centuries to the extent that even today, people will believe

what they have read in print, or heard, although the information is scientifically inaccurate by today's standards. These former beliefs, which have become part of the folklore, are threatened by new scientific facts, herefore people cling to what they "know". The inherent nature of stigma is that even when scientific fact is acknowledged, folk beliefs persist and assume a position of importance.

In summary, therefore, it is suggested that stigma may begin with the manifestation of an abnormality, which is interpreted as divine retribution for some earlier moral transgression. Since it fails to respond to "treatment", the abnormality remains in evidence to reinforce this idea. Medical-religious emphasis on the association of sin and disease inhibits the development of scientific ideas about disease and fosters traditional beliefs, which are further perpetuated in literary works of all kinds. The stigma can only be broken when people accept new scientific evidence and reject out-dated beliefs. The more of the above characteristics (mystery, deformity, visibility, abnormality, religious ideas on sin and contagion) that are identified with a stigmatised condition, the stronger the stigma which it is likely to bear and the harder it is to remove. It is the intention of this study to test these propositions by using a particular disease, because those

who have been, and are, afflicted with it have been, and are, almost universally stigmatised. The reasons for selecting this disease and the rejection of other possible candidates is set out below.

Throughout history and transculturally, certain conditions have been associated with social odourness which we now call stigma. The specific conditions so identified vary with time and culture. One condition, however, is unique in the degree of social odourness it has attracted over time and space: leprosy. No other condition has attained such widespread, almost universal, notoriety. In this study, leprosy will be examined as a disease apart, to test the above propositions. It will be argued that the disease, now clinically identified as leprosy, is intrinsically predisposed to become stigmatised, for it fulfills all the conditions outlined above:

- (1) There is mystery about the cause: even in modern times the source of infection and the manifestation of the disease may be separated by an incubation period of several years, so no immediate link is apparent.
- (2) It is a progressive disease: that is, it can be seen steadily to get worse.
- (3) It is deforming as it progresses.
- (4) The deformities are in visible places - especially face

and hands - where they cannot easily be concealed.

(5) The type of deformity is ugly, unaesthetic and frightening.

(6) It is, or has been, frequently explained in terms of moral transgression of self or parents.

(7) Having been marked out for divine intervention, the victim is "impure", therefore a fear of contamination or association exists.

(8) The disease does not kill, so the sufferer remains in visible evidence to support the belief and perception that it is incurable.

(9) Finally, the victim is socialised in the same milieu as other members of his society, and consequently holds the same beliefs.

For comparison, the following conditions, all of which have carried some stigma at one time or another, are offered:

(a) Tuberculosis

Tuberculosis is not particularly visible: if cured, it leaves relatively minor deformity, with minimal further degeneration. The victim, being pale, thin, or with "radiant flushes", presents an "acceptable" picture. In the past it killed relatively quickly. Bacillus Calmette-Guérin (B.C.G.), has been used prophylactically, although current

debate questions its usefulness as a preventative vaccine. It can be diagnosed with Xrays and sputum tests, and effectively treated with a combination of drugs.

(b) Multiple Sclerosis

This is a relatively common, progressive, degenerative disease, with marked disability as it progresses. It is mysterious, advancing and then giving the impression of improvement, followed by further degeneration. In the advanced stage it is totally incapacitating, removing victims from public view. At earlier stages, non-visible symptoms may make apparently healthy, young to early middle-aged individuals appear "lazy". Although death does not result quickly, life expectancy is curtailed. If it existed historically, sufferers would have survived for even shorter periods, therefore stigma did not become established.

(c) Polio ~~myelitis~~

In its most virulent form "polio" kills quickly or leaves victims totally incapacitated, requiring life support systems such as the "iron lung", and the patient is not publicly visible. In less virulent forms, permanent disabilities of varying degrees of severity result, but the condition remains stable with no further degeneration. Thus it is seen to be "controlled".

(d) Sexually-Transmitted-Diseases-(STD)

Stigma is attached to STD where social attitudes condemn promiscuity. Until the advent of microbiology, untreated syphilis manifested itself with ugly lesions which bore similarities to those of many other diseases, including leprosy, allowing it to be confused with these diseases. With available treatment, however, the disease is rarely visible. More permissive societal attitudes have helped to reduce the stigma of STDs. Herpes II, or genital herpes, provides a contrary example in this category. The incidence has increased rapidly in recent years. Unlike gonorrhoea and syphilis, however, it is, at present, incurable. While lesions disappear within a short time, it can recur without notice. It can be transmitted unknowingly to sexual partners. Infected mothers can transmit it during delivery, causing brain damage to the infant. In herpes II, then, we have an example of a puzzling disease, which manifests itself, but then mysteriously disappears, although it lurks in the body and may return. It is transmitted sexually, and the greater danger is in promiscuous sexual activity. It is incurable. The sufferer is psychologically traumatised, and sharing the beliefs of society in general, the sufferer is likely to feel a social outcast, although the disease is not visible in the way that advanced leprosy is.

(e) Acquired-Immune-Deficiency-Syndrome-(AIDS)

AIDS provides a modern example with many similarities to those associated with leprosy. "Discovered" in 1980, it is only within the past year that the causal agent has been positively identified as a newly discovered sub-group of the human T-cell leukaemia virus family, designated HTLV-III, although a link between HTLV and AIDS was theorised in 1983 (Gallo et al, 1984; Popovic et al, 1984). There are many vague symptoms, but included are blue-violet or brown spots which may ulcerate and hence appear repulsive to observers. Its transmission is associated with illicit sexual activity, which tends to identify it as a venereal disease - even worse, a homosexual venereal disease. Other cases are associated with intravenous drug abuse, hence it is deemed "immoral". Its origin has been linked to Haiti, which introduces a racial stigma. Although AIDS has not been confined to these groups, "suspicion" about sexual preferences causes sufferers to be shunned, or makes them isolate themselves, rarely speaking out and acknowledging the illness because of its homosexual associations. If this condition existed in former times, sufferers would not have survived long enough to become stigmatised. AIDS and Herpes II may provide the opportunity to study stigma in the process of development.

Returning to leprosy, we have in the Judaeo-Christian religious tradition concrete evidence of the perpetuation of misconceptions stemming from the Old Testament association of ritual uncleanness with leprosy. Biblical translations into Greek, Latin and later into other languages, did not reduce this association, and in fact fostered it. In Mediaeval Europe, Christianity, in the form of one unified Church, provided religious and medical authority for a largely uneducated and ignorant population. Older medical texts were copied but new ideas were not encouraged by the patristic ideology. The Crusades appear to have contributed to the spread of leprosy in Europe, although the extent of this influence has undoubtedly been over-estimated. The occurrence of leprosy among former Crusaders necessitated a slight reformulation of theological ideas, in order to explain how participation in a Holy War could be "punished" in this way. The academic answer, by a convoluted interpretation of the parable of Dives and Lazarus (Feeny, 1964; Brody, 1974), indicated that the victim, stricken with leprosy in this world, was assured of God's grace, and after death would go straight to paradise. However, although the victims became "Christ's Poor", they did not escape social opprobrium in their "living death".

Social attitudes are expressed in popular as well as ecclesiastical literature from the Middle Ages onward.

Despite the scientific developments which have now made it possible to identify the causal agent and control or cure leprosy so that the severe deformities should not occur, the old notions are perpetuated as fact in modern popular literature, printed and visual media. The word "leper" is still in everyday usage to refer to any social outcast. When avoidance situations are referred to as "being treated like a 'leper'" or "as if one has leprosy", the erroneous implication that leprosy is a highly contagious disease is sustained, and the stigma is reinforced.

Leprosy will be examined historically and cross-culturally to see whether the association of characteristics outlined above is widespread, or has spread with western influence. It has been suggested that the spread of western Christian influence introduced the stigma of leprosy to areas where it did not previously exist (Rottberg, 1972). It is asserted here, however, that the widespread and unique attachment of social opprobrium to one disease cannot be solely attributed to one religious tradition, although that tradition encouraged its persistence. Before considering leprosy specifically, however, the variations in beliefs about disease causation will be examined.

DISEASE AND DEFORMITY: CONGENITAL ABNORMALITIES OF THE EYE

"C-35 C6 DISPOSED OF BY THE COMPANY IN A MANNER THAT NO RECORD
WAS KEPT OF THIS DISPOSAL AND THEREFORE IT IS NOT KNOWN WHERE
IT WAS SENT."

[illegible]

Theories about the causation of disease and its products and consequently must be viewed within their cultural context. Modern, technological civilization has developed means of diagnosing disease and their associated symptoms by methods which were unknown to earlier

societies. Beliefs and practices in those societies should therefore not be regarded as an irrational assortment of unconnected, meaningless customs. Definite ideas about the causation of disease led directly to methods of treatment and attitudes towards the victims of disease. The practices were not vague and indefinite, but the logical consequence of the prevalent beliefs about causation.

Throughout history, the most widespread theories of disease causation have been magical and religious. Rivers (1924/4) distinguishes between magic and religion thus:

[Magic is] a group of processes in which man uses rites which depend for their efficacy on his own powers believed to be inherent in, or the attributes of, certain objects and processes which are used in the rites...[and religion is] a group of processes, the efficacy of which depends on the will of some higher power, some power whose intervention is sought by rites of supplication and propitiation...[Thus,] religion differs from magic in that it involves the belief in some power in the universe, greater than that of man himself.

In theories of disease, however, this distinction is not necessarily clear, and treatment may involve a combination of magical, religious and medical practices.

Beliefs about disease causation can be classified in various ways: chronologically, geographically, or by causal agent. All are problematic. Since the intent of this study is to show that out-dated beliefs persist, and are reflected in the social response to diseases with which a stigma is associated, the approach to be used here will consider

theories about disease causation in two main categories: magico-religious beliefs in which cause is attributed to human or supernatural agents; and, "scientific" theories which attempt to theorise about disease on the basis of observation, experiments and eventually on verification.

1.1.1.1. MAGICO-RELIGIOUS BELIEFS ABOUT DISEASE CAUSATION

Magico-religious beliefs about disease causation are found in all societies throughout history, even when they co-exist with rational scientific knowledge and are relegated to a status of "superstitions", "folk medicine" or "old wives' tales". Such beliefs generally focus on a human or supernatural causal agent. In the former cases, the condition is believed to be due directly to the action of one human being with the ability to exercise power over others, and is totally magical in its ramifications. When disease is attributed to the actions of a non-human, but personified supernatural being, it is associated with religious practices, although some magical elements may remain.

Malinowski (1961) argued that diseases, health and death were all attributed to magic or counter-magic by the Trobrianders. Minor ills, considered "ordinary", did not cause anxiety and were short-lived. Other ailments,

longer-lasting, less explicable by natural causes, therefore raising anxiety, were attributed to sorcery or witchcraft. All conditions attributed to magic involve a human agent, even when other causes are obvious. It is thus a human agent who magically affects the spear which causes the wound, or causes a pain by casting a spell over the food. The diagnosis and treatment of such conditions depend on the power believed to be inherent in the practitioner and his rites (Rivers, 1924:12). As a result, care is taken not to anger a person thought to have such power, and to avoid those individuals seen as victims, for fear of contamination by association. Rituals vary, but all are based on the acceptance of one human being's ability to exercise power over others. These activities are discussed below.

(a) Sympathetic Magic

Sympathetic magic is used to bring direct or indirect harm to a victim (Frazer, 1935:52). In imitative magic, models of the victim are subjected to mutilation with the intention of causing the victim to become sick or die, while contagious magic makes use of bodily products, such as nail and hair clippings, excrement, names or shadows, simulating the desired effect (MacKenzie, 1927). Such beliefs, states Frazer (1935:175) made primitive peoples careful of their refuse, for sorcerers and victims alike

believed that sickness could result. Sympathetic magic is not confined to primitive groups however, as indicated by the burning of effigies by modern protesters, and the retention of folk practices in dealing with diseases which are puzzling.

The "soul", located in various parts of the body, according to different cultures, was singled out for special attention, being lured away by a sorcerer, or captured while wandering outside the body (Rivers, 1924:25). Loss of consciousness and chronic diseases were frequently attributed to the loss of the soul (Clements, 1932:225). Every effort was made to entice the soul back into the body to ensure the victim's recovery.

(b) Object Intrusion

In object intrusion, the body was thought to have gained some foreign object as a result of magical or spiritual intervention, with no clear boundary between the two, for the spirit contained in the object was thought to be the real cause. Magic rituals, often involving sleight of hand, enabled the magician to extract, and to produce the offending object (Black, 1970; MacKenzie, 1927).

(c) Transfer of Disease

Just as it was believed that disease could be magically caused, the idea that disease could be magically transmitted was widespread. Running water was believed to

carry disease away, and numerous springs and wells acquired reputations for their healing powers, even where scientific analysis reveals no potentially healing properties in the water. Their use was widespread in the treatment of chronic conditions and skin diseases. It was also thought that disease could be transferred to animals, just as the Hebrews symbolically transferred sins to the "scapegoat" (Leviticus 16:8-16). Transferring disease to a scapegoat was a common mediaeval European practice (Black, 1970). It precedes any notion of transmission of infection by direct contact with an infected individual. Even today, a commonly held folk belief in northern England suggests that warts can be transferred to another person by burying, at a crossroads a piece of meat with which the warts have been rubbed.

(d) Evil-Eye

A glance from a person with the faculty of the "evil eye" was thought responsible for sickness in ancient times from India to the Mediterranean (Sigerist, 1951) and in mediaeval Europe (Black, 1970). It is still a very common belief in the Middle East, where more than half of all deaths are attributed to it (Shiloh, 1968). There, the faculty of the evil eye is usually associated with envy. The healthy, the beautiful, the happy, and children are thought to be especially vulnerable. Children are disguised, made less attractive with dirt, given false names

and scolded to deceive the evil eye (Mackenzie, 1927; Shiloh, 1968). Good health or business success is down-played, while boasting and broadcasting future plans court disaster. When praise is accepted, the Will of Allah is simultaneously invoked, to counter the power of the evil eye. The best protection against the evil eye is an amulet of blue beads, worn on the person or displayed in the house or automobile, to deflect the evil eye or turn the malignant glance back against the perpetrator (Shiloh, 1968). Other examples of the effect of the evil eye come from Greece (Campbell, 1964; Sanders, 1962), nineteenth century England and Scotland, and from China (Black, 1970).

Magic depends on suggestion for its efficacy. Individuals believe in the possibility of being so afflicted, or cured. Some prophylactic measures, such as the disposal of refuse are pragmatic. Others, such as charms and amulets, are effective in many cases, because the individual thinks that they will afford protection. Curative procedures similarly depend on suggestion and a belief that they will work. Closely related to these magical beliefs which focus on human agents are those beliefs and practices which rely on supernatural explanations for their efficacy.

(e) Supernatural Agents

Once the causal agent is regarded as supernatural, the emphasis moves from magic to religion, gradually introducing the notion of disease as divine punishment. As postulated in chapter 2, when disease is seen as punishment for "sin", the development of stigma is fostered. Religious rituals, unlike magic, attempt to influence supernatural beings by supplication, incantation and prayers, sacrifices, propitiation and thanks, in various prescribed forms.

In pre-literate societies, all spirits were thought capable of producing disease when provoked, but in most human groups, a distinction was made between "good" and "evil" spirits, the latter considered "specialists" in causing disease. Three different groups of supernatural agents can be identified: (i) demons or evil spirits; (ii) spirits of the dead; and (iii) divine beings (Black, 1970; Sigerist, 1951). Each of the supernatural causal agents will be considered separately.

(i) Demons and Evil Spirits

Disease-causing demons or spirits were inherently evil, capable of affecting individuals or communities who carelessly neglected taboos or did not possess the right amulets (Sigerist, 1951). In such cases, disease could be considered avoidable by simple prophylactic measures, whether charms, amulets or incantations. Archaeological

evidence provides insights into some of the earliest beliefs and practices in Egypt, Mesopotamia, India and China, indicating that disease was attributed primarily to supernatural causes (Kutumbiah, 1962; Major, 1954; Sigerist, 1951). The earliest literary works from these areas contain incantations and chants to ward off such evil spirits.

In ancient Egypt, the aid of a rich pantheon of gods and spirits was enlisted to frighten away disease spirits, by means of incantations, often accompanied by manual rites. Amulets were believed to give more permanent protection, but those thought most efficacious usually contained specific costly or rare items. Successful treatment required the selection of the right drugs, the correct magical preparation and the appropriate incantation (Major, 1954; Sigerist, 1951). Similarly, the Vedic literature refers to various Indian gods and spirits concerned with the preservation of life, prevention of illness and the treating of the sick (Major, 1954; Sigerist, 1951). Diseases were sometimes associated with specific demons or spirits in India (Filliozat, 1964; Kutumbiah, 1962), and similarly identified in Mesopotamia (Black, 1970) and in China, where oracle bones were used in divining disease (Lu and Needham, 1967). Spirit intrusion differs from possession by a demon. In spirit intrusion, the spirit IS the disease, and the patient is cured when the disease (alias the spirit) has

been driven out. Possession by a spirit, on the other hand, results not in pain, but in disorders such as epilepsy. Those who become possessed may even be seen as holy men, in communication with the spirits (Clements, 1932:188, 219).

The idea that disease is brought by evil spirits remains widespread among many societies in Asia, Africa and Oceania, often being cited as the source of illness. Among the Chukchee of Siberia, males formerly wore labrets to ward off the spirits and childless women wore facial tattoos to drive away barrenness, a practice shared by the Koryak (Wheatley, 1978). Even in modern western society, amulets, such as copper bracelets to ward off rheumatism, are employed, and Black (1970) noted that an open Bible was thought to protect a child while asleep. Even nursery rhymes and the Office of Compline enlist supernatural assistance for protection through the night. The association of disease with a supernatural cause thus persists at the present time.

(11) The Spirits of the Dead

Amongst primitive societies, it was widely believed that the spirits of the dead could bring disease. Spirits, not wishing to be separated from the living might return to haunt the survivors. Fear of such spirits made burial sites places to be avoided in many societies. In societies where ancestor-worship was practised, failure to observe the

proper respect for the deity was thought likely to induce
inner and physical sickness or sterility (Gamble, 1970).
Again, the emphasis is on the healthy to take the necessary
precautions to avoid disease.

4.1.1. Divinities

Injecting the idea of a divine cause for disease
consequences on the health of mankind. A sense of
divine revenge comes from myths, legends and literatures,
such as the *Iliad* and *Odyssey* of ancient Greece, where
disease was thought to be inflicted directly by an angered
god. Thus, Apollo the god of health was also the remover
of disease and had to be propitiated and placated.
Other Greek gods had healing powers. At religious healing
centers its center in the sixth century B.C. with the cult
of Asclepius, the "wandering son of Apollo". To temples,
called Asclepeions, the patient underwent a purification
rite followed by "incubation", a sleep state in which
Asclepius effected a cure in a dream (Gardiner, 1970;
Gardiner, 1961). Large numbers of votive offerings
representing cured organs have been found in archaeological
sites, especially Epidauros (Gardiner, 1961).

In India also a divine cause of disease is
indicated in the prescriptions for treatment by
primitation, offerings, penance, purification and fasting
mentioned in the *Attharvaveda* (Gardiner, 1962). Hinduism

covers all aspects of life in its theological system. As indicated in chapter 2, while not carrying an association of guilt, moral transgressions were held responsible for unwanted consequences, including disease and untimely death. Buddhism, more a philosophy than a religion, incorporating many of the Hindu beliefs and practices, offers the possibility of liberation from suffering to everyone who practices moderation in all things. A similar philosophy is observable in the teachings of Confucius, who ascribed disease to the excesses or faults of the parents. At the same time, gods associated with indigenous Chinese religious practices are thought to seek retribution by sending disease.

With disease attributed to angered gods, a new dimension is introduced. Avoiding evil spirits no longer provides adequate protection. When powerful, offended gods seek revenge, disease comes to be seen as punishment for some legal or moral transgression. When disease occurs, the offence must be identified and retribution made. In Mesopotamia, for example, "sin" gradually came to be considered the main cause of disease, legal transgressions such as theft and moral transgressions being equally considered sin. Sigerist (1961:472), suggests that the sin-punishment concept acquired prominence as the concept of the deity became purer. Certainly the idea that human

failings were punished with suffering sent from the gods was widespread in the Middle East.

So far, with the exception of Buddhism, reference has been confined to beliefs in specific geographical areas. However, magico-religious beliefs are present in major world-wide religions. Judaism, Christianity and Islam all have their origins in the Middle East, and illustrate the purer concept of the deity to which Sigerist referred. How these religions view disease will now be considered.

Judaism, Christianity and Islam

The Old Testament is part of the common ancestry of the three religions, but it most clearly identifies the essential beliefs and affirmations of Judaism. It sets out the socio-religious code of conduct for the "Chosen People". Prophets warn of the consequences of neglect. God's wrath is illustrated by the plagues sent to Pharaoh, the "leprosy" inflicted on Miriam (Numbers 12:10-12; Deuteronomy 24:8-9), Uzziah's "leprosy" for wrongfully performing a religious ritual (II Chronicles 24) and the sufferings of Job. All testify to the dreadful might of an omnipotent God, who is both creator and law-giver. Afflictions occur suddenly, victims being stricken or smitten, as a result of their transgressions. The book of Leviticus clearly identifies conditions which are considered ritually impure or unclean, which require withdrawal of the individual from social

8-

intercourse. Jews dispersed after the fall of Jerusalem in 70 A.D., impressing other peoples by their moral way of life and their care of the sick and needy (Cartwright, 1972). Although Jews have assimilated many aspects of culture of the countries in which they have settled, they have retained a strong adherence to their concept of ritual purity.

Christianity was taking root at the time of the Jewish dispersal. With a strong emphasis on healing, it offered a new kind of hope, through the miraculous and divine healing power which appeared to have been given to the disciples (Cartwright, 1972). While both Jews and Christians cared for the sick, Old Testament teaching emphasised sickness as punishment for transgressions, whereas Christianity, as expressed in the New Testament, taught that disease was not punishment but a means of purification. Suffering perfects the sufferer (Siderist, 1943). Self-flagellation and fasting were practical expressions of this belief. Christianity, therefore, offered not only the possibility of a physical cure, but the promise of a future reward for the truly repentant sinner (Cartwright, 1972).

Miraculous healing powers were later attributed to saints who were invoked for protection and cure, just as primitive societies called upon spirits. After Christianity became the state religion of the Roman Empire in the fourth

century A.D., medicine was concentrated in the Church. The practice of medicine depended primarily on supernatural interventions, and many treatments were pure magic (Cartwright, 1972). With the development of the concept of sin (see chapter 2), disease and moral transgression were again associated. The revival of learning at the end of the Middle Ages was under the patronage of the papacy, and the birth of modern science met with a hostile reception from the Roman Catholic Church. The Christian practice of caring for the sick was carried to new areas, with European expansion. Also introduced at the same time were the moral concepts associated with certain specific diseases which had crystallised during the Middle Ages.

Islam is also a missionary religion. Over time it has spread across Africa and large parts of Asia. Islam encompasses a belief in a provident and merciful God, whose power is unlimited. For the faithful, repentance is always possible and returns the penitent to a state of sinlessness. Man exists to serve God, and alleviating suffering and helping the needy are integral parts of the teaching. Although disease is frequently attributed to moral transgressions, especially sexual misconduct, the evil eye is widely held responsible for the occurrence of disease in areas under Muslim influence (Shiloh, 1968).

while all diseases appear mysterious to the uneducated, physical abnormality constitutes a bigger threat. It was shown in chapter 2 that in many societies, abnormal births, whether multiple births or deformed infants, attract special attention. Most abnormal births are attributed to supernatural intervention, either by malevolent spirits or as punishment for moral transgressions of the parents, especially the mother. Thus abnormality is viewed in magico-religious terms.

When the concept of sin becomes more developed, moral transgressions alter in character, with the implication of willful disobedience and guilt. Sin is held responsible for such mysteries as congenital defects, and a particular transgression is sought as cause. Where religious teaching threatens that "sin" will be punished by physical suffering in the form of disease or deformity, the association becomes firmly ingrained. Abnormality marks out a transgressor. If no transgression is immediately evident, divine intervention, non-specific in nature, may be substituted - "God's Will" or "the Will of Allah". Such explanations are emotionally satisfying (Berger, 1969), for "God's will" is not necessarily comprehensible. God knows why, so further explanation is not necessary. Thus, in some conditions which cause anxiety or are in other ways difficult to explain, magico-religious notions persist.

Such over-simplified notions prove resistant to scientific explanation.

Magico-religious therapy was not confined to conditions attributed to magic, but co-existed with attempts to explain disease in a rational, scientific way. These attempts are discussed in the following section.

II. RATIONAL-SCIENTIFIC BELIEFS ABOUT DISEASE CAUSATION

In this section we will consider attempts to understand disease without relying on magical or supernatural explanations. Even where, from our current understanding, the ideas seem fanciful, they must be recognised as the early "gropings" from which modern scientific knowledge developed. Kuhn (1970) and others have discussed how scientific knowledge advances when the prevalent explanations are no longer adequate. An essential factor is that old information is retained or rejected on the basis of whether or not it fits in with new theories. There is not necessarily a consensus of opinion on the subject. The early ideas to be discussed here will be termed "proto-scientific theories", but they correspond roughly to Sigerist's (1961) "empirico-rational" medicine.

(a) Proto-scientific Theories About Disease Causation

(i) Observation and Examination: In the positivist tradition, which is widely accepted in the Western world today, all scientific explanation begins with description based on observation, examination and experiment. The simplest form of experiment is to try something then see what happens. Observing the progress of disease is less easy, but by process of trial and error, some treatments will be found more successful than others. Trauma has been treated rationally in most societies, not only the more advanced civilisations. In many societies magico-religious practices co-existed with attempts to identify, treat and cure disease in a logical, scientific way.

This co-existence is clearly seen in ancient Egyptian medicine as revealed in the papyri, dating back to 1900 B.C. Based on observation and examination of the patient, diseases were described, named after the main symptom, causes suggested and appropriate treatment prescribed (Sigerist, 1951:302). A reference manual was thus provided for future use. Emphasis on observation and examination revealed combinations of symptoms but could not identify them with a single cause (Sigerist, 1951). Clay tablets from Mesopotamia from the second millenium B.C. provide information which indicates a similar emphasis on

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observation (Kinnier Wilson, 1967). In India too, close attention to detail provided descriptions of recognisable diseases (Filliozat, 1964; Kutumbiah, 1962; Major, 1954; Sigerist, 1961; Zimmer, 1948). Detailed case histories from the first millenium B.C. in China reveal a similar emphasis (Lu and Needham, 1967), as do those of the Greek physicians of the Hippocratic tradition (Brock, 1951; King, 1978; Sigerist, 1961; Smith, 1979).

(ii) Classification: With the close attention to detail indicated in the preceding section, the classification of diseases was an obvious development. In India, Caraka classified diseases as physical, accidental or mental, while Susruta's four groups were trauma, physical, mental and natural (Kutumbiah, 1962) and were closely associated with the tridosha theory (see humoral theories below). Similarly, Chinese and Greek physicians classified diseases by the predominance of particular "humours" (Lu and Needham, 1967; King, 1978).

(iii) Environmental Theories: Hippocrates, the fifth and fourth century B.C. Greek physician, is generally acknowledged in the western world as the first to seek the cause of disease in earthly influences, rather than as visitations from the gods. He asserted that each disease

had a nature of its own, stemming from an external cause. Hippocrates' treatise on "Airs, Waters, and Places" discussed the effect of food, occupation and climate on disease causation (Sigerist, 1961). Indian medicine, however, also sought the underlying cause in:

(a) excessive, deficient or wrongful use of sense objects such as loud noises, bright lights, unpleasant sounds or smells, or unbalanced diet.

(b) climatic conditions which were unnatural for the time of year.

(c) the misuse of intelligence - that is, not doing the right thing at the right time (Caraka, cited by Kutumbiah, 1962).

During the first millenium B.C. Chinese physicians were also very conscious of the relationship of diseases to geography, climate and seasonal changes, very much like the Hippocratic concept of "airs, waters and places". By the second century B.C., characteristic epidemics were associated with each season: fever and headaches with spring; itching, scabies-like epidemics with summer; malaria and other fevers with autumn; and respiratory ailments with winter (Lu and Needham, 1967). The Smith papyrus from Egypt contains incantations against "pest" - diseases caused by wind, asses, geese or flies (Major, 1954) and there was an apparent awareness of the effect of air and dirt in

promoting disease (Sigerist, 1961). All these ideas are similar to modern concerns with the effects of environmental factors on health. They indicate that at an early stage the complex inter-relationship of internal physical causes and external environmental influences was recognised. From this realisation developed the earliest pathological theories.

(iv) Humoral Theories: The Greek humoral theory grew out of attempts to explain nature as an orderly system, composed of four elements (fire, air, earth and water) with which were associated four bodily humours: blood, phlegm, yellow bile and black bile, on the equilibrium of which good health depended. A similar concept current in India, known as the tridosha theory, attributed disease to the imbalance of the three dosas or humours - air, bile and phlegm (Kutumbiah, 1962). The dualistic cosmic theory of traditional Chinese medicine, in which the preponderance of the male principle Yang or the female principle Yin determined health, can also be considered "humoral". One school classified diseases according to excess of one of the six elements - Yin, Yang, wind, rain, twilight and brightness (Lu and Needham, 1967). Resting on a humoral pathological theory of disease, all these systems recognise different types of disease. No pathological theories of disease were developed in Egyptian and Mesopotamian medicine, but a rudimentary theory of

inter-connecting vessels in which disease originated (Sigerist, 1951) suggests thinking along the lines of the humoral theories.

Given that Greek medicine, on which European medicine depended for centuries, and Indian and Chinese medicine, which influenced Asian medicine, developed spontaneously and contemporarily, the similarities in their understanding are worth considering. All took a holistic view of medicine recognising the importance of external factors, but at the same time aware of physical changes. All placed importance on diet and also recognised heredity as an important factor. Minute details and variations were observed and described, such as quotidian, tertian and quartan fever, typical of malaria, or the characteristics of what is now known as tuberculoid and lepromatous leprosy (Browne, 1975). Comprehensive systems of medicine were based on extensive classificatory systems, diagnostic techniques and treatment procedures associated with the findings. This holistic approach to health and disease seems far removed from the purely magical and religious beliefs about causation discussed earlier in this chapter. Nevertheless, omens were consulted in making decisions on whether or not to treat, and were an integral part of Hindu (Kutumbiah, 1962), Chinese (Lu and Needham, 1967) and Greek

(Sigerist, 1961) medicine. Thus, alongside rational attempts to identify and treat disease, magic and religious ideas persisted. Of particular relevance to this study is the fact that diseases thought incurable were not treated according to the current medical theories, but were consigned to animistic explanations and magical therapy (Sigerist, 1961). Whereas medical practitioners treated victims of conditions they identified as curable, the care of "incurables" remained in the hands of magico-religious practitioners. Thus, incurable conditions were transferred from the sphere of medicine to the sphere of religion. Only through divine intervention could "incurables" be cured.

Western proto-scientific theory

The basic notions of causation persisting until the seventeenth century in Europe, derived from traditional Greek medicine extending back through Galen to Aristotle and Hippocrates. It was based on the Aristotelian doctrine of four causes, on which logical analysis rests, and the distinction between concrete and abstract, particular and universal, experience and knowledge, and scientific knowledge and art (King, 1978:216). Scientific knowledge (*episteme*) was supreme, dealing with what is necessary, eternal and invariable, like mathematics. Knowledge related to medicine is clearly different in character, for it

implies choice and the possibility of variation. Aristotle termed this conceptual approach *techné*. In medicine *techné* applies to generalisations about a whole group based on individual experiences. Such an approach was taken by Hippocrates. Aristotle argued that men of experience know what is, but not why it is so, whereas those with *techné* know both the what and the cause of it being so. *Techné*, the theoretical background, is the rational component of medicine. Empiricists, not knowing the theory, are ignorant of causes and proceed from one specific case to another (King, 1978:236-238). This distinction between theory and practice in western medicine persisted until the eighteenth century.

Galen, a second century Greek physician from Asia Minor, who spent much of his professional life in Rome, was a prolific writer and left a clear picture of medical understanding at the time. In a textbook, he outlined the different contemporary schools of thought which had developed from the time of Hippocrates. The Dogmatists, or Rationalists, he noted, relied on theory and reason, while the Empiricists relied on experience alone. The Methodists, who distanced themselves from both schools, were empiricists in their rejection of research, anatomy, and consideration of circumstances surrounding disease, looking only at the "obvious" causes. Yet they were dogmatists in professing a

pathology of disease, a sort of "flux" theory, attributing everything to "flux" or obstruction (Galen, 1929). Galen studied at Alexandria in Egypt, where the study of anatomy had flourished under Herophilus, a first century B.C. physician. Although human dissection was prohibited, he dissected animals and related his findings to human beings. He developed a theory of the circulation of blood from the liver, through the lungs, to the body, which was discharged its residues and was supplied with blood again.

Apart from trauma, most conditions were attributed to **crisis** - the lack of balance among the humours. It was important to distinguish the cause from the symptoms and symptoms, so that the cause could be treated and the body restored (Smith, 1979). Galen on Crises: Evidence of four causes. Galen argued that, as well as obvious or immediate causes, obscure factors and original or remote causes should be considered, together with the accompanying circumstances (Brock, 1929; King, 1979; Smith, 1979).

From the time of Hippocrates, the influence of Greek medicine has been widespread. Under Alexander the Great, the empire stretched from southern Italy, through North Africa and Egypt, into Asia Minor and Mesopotamia. With the rise of Roman and decline of Greek political power, medicine and other Greek achievements were incorporated by the Romans. Greek medicine flourished on the periphery,

especially at Alexandria, and Greek physicians, notably Galen, found their way to Rome. The only extant Roman commentary of medicine is *De Medicina*, written by Celsus in the first century. In this work, which seems to have been overlooked in his lifetime, he gives his version of the Hippocratic writings and indicates a sophisticated level of medical practice. He particularly emphasises the need for cleanliness in the treatment of wounds (Smith, 1979).

After the death of Galen in 199 A.D., no innovative work appeared for centuries (Sigerist, 1979). However, Greek medical ideas were copied and preserved in Christian monasteries in Europe. In Asia Minor and Syria, Greek texts were translated into Arabic by the Nestorian Christians who branched away from the Roman Church in the fifth century A.D. Interest in Greek scientific works intensified with Arabic expansion in the seventh century, and they were used in training Arabian physicians. Of these, Rhazes (865-925) and Avicenna (980-1037) contributed most to the development of medical thought (Sigerist, 1970). Rhazes produced a monograph distinguishing measles and smallpox, and began compiling an encyclopaedia of medical knowledge, recording all that had been known to Greek, Arabian and Indian physicians, plus his own observations. He emphasised the importance of clinical histories and criticised theoretical "hair-splitting" (Sigerist, 1970). Avicenna was a

systematic thinker, regarding Aristotle as mentor in philosophical matters and Galen in medicine. He attempted to make medicine a scientific discipline embracing all Greek and Arabian knowledge (Sigerist, 1970). While no advances were made towards finding the cause of disease, Arabian medicine contributed the use of chemical preparations in their treatment.

Thus Greek ideas on disease causation were spread eastward to Persia, and then carried westwards with later waves of Islamic expansion. "Arabian" medicine flourished in Spain until the end of the fifteenth century and persists in the east until the present time. In the period when Arabian medicine flourished, the Greek ideas were kept alive in monasteries in Europe. It was not until the end of the eleventh century, however, when Constantinus Africanus translated some of the Hippocratic Writings and the works of Galen from Arabic into Latin that Galen's influence was fully felt in the west. The wealth of "new" knowledge thus exposed inspired the founding of medical schools in the west, the first at Salerno in 1171, paving the way for the development of scientific theories about disease causation. For centuries, however, the proto-scientific humoral theory remained prominent, accompanied in the western world, as in other geographical areas discussed, by religious and magical elements. Thus, even as scientific theories were taking

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shape, the victims of incurable or mysterious conditions were part of the domain of religion rather than the domain of medicine.

The Rise of Scientific Theories of Disease Causation

Scientific theories of causation developed out of the desire to escape the limitations of old traditions. The process was slow in medicine, as in other spheres, for tradition proves a formidable opponent. Only through careful observations which revealed errors in Galenic theories were individuals able to contribute to the process. Paracelsus (1493-1541) questioned traditional theories and therapeutic methods, especially the doctrine of the humours, which, he maintained, inhibited the practice of medicine. In 1546, Frascatoro (1470-1553), in De Contagione, theorised that certain diseases arose from imperceptible particles carried in the air or passed on by contact, the first real "germ" theory. With the reacceptance of human dissection, it became obvious that the human body did not conform to the descriptions by earlier masters. Vesalius (1516-164) produced an anatomy textbook based on his own dissections. Then, in 1626, William Harvey (1578-1651) published his great, but controversial, work on blood circulation, displacing Galen's tidal theory (Sigerist, 1970).

All these developments were based on what could be

seen and proven through observation and experiment. These methods were facilitated by the invention of the microscope, which revealed details not visible to the naked eye. Other instruments, such as the clinical thermometer, aided clinical practice. All these innovations were necessary steps in developing scientific theories of causation, but they met with strong resistance in academic circles where Galen's theories were still esteemed. Since the international language of science was Latin, and the same academic customs prevailed throughout central and western Europe, the old traditions were difficult to undermine.

The seventeenth century physician Thomas Sydenham (1624-1689) denounced speculation, regarding illness as a natural process in which the doctor's role was to assist nature's healing power, much as Hippocrates had stated some two thousand years earlier. He devoted his attention to specific diseases rather than disease in general, using keen observation to identify the onset, progress, and effects of treatment that distinguished one disease from another. Although attributing all diseases to "noxious influences" reflecting humoral pathology, Sydenham's descriptions of disease entities - smallpox, measles, dysentery, syphilis - started a new trend, paving the way for the eventual recognition of specific causes.

The concept of disease entities was reinforced by

anatomical research which enabled causal relationships to be made between symptoms and abnormal organs at post-mortem examination. Auenbrugger's (1722-1809) method of percussion made it possible to identify diseased organs before death. Throughout the eighteenth century, the understanding of the human body was expanded by research in anatomy and pathological anatomy, which in turn led to the study of physiology.

The nineteenth century saw the development of physiology and bacteriology. Jenner's (1749-1829) work on smallpox at the end of the eighteenth century had renewed interest in tracing disease to a specific cause. The discovery of the cell as the basic unit of animal structure was to revolutionise medical ideas. In 1839, Schwann (1810-1882) published his cell theory, stating that cells are organisms, and that animals as well as plants are aggregates of these organisms. (Encyclopaedia Britannica, 1975). Schwann believed that cells became "organised", that is, acquired cellular structure, when they formed out of a dead, undifferentiated substance. Virchow (1821-1902) refuted that theory, proving that cells grow out of cells. In his book on cellular pathology, published in 1858, he located the seat of disease in the cell, stating that disease was the reaction of the cell to abnormal stimuli (Sigerist, 1970).

While Virchow was working on cells in Germany, Pasteur (1822-1895) was developing the preservation process known as pasteurisation in France. He had confirmed that living organisms were the cause of disease, but it was still widely believed that these microbes were the result of spontaneous generation. After years of experiment, he was able to prove that disease causing micro-organisms were in the air. He then worked to develop "vaccines" to protect workers from infectious diseases such as anthrax that they might acquire from animals, (Sigerist, 1970), although he found it difficult to convince physicians of its success.

In 1840, Henle (1808-1883) theorised that specific diseases could be attributed to specific organisms, using the term "miasma" to describe the infective substance which produced disease. A miasmatic disease came directly from the environment and was not passed directly from one person to another. He described the latter as a "contagium". He argued that disease could only occur if these infective substances were living organisms, but he was unable to demonstrate their existence (Sigerist, 1970). It was microscopic examination of blood which enabled keen observers to identify micro-organisms. Other close observers were noting the presence of organisms in cases of infectious disease. Then, in 1873, the Norwegian Armauer Hansen became the first to identify and associate a specific

bacillus with a specific disease. He identified *M. leprae* as the cause of leprosy. It was Robert Koch (1843-1919) who demonstrated conclusively that specific organisms were responsible for specific diseases, by cultivating bacteria artificially and injecting the culture into healthy animals which then manifested the original illness (Sigerist, 1970). This work, together with the staining methods he introduced, made possible the identification of several bacteria as causes of specific diseases before the end of the century.

Medicine in the twentieth century has been characterised by further developments in chemotherapy, immunology and endocrinology and improved diagnostic techniques. The developments of the nineteenth and twentieth centuries have made it possible to identify the causes of disease scientifically. Perhaps the greatest advances came at the end of the nineteenth century when infectious diseases started to become controllable, and raised the expectation that all disease would succumb to scientific study. That dream has not been realised.

In this chapter we have examined various ideas about disease causation. Although centuries of scientific endeavour separate beliefs in spirit intrusion and the identification of micro-organisms with the aid of electron microscopes, there is a remarkable parallel in the

recognition of a living cause. Medical knowledge in the past was confined to a limited number of individuals - shamans, priests, or an educated elite. Today, medical scientific knowledge is widely disseminated among the general public by means of printed material and open discussion. Yet, despite all the spectacular advances, of which the public is aware, many folk beliefs are retained, and influence the social response to certain conditions.

Ideas about disease, life and death have varied through time. To primitive men, all diseases were seen as life-threatening and were explained in terms of evil spirits, demons or magic. Protective measures consequently included charms and incantations, while "cure" was effected by appeasing the offended spirit or counteracting the sorcerer's magic. A more scientific approach, based on the study of symptoms, observation and examinations developed in Egypt, India, China, and later in Greece and the rest of Europe. But, even in these societies, old magico-religious ideas persisted. Only with the development of bacteriology in the nineteenth century did many diseases become identified as clinical entities. Until that time, the medical understanding of many diseases, leprosy among them, was limited. The medical understanding of leprosy, however, is difficult to disentangle from the socio-cultural overtones. As far as possible, the following chapter will

concentrate on the clinical understanding of leprosy in different eras and different cultures. This will provide a basis for understanding the special treatment leprosy has been afforded, medically, and socially, to be discussed in chapters six and seven.

CHAPTER 4

LEPROSY: A DISEASE LIKE OTHERS

"If there is one diagnosis that should not be established unless there is absolute certainty, it is that of leprosy"

World Health Organisation (1980)

In chapter 2 the various socio-cultural factors which together influence the development of stigma associated with certain health conditions were examined. Then in chapter 3, cross-cultural and historical variations in beliefs about causes were explored in order to place leprosy in historical-cultural context. Having dealt with the historical and cultural issues about disease in general, it is now necessary to set out the current scientific and medical facts about leprosy, in order to show how stigma drastically distorts the popular concept of the disease, despite the scientific evidence. In this chapter, it will be shown that the medical understanding of leprosy, like that of other diseases, has undergone considerable change over time, as new information and techniques have become available. An understanding of the medical facts about leprosy will prepare the way to explore the myths and

misconceptions which have accompanied leprosy in most societies and most historical periods and have encouraged its stigmatisation.

The Medical Understanding of Leprosy in Former Times

It is well established that in India by 600 B.C. many of the characteristics of leprosy were known. The Susruta-Sambhita distinguishes between two kinds of skin lesions, the first characterised by local anaesthesia and deformity, and the second featuring ulceration, falling off of fingers and the sinking of the nose (Dharwadra, 1947, 1967). This is clearly a distinction between the tuberculoid and lepromatous forms of leprosy discussed below. Sigerist (1961) states that in the earliest Indian medical literature leprosy was recognised as an entity in itself, being considered contagious and transmissible from parent to child. According to Jolly (1951) the Susruta-Sambhita also recognised other characteristics of leprosy, such as hoarseness. He also noted that close contact could cause it to be transmitted, like fever.

Kutumbiah (1962), citing Susruta-Sambhita I, 24 (to which Sigerist may well be referring) indicates that leprosy was believed to be hereditary, resulting from diseased semen or menstrual blood, although in Susruta-Sambhita I, 15 it is attributed to "disordered blood" (Kutumbiah, 1962:80-86).

Although certain "impurities", including skin disease, were generally thought minor, some signs and symptoms were considered to offer a poor prognosis. Among these were abnormal changes in physical condition, such as loss of sensation of touch, change of colour of any part of the body, or dryness of any area of the skin. Also, certain skin diseases were viewed as potentially fatal for lack of possible treatment (Kutumbiah, 1962:103). Leprosy could have been identified in this category on the basis of depigmented patches, anaesthesia, loss of sensation of touch and loss of perspiration. Thus, it seems that in ancient India, leprosy was identified as an entity and regarded as a serious medical problem. *Kushta*, the Sanskrit word in medical texts which is translated as "leprosy", was believed to be the worst of diseases, since death from *kushta* meant automatic affliction by it in a future life.

In the Far East, in China, certainly before 200 B.C., the loss of eyebrows, nasal destruction, nodules, ulceration and hoarseness were recognised as characteristics of leprosy (Lu and Needham, 1967; Skinsnes, 1964b). Accurate references to leprosy can also be found in the second century A.D. when Hua T'o, a Chinese surgeon, clearly described the progress of the disease. In the seventh century, Sun Szo-mo devoted a whole chapter to leprosy, insisting on long term treatment, including dietary

modification and the use of a preparation made from dried, powdered turpentine (Skinsnes, 1964b). The extensive use of plants in treating disease included chaulmoogra oil. This plant extract was used throughout the centuries in China, and late in the nineteenth century it was adopted as a treatment and potential "cure" by Western societies.

During the first half of the eighth century, the first leprosy hospital was opened in Japan, by the Emperor Komyo. Japanese law recognised leprosy as contagious, and the oldest Japanese medical text in existence, from 800 A.D., regarded leprosy as a disease communicable from man to man (Skinsnes, 1973).

Debate continues as to whether leprosy was known in Ancient Egypt, Mesopotamia and Biblical lands, but certainly by 300 B.C. it was known in Grecian medical circles. An accurate description of leprosy was given by the Alexandrian physician Erasistratos (c.300-250 B.C.) (Gronow, 1972). Second century A.D. Greek physicians, including Aretaeus, Galen and Soranus, and the first century Roman scholar Celsus, all gave good descriptions of leprosy (Kalisch, 1975). Medical knowledge concerning the disease declined in the west, but Greek works were translated into Arabic (Kalisch, 1975). Arab physicians considered leprosy transmissible by contact, but it was commonly attributed to the eating of asses (Mettler, 1947). Greek and Arabic

medical texts were reintroduced into Italy at the end of the eleventh century by Constantinus Africanus (Kalisch, 1975). His theory of four species of leprosy was based on Avicenna's, who in turn based his theory on Greek humoral theory.

The humoral theory persisted as the basis of mediaeval European medicine. A comparison of important thirteenth and fourteenth century writers led the German medical historian Carlowitz (1913) to conclude that, in describing leprosy, the author depended on the works of Rhazes, Ali Abbas and Avicenna, and the commentaries on them by Constantinus Africanus, all of which relied heavily on Greek sources, rather than using their own observations (cited by Brody, 1964:45). The works differed only slightly, frequently using the same phraseology. It was pointed out that mediaeval medical literature's clinical descriptions were very vague and could apply to many possible conditions. As an illustration of this point, Theoderic (1207-1298) identified as characteristics of leprosy, symptoms such as "corrupt sweating" and "the face becomes puffy", which either do not occur in leprosy or apply also to a wide variety of conditions.

Adherence to tradition was paralleled in medical ideas on causation of leprosy in mediaeval times. Notions of sin, punishment and moral impurity led to leprosy being

regarded not only as a physical but also as a moral disease and resulted in additional, non-observable characteristics being attributed to it. Foremost among these was the association of promiscuity and lust with leprosy, therefore it was commonly regarded as a venereal disease. Desire for coitus was frequently considered a symptom of leprosy, and castration was just one of the extreme measures recommended as a cure (Kalisch, 1975). The consequences of leprosy being regarded as a moral disease are discussed in detail in chapters six and seven. Dietary causes, such as bad wine, rotten or highly spiced meat, and fish were also put forward by mediaeval physicians.

The approach to medicine during this period was generalist rather than specialist. The introduction of the printing press, which facilitated access to medical knowledge, awakened a new interest in learning and led scientists to question earlier traditions. In 1540, Frascatoro, an Italian physician/poet, helped to differentiate syphilis from leprosy (Kalisch, 1975). In the same year, a French physician, Pierre Bocellin, wrote a 47 page treatise on the contagiousness and infectiousness of leprosy. Other publications followed, the most notable of which was Ambroise Paré's Traite de la Peste... avec une Brefve Description de la Lepré in 1568 (Kalisch, 1975). The greatest advances, however,

did not come until well into the nineteenth century.

The first significant development was a publication by Danielsen and Boeck in Bergen, Norway in 1847. This seminal work gave a meticulous description of the disease picture of leprosy and its associated pathology. Danielsen did, however, regard leprosy as a hereditary disease, leading Danish authorities to close leprosy hospitals in Iceland, on the basis that segregation was not necessary (Skinsnes, 1973). In Britain also, the Royal College of Physicians declared in 1867 that "there is an almost unanimous concurrence of opinion that leprosy is often hereditary" (Browne, 1975). However, Armauer Hansen, a Norwegian physician, believed that the hereditary cause of leprosy had not been substantiated, and being firmly convinced that leprosy was infectious, he committed himself to proving it. After repeated microscopic examinations of leprous nodules, in 1873 he identified and described the bacillus *Mycobacterium leprae* as the causative agent. Both Danielsen and Hansen tried unsuccessfully to inoculate themselves with leprosy.

The First International Leprosy Congress, held in Berlin in 1897, recognised skin and nasal discharge of bacilli and the contagiousness of leprosy, and accordingly recommended its control by segregation of patients with leprosy (Skinsnes, 1973). Despite these findings, the

Journal of the Medical Graduates' College London in 1903 scorned the consideration of leprosy as a contagious disease like tuberculosis. Various attempts to cultivate *M. leprae* were made in the early twentieth century, but the claims to success were not substantiated. Chaulmoogra oil and its derivatives, long recognised as a treatment in China, became the standard treatment for leprosy about the time of the first world war. Large doses were necessary, side effects considerable and relapses were frequent. However, the use of chaulmoogra oil was widespread until it was superseded by sulphone therapy in the 1940s (Cochrane & Davey, 1964:377).

The Medical Understanding of Leprosy Today

Despite the great advances in knowledge about the disease over the past one hundred and fifty years, leprosy remains a complex disease in all its aspects. Each advance has raised hopes of eradication within a relatively short time, the latest target by WHO being the year 2000 (WHO 1976), a goal which now appears unattainable. What then are the known facts and the problems in controlling and eradicating this disease? The following discussion is based on the standard medical text for leprologists, Leprosy in Theory and Practice by Cochrane and Davey, comprising contributions by eminent leprologists from around the world. First published in 1951 it has been through two

further editions as understanding has increased. Other information comes from WHO publications of Expert Committees on Leprosy (1965, 1976, 1977, 1980, 1982), and from specialised leprosy journals which report current research.

Aetiology

Leprosy is caused by a bacillus, *M. leprae*, the first pathogenic micro-organism described and associated with a specific disease. *M. leprae* is a human pathogen, that is, it causes disease in human beings, whereas animals are not naturally susceptible to infection by it. Even in human beings, its infective power is low. The bacillus has an affinity for nerve tissue and cool areas, and therefore primarily affects superficial nerves and skin. It is considered only slightly contagious because about 90% of the world's population is not susceptible. Within the susceptible group, there is a spectrum of disease characteristics dependent on the degree of susceptibility. This ranges from the type of leprosy known as "tuberculoid" leprosy, which occurs in susceptible patients who have some immunity, to "lepromatous" leprosy which occurs in patients with no immunity. In tuberculoid leprosy, the disease is localised by the body's defence mechanism. In lepromatous leprosy, where there is little or no resistance, the disease is disseminated throughout the body. Tuberculoid leprosy is not infectious, whether or not the patient is on treatment.

Lepromatous leprosy, on the other hand, is infectious when the patient is untreated, but becomes non-infectious within weeks of commencing adequate treatment.

Transmission

The disease is transferred from an infectious human being to another susceptible human being. Contrary to popular belief, it is not a tropical disease, but rather a disease most commonly found in Third World situations. It was endemic in Europe in earlier times, only recently died out in Norway, and still persists in countries in southern Europe. Because of its low infectivity, prolonged, fairly close contact is needed, a situation which is facilitated in overcrowded living conditions, conditions characteristic of developing areas. The relative difficulty of transmission is seen in the small number of leprosy workers who become afflicted with the disease. It used to be thought that the route of transmission was skin to skin, as African children carried on the mother's bare back frequently had the first lesion in the middle of the forehead, whereas Korean children whose mothers' backs were covered did not have this lesion. It is now recognised that live bacilli may be shed from ulcerative lesions or be spread by droplet infection from the nasal mucosa where high concentrations of bacilli are located.

Signs and Symptoms

One of the complexities of leprosy is the wide variation in signs and symptoms associated with the infection, depending on the type of leprosy and the stage the disease has reached. Some of the early signs, such as an area of numbness and a slight alteration in skin pigment, may go un-noticed, unless a whole population is being surveyed. In tuberculoid leprosy, skin lesions, whether small or large, are clearly defined, and the area exhibits loss of pigment, hair, absence of sweating and the most characteristic symptom, loss of sensation to touch. Nerves become enlarged and tender, especially the ulnar nerve, just above the elbow where it is close to the skin, and the posterior tibial and lateral popliteal nerves in the leg. As a result, patients lose sensation in hands and feet, which are then damaged by sharp or hot objects. Although the resulting trauma are often taken to be direct signs of leprosy, they are actually only indirectly due to leprosy, being the consequence of repeated injury to insensitive hands and feet. Nevertheless, observers respond to these deformities as characteristic of leprosy, and victims are avoided as if they are contagious. A direct result of ulnar nerve damage is the development of a "claw" hand, and foot drop is due directly to weakened muscles resulting from damage to nerves in the leg.

In lepromatous leprosy, the skin lesions are more numerous and not clearly defined. They may ulcerate, and the skin around them thickens. The infection spreads along the superficial nerves, gradually involving the whole skin and infiltrating the face, mouth and nose, destroying the eyebrows, nasal septum and hard palate and damaging the larynx, producing hoarseness. Nerve damage occurs later than in the tuberculoid form. Peripheral nerves are gradually destroyed, resulting in progressive sensory and motor loss and the consequent traumatic damage to the extremities. Facial paralysis may inhibit the closing of one or both eyelids, causing eyes to be damaged and ultimately resulting in blindness. The advanced case of untreated lepromatous leprosy provides the stereotypical picture of the leprosy victim. This picture is perpetuated in literature.

Differential Diagnosis

The wide variety of presenting signs, depending on the type of leprosy and the stage of its development, make it necessary to differentiate leprosy from a number of other diseases with which it may be confused. These include patches caused by birth marks, prolonged malnutrition and drug reactions, yaws, onchocerciasis, raised lesions such as psoriasis, lichen planus, tuberculosis of the skin, sarcoidosis, nodular lesions like Kaposi's sarcoma, and many

minor skin lesions. The differential diagnosis is especially important because of the tremendous social impact (segregation and isolation) that a diagnosis of leprosy entails for the patient and the community (See chapters six and seven).

Treatment and Control

Once diagnosed, leprosy can now be treated "scientifically". A large number of drugs have been tried in the past with limited success, the most notable being chaulmoogra oil and its derivatives. A turning point came with the introduction of sulphonamides in the 1930s. Following limited use in the United States, the mainstay of leprosy treatment since 1947 has been Dapsone, a relatively non-toxic, inexpensive sulphonamide, usable in all types of leprosy. It is administered orally for at least two years to those with tuberculoid leprosy. In lepromatous leprosy, it is continued on full dosage for three or four years after leprosy appears to have been arrested, and then continues at a reduced dose for life. Relapse after an adequate course of treatment with Dapsone is rare. However, some cases of leprosy have proved resistant to Dapsone. Newer drugs, such as Clofazimine and Rifampicin can be used in these cases, but they are more expensive. One side effect of Clofazimine is a reddish pigmentation of the skin which is disturbing to light-skinned patients (WHO, 1965, 1970). More recently,

combined therapy, using Dapsone with one of the more expensive drugs has been recommended to render patients non-infectious within days rather than weeks (WHO, 1960, 1982).

Drug therapy inhibits the multiplication of bacilli or kills them, rendering them non-infective within a few weeks. Since patients undergoing treatment are not infectious, treatment can be provided on an out-patient basis, removing any need for segregation or isolation from other members of the community (WHO, 1970, 1977, 1980). Early commencement of treatment prevents the development of disabilities which make leprosy a visible disease - a visible disease which has been stigmatised.

Physical deformities which occur in association with advanced or untreated leprosy can often be treated surgically. The nose can be rebuilt, eyebrows restored, eyelids made to close, and "claw" hands straightened, thus removing some of the visible signs of leprosy and helping the patient to live a more normal life. Many deformities, however, result from trauma secondary to nerve damage. As well as treating these injuries, patient education is given to help prevent damage to insensitive hands and feet.

Dapsone has proven successful in treating leprosy once it is diagnosed, but large scale surveys are also made to "find" previously undetected cases in endemic areas.

people are educated to recognise early signs and advised to come forward for treatment as soon as the disease is suspected. Mobile clinics monitor contacts and attendance for treatment. Until an anti-leprosy vaccine is developed it is imperative to find and treat as many as possible of the sufferers. Small doses of Dapsone have been given to children prophylactically and BCG vaccinations against tuberculosis may reduce the incidence of tuberculoid leprosy in children.

Despite the efforts of leprosy workers all over the world, an estimated 15 to 20 million people are victims of the disease, and perhaps as many as half of these are not yet on treatment (Wheatley, 1970). Although leprosy can now be diagnosed, treated and controlled, old fears associated with the disease still provide a formidable barrier to its eradication.

Research

Although tremendous advances have been made in the medical understanding of leprosy since Hansen identified the bacillus in 1873, leprosy still poses many unresolved problems which make efforts to eradicate the disease difficult. In most diseases, the identification of the causative agent has been followed relatively quickly by the artificial culture of the organism and the development of a vaccine to prevent the disease. Despite the similarity of

the leprosy bacillus to that which causes tuberculosis, cultivation of *M. leprae* has proven difficult. Animals appear not to be naturally susceptible to *M. leprae*, unsuccessful attempts having been made with many animals. Some success has been achieved by inoculating bacilli taken from a patient with active leprosy into the footpads of mice which have been irradiated and had the thymus removed (Shepard, 1960). The most promising results have been achieved using the nine-banded armadillo (Kirchheimer et al, 1971; Storrs, 1971; Kirchheimer et al, 1972). This research provided the opportunity to study the properties of the bacterium which would normally be studied *in vitro* - rate and pattern of multiplication, incubation period, and the effect of anti-leprosy drugs, for example.

As a result of these investigations, it has recently been shown that leprosy bacilli grown in armadillos can elicit strong immune responses in experimental animals and prevent the multiplication of leprosy bacilli in mouse footpads. Bacilli from armadillo tissues need to be purified to make them acceptable for human use. At this time a vaccine suitable for testing on humans has been prepared and studies on human volunteers are imminent (Godal, 1983).

The most important research problems now being addressed in the laboratory, therefore, are the culture of the bacillus and the development of a vaccine. At the same time, research is in progress to find new drugs to improve the treatment regime and to expand rehabilitation services to those afflicted. In the social sphere, research is needed to change social attitudes which inhibit the early identification and treatment of sufferers.

In this chapter, it has been shown that leprosy, like other diseases, has posed considerable challenges to those trying to eradicate it. Despite the vast amount of research which has been undertaken, however, leprosy remains mysterious. The long incubation period, variation in susceptibility and the different manifestations it presents have challenged the scientific community. To the general public it is even more mysterious, shrouded in the mists of past myths and misconceptions. The inherent nature of the disease helps to perpetuate the mystery. It has been demonstrated in this chapter that there is now no sound reason for leprosy to retain its unique notoriety among diseases, since it is only mildly contagious, most people are not susceptible, and once diagnosed it is treatable. Nevertheless, its confusion with other conditions, and the

persistence of old ideas, even in the light of new, proven, scientific facts, combine to make leprosy remain one of the major health concerns in the world today.

CHAPTER 5

THE HISTORY OF LEPROSY

"Prevalence is an image of the past.

Incidence is a window on the future"

Lechat (1934)

In the previous chapter, the medical understanding of leprosy during the past 2500 years was reviewed, rather than the social attitudes towards leprosy during this period. The medical mysteries, some of which still exist, have contributed to the fear of leprosy and the stigmatisation of the disease and its victims. One of the mysteries of leprosy throughout history is its strange distribution pattern. Since leprosy is still stigmatised, even in areas where the general population is not acquainted with the disease, the origin of the stigma must lie in the past and in the characteristics of the disease. In this chapter an attempt will be made to trace the historical evidence of leprosy in order to get a better understanding of its distribution, and the degree to which the stigmatisation of the disease and rejection and segregation of its victims have been, and are, universal.

The history of human disease is as long as that of human life. Disease is the biological process which results

when an organism (in this case the human body) is subjected to stimuli to which it is unable to adapt. Physiologically, a variety of stimuli, such as viruses, bacteria and environmental factors, may produce disease affecting individuals or groups. Socio-psychologically, the response to disease is determined largely by cultural factors influencing attitudes to life and death, in particular religion and social and economic conditions. Disease is thus closely linked with cultural development. Patterns of disease change over time as a result of man-made changes to the physical environment, which habitats for insects or animals which are responsible for diseases in human beings (Brothwell, 1967).

Viruses and bacteria which produce diseases thrive in a variety of habitats: some organisms thrive in soil, water or decaying matter; others have wild animals as their normal hosts. With the exception of rabies and plague, it is unusual for the latter to produce diseases in human beings. Other organisms depend on their human hosts for survival (Hare, 1967). As far as we know, the leprosy bacillus has only one host: man.

Unlike the organisms which produce acute infections, such as measles and smallpox, infections in which the organisms disappear when the sufferer recovers or dies, leprosy is one of a number of diseases in which the

organisms can persist for years. The former group of diseases have high mortality rates, but survivors remain immune for life. A large population with a high birth rate is therefore required for the organisms to become permanently established. Conversely, organisms which produce chronic infections or are able to survive for long periods in sputum, mucous or discharges can be supported by widely dispersed or sparse populations. It can therefore be postulated that leprosy existed in antiquity when population density was low.

Evidence

The clinical picture of leprosy presented in the previous chapter indicates that the medical understanding of leprosy has not been constant. Leprosy was generally considered a highly infectious and easily transmissible disease and on that account anyone thought to have leprosy was justifiably avoided. But, as some of the outward signs are not easily distinguishable, even with present knowledge, from other skin diseases, wrong diagnoses must have been frequent (cf. differential diagnoses in previous chapter). Consequently, all references to "leprosy" cannot automatically be accepted as evidence of true leprosy. Medical references to characteristics of a disease which is identifiable as leprosy indicate only that the disease was known at those specific times in the areas concerned, and

does not provide evidence for its presence. Conditions throughout recent human history, however, were amenable to the organism causing leprosy, making its presence a possibility.

Other clues to the possible existence of leprosy can be found in artistic representation, but such evidence is unreliable. For example, the face on a Canaanite storage jar from the fourteenth century B.C. has been cited as evidence of leprosy in the society of that time (Yeoli, 1955) and Wells (1964) agrees that the features of the face resemble those found in lepromatous leprosy. However, Browne (1975) argues that a condition which, in that culture, was associated with ritual uncleanness would be unlikely to be represented on a storage jar associated with food. In other cases, artists' depictions of diseases are clearly influenced by the prevailing societal views, as evidenced by the portrayal of leprosy in the Middle Ages in Europe (Sigerist, 1943). On the other hand, palaeo-pathological evidence of the disease is incontrovertible. Unlike diseases which affect the soft tissues of the body, untreated leprosy leaves specific, marked changes on the skeleton. In careful examinations of hundreds of skeletons from the cemeteries of four Danish leprosaria, Moeller-Christensen and his associates (1953) identified these changes and compared and contrasted them

with the changes occurring in other disease such as syphilis. Such incontrovertible evidence is unfortunately not universally available. Societies which cremate their dead destroy most of the pathological evidence, and burial sites frequently yield incomplete skeletons. The changes in leprosy occur bilaterally and symmetrically. Consequently, of 18,576 skeletons or partial skeletons examined, Moeller-Christensen (1967) would only tentatively attach a diagnosis of leprosy to 328 skeletons in which the skull, both tibiae and fibulae, and hand and foot bones all showed marked changes.

Evidence of Leprosy in Former Times

Ancient Leprosy

The earliest palaeo-pathological evidence of leprosy is from Egypt and is dated around 550 A.D. (Moeller-Christensen, 1967). Nevertheless, a general consensus now locates the earliest known cases of true leprosy - that is, a disease which can be identified by leprologists as leprosy - in Asia (Browne, 1975; Hare, 1967; Skinsnes, 1973), although Zambaco Pacha (1914) and Felsenfeld (1968) place the origin of leprosy in Central Africa. The claim to an Asian origin rests on the firmer foundation of early written records, the actual dates of which are disputed (see Kutumbiah, 1962 on India and Lu and

Needham, 1967 on China). The earliest written records in both India and China however, undoubtedly stem from earlier oral traditions.

Skinsnes (1970) cites the Rgveda, one of the earliest Indian written records, from about 1500 B.C., as the earliest reference to leprosy, using the term kushta which applied to leprosy and some other skin diseases. Under the same designation, the Susruta-Sambhita identified characteristics of a disease recognisable as leprosy (see chapter 4). The Vedic texts Rgveda and Artharvaveda from the period 1500 to 800 B.C. use the term kilasa to refer to leprosy and skin diseases (Zimmer, 1948:32). Diseases are not described in any detail, but are mentioned in incantations (Sigerist, 1961).

There seems little doubt that leprosy was present in China, at least as early as the sixth century B.C., when Po Niu, a disciple of Confucius, was afflicted with the disease q-shi, which literally means "evil disease", and traditionally has referred to leprosy. The Chinese Dictionary of 100 A.D. gave it as a synonym for lai (sometimes confused with li) the newer term for leprosy (Lu and Needham, 1967). A recent archaeological find of a bamboo book in the tomb of Magistrate Hsi who died in 217 B.C. indicates that a disease known as "li" bore the characteristics of leprosy (Skinsnes, 1980).

Further west, Mesopotamia yields the oldest written language in existence, Sumerian, dating back to 3100 B.C., but this cuneiform script is not yet well understood. With the ascendancy of Babylon from about 2000 B.C., Sumerian declined as a spoken language, although it persisted in written form until the time of Christ. Many stone tablets, some of which record symptoms of disease, have been recovered from this period (Kinnier Wilson, 1967; Oppenheim, 1960). On certain boundary stones appears the word *saharsubbu*. This term is associated with any persistent skin disease. Some interpreters suggest that it refers to a disease covering the whole body and requiring sufferers to remain outside the city. It is difficult to determine whether this is an indication that a disease, possibly leprosy, was stigmatised to the extent that its victims were excluded from the city, or whether interpreters have taken the liberty of imposing preconceived ideas on this artifact.

Kinnier Wilson (1967) finds support for leprosy's presence in Mesopotamia in a German publication of an Old Babylonian omen text. Two distinct skin lesions, one nodular, the other macular, are cited as evidence that a man has been rejected by his god and should be rejected by his fellow men. In Kinnier Wilson's opinion, it is possible that tuberculoid and lepromatous leprosy are being distinguished here. Browne (1975), however, rejects these as

"ingenious conjectures and interpretations" on the basis that this area furnishes no written records describing a human disease with characteristics by which leprosy can be identified as a clinical entity. It is nevertheless in this geographical area that it should be possible to trace evidence of leprosy, especially as the returning armies of Alexander the Great after 330 B.C. are credited with introducing leprosy into Europe (Feeny, 1964).

The geographical area under discussion was the site of continuous interaction during the first millenium B.C. as neighbouring territories vied for supremacy. Babylon, Assyria, Persia and Greece in turn controlled the area extending from northern India to Egypt and Greece. During this period troops were mobilised on a scale never before experienced. Yet from this whole period there seems to be no definitive evidence of leprosy. Old Testament literature, however, which is contemporary with the period under discussion, makes frequent references to "leprosy".

The Western world has been greatly influenced by biblical references to leprosy and its victims over the past 2000 years. Yet, despite the frequency of references to "leprosy", "leprous" and "lepers", there is nothing in either the Old or New Testament which definitively describes or proves the existence of leprosy in Biblical lands and times.

In the Old Hebrew version of the Old Testament, the Hebrew word tsara'ath is the word which was eventually translated into English as leprosy. An examination of the usage, meanings and translations of tsara'ath as it appears in Leviticus chapters 13, and 14 was undertaken by Wilkinson (1978). In these two chapters, tsara'ath is used in connection with a condition of the human skin (Lev.13:1-46), textiles and leather (Lev.13:47-59) and buildings (Lev.14:33-53). In Leviticus 14:1-32, the ritual for the cleansing of a person healed of tsara'ath is set out and finally, there is a summary of the law of tsara'ath, which includes "all manner of plague of leprosy, and scall, ...garment...house...a rising...a scab...bright spot" (Lev.14:53-57). Those with doubtful symptoms are shut up for seven days (Lev.13:4,5, 21,26,31,33), but anyone with "leprosy" is "unclean" and

shall dwell alone, without the camp shall his habitation be

(Lev. 13:46)

Wilkinson argues that although tsara'ath is used 29 times in Leviticus, the variations in its usage make it a generic rather than a specific term, as no specific disease encompasses all the symptoms associated with tsara'ath - especially as it applies to non-human conditions also. Several different conditions of the skin are mentioned in Leviticus 13:1-46: a rising, scab, bright spot, quick raw

flesh, boil and inflammation - none of which describe leprosy. Neither do the frequent references to "white as snow" fit with leprosy. tsara'ath is diagnosed on the basis of its appearance and the degree of spread in seven days, whether human or on textiles or buildings. It is used in a ritual sense rather than a medical context. No treatment is prescribed. The condition is re-examined and, if healed, is followed by cleansing. This cleansing is not part of the treatment but the purification following recovery. The conditions mentioned here are not compatible with leprosy, which is a purely human disease and does not affect leather or stone. In addition, leprosy would show no change whatsoever in a seven day period. Nevertheless, those afflicted with conditions considered ritually impure were obliged to withdraw, temporarily, from society. The fact that these conditions have been regarded as leprosy has contributed to the notion that leprosy was widespread in biblical times, despite the lack of definitive evidence.

The meaning of tsara'ath is derived from a verb meaning to strike, as of disease, and the noun is consequently that by which one is struck (Wilkinson, 1978). It has no implicit clinical meaning but is given to conditions with different clinical appearances which have been declared ritually unclean by the priest. The origin of the word suggests suddenness. In Wilkinson's opinion, the

meaning undergoes a transformation. Whereas the Old Hebrew version concentrates on tsara'ath in Leviticus 13 and 14, the Mishnah from about 200 A.D., does not use the word at all, although a whole section is devoted to signs of leprosy. The word nega, which equates more closely with "disease", is used, occurring 60 times in the same two chapters. According to Danby (1933), the Talmud specifies that "all can contract uncleanness from leprosy-signs excepting Gentiles and resident aliens". This could account for the fact that Naaman, the Syrian captain who was alleged to have leprosy, was neither ostracised nor segregated (2 Kings 5).

While some have argued that true leprosy is presented in the Old Testament (Harrison, 1962), the absence of references to leprosy's characteristic features - anaesthesia, progressive ulceration of the extremities, depressed nose and facial nodules - is seen by Browne (1979) as an indication that leprosy was not present. Browne's opinion is supported by the lack of palaeo-pathological evidence. Moeller-Christensen (1967) found no evidence of leprosy in almost 700 skeletons from seventh century B.C. southern Palestine. Given that adequate descriptions of leprosy existed in India and China to indicate that certain of its characteristic features were known, it is unlikely that these same characteristics would have escaped comment

in areas where strong emphasis was placed on observation to differentiate the *tsara'ath* (unclean) from the non-*tsara'ath* (clean) conditions as set out in Leviticus.

The Old Testament was first translated into Greek by Alexandrian Jews about 300 B.C., by which time Alexandrian physicians knew about leprosy. The word *tsara'ath* was translated as *lepra*, introducing the notion of scaliness or peeling, although scaliness was not mentioned in the original Leviticus (Wilkinson, 1978) and is not a characteristic of true leprosy. Leprosy was known in Greek as *elephas* or *elephantiasis*, although *lepra*, not *elephantiasis*, was the Greek term used to translate *tsara'ath* whenever it occurred in the Old Testament, and was also used later in the New Testament. There are, however, no symptoms of disease indicated in any of the references to "lepers" (Matt. 8:2-4; Mark 11:4; Matt. 26:6; Mark 1:40-45; Mark 14:3; Luke 5:12; Luke 17:11).

Although we have no definitive evidence of the existence of leprosy in Biblical lands at that time, its presence is a possibility. Leprosy was known in Greece before the time of Christ and its origin in Greece has been attributed to Persian contact, therefore it is unlikely that Palestine would have escaped. Also, "Phoenician Disease", mentioned by Hippocrates (Pacha, 1914) has been thought to refer to leprosy. Diseases to which a stigma is attached

are frequently regarded as "foreign", therefore there is a suggestion of stigma at that time in Greece. The Phoenicians were centred in what is now Lebanon, with trade routes and colonies extending as far as Spain in the west and India in the east. Phoenicia was overrun by various armies, raising the possibility of transmission of infection. Pacha (1914) asserts that no other people travelled so widely (and fraternised so completely) as did the Phoenicians. It is therefore plausible that they could have carried ~~leprosy~~ leprosy to other countries.

While the lack of palaeo-pathological evidence from the area casts some doubts on the issue, the weight of other circumstantial evidence leads this author to the opinion that it is highly probable leprosy did exist, albeit only with a low prevalence. If such were the case, it emphasises the tremendous impact that the misuse and mistranslation of terms has had in transmitting the erroneous impression that leprosy and the rejection of its victims were widespread at that time, misconceptions which have persisted until the present.

The medical papyri from Egypt refer to treatments for skin diseases (Sigerist, 1951), some of which can be identified with varying degrees of confidence. Leprosy is assumed to be the disease termed *lepra mutilans* in the Ebers Papyrus (Sandison, 1967) and *uchedu* in the Ebers and Brugsch

Papyri from 1300-1000 B.C. (Skinsnes, 1973). Warren Dawson, the Egyptologist, finds the evidence flimsy, but calls attention to a disease called *shh* in magical texts from the same period. A word similar to *shh* has survived in Coptic Biblical texts wherever the term *legga* occurs in Greek translations (cited by Moeller-Christensen, 1967). Pacha (1914) asserts that Assyrians took leprosy, perhaps a more virulent form, to Egypt and that the Hebrews undeniably had leprosy before the Exodus. It would appear, however, that this opinion is based on the statements in Leviticus, which, as indicated above, do not positively identify true leprosy. On the other hand, Alexandrian physicians knew of it by about 300 B.C. and Pliny asserts that Pompey's troops, returning from the Egyptian campaign of 62-61 B.C., brought the disease to Italy (Browne, 1979). In his examination of some 18,000 Egyptian skeletons, however, Moeller-Christensen (1967) found no conclusive evidence of leprosy in Egypt prior to the sixth century A.D.

Leprosy in Europe

The earliest known references to leprosy in Europe, in Greece, is dated by Skinsnes (1973) about 480 B.C., at the time of the conquests of Greece by the Persian rulers Darius and Xerxes. Others (Anderson, 1969; Browne, 1979), place its arrival after the conquest of Persia by Alexander the Great in 327 B.C. As indicated above, frequent

skirmishes and prolonged encounters between Greeks and Persians occurred over this period, as well as trading contacts. Leprosy does not suddenly develop, like an epidemic of smallpox or measles, therefore it is probably more accurate to say that leprosy became established in Greece sometime during this period, thus refuting the argument that contact was not sufficiently prolonged for the infection to spread. Modern evidence has shown that in much shorter campaigns, such as the Spanish American wars and the Vietnam War, American servicemen have contracted leprosy (Aycock & Gouda, 1947; Bruhaker et al, 1969; Burgess, 1940; Haseltine, 1940). Nevertheless, About 400 B.C., Hippocrates, noted for his detailed observations of pathological conditions, was not familiar with leprosy (Browne, 1975). A similar conclusion had been reached by Hare (1967). Apart from the medical descriptions mentioned in the previous chapter, there were popular descriptive names for leprosy, including *leontiasis* and *satyriasis* (Browne, 1975) indicating that certain characteristics were visible. Later, leprosy became known as *elephantiasis Graecorum*, to distinguish it from *elephantiasis Arabum* (*filiariasis*). The term *lepra Arabum* was equivalent to *elephantiasis Graecorum* (Browne, 1975), further contributing to the linguistic confusion which frustrates the process of positive identification of true leprosy in written works.

Pliny the Elder (23-79 A.D.) supplied an account of a new disease in Rome, which "...[t]hough painless and without danger to life. yet...so disfiguring that any kind of death would be preferable" (cited in Brothwell, 1967). Celsus also attests to the rarity of true leprosy in Rome (Browne, 1975). It would appear, therefore, that leprosy did not arrive in Italy until after Roman sovereignty had extended to areas where leprosy was already present.

The spread of leprosy across Europe seems to have been facilitated by Phoenician sailors and traders and the expansion of the Roman Empire northwards and westwards. In Spain, for example, successive waves of Phoenicians, Romans with slaves, Arabs and Crusaders, and to a lesser extent Jews and gypsies, are credited with introducing and spreading infection (Contreras et al, 1973). Major (1954) suggested that returning Crusaders introduced leprosy into western and northern Europe, but there is ample evidence that leprosy was well established in Europe before the Crusades, which took place after 1095. The first "leper house" in England was opened as early as 625 A.D. Brothwell (1962) describes leprosy in a seventh century British skeleton. Moeller-Christensen (1967) refers to leprous British skeletons from the middle of the sixth century, and Reador (1974) cites palaeo-pathological evidence of leprosy in Britain as early as the middle of the fourth century.

It is not known exactly when leprosy reached Norway, but Viking raids on the northern British Isles have been suggested as the source. Under the Dane Law of the ninth century there was also frequent contact between the Scandinavian settlements in Britain and the Scandinavian countries. Legal documents indicate its presence in Norway by 1000 A.D. (Vogelsang, 1975). Leprosy was first noted in Iceland in the twelfth century (Skinsnes, 1977).

Whatever the role of Crusaders, the incidence of leprosy did increase in the twelfth and thirteenth centuries, although actual numbers of leprosy sufferers will never be known. Large numbers of "leper houses", "lazar houses" and "lazarettos" were opened across Europe. Foucault (1965) cites a figure of 12,000 "lazar houses" across Christendom, and 2900 lazaret houses in France in the twelfth century. There were some 250 in England and Scotland (Clay, 1966). The residents of these houses, however, were by no means all victims of leprosy. Diagnosis was made by priests, gatekeepers and other non-medical personnel (Brody, 1974), and we have already seen that even with modern knowledge and technology, other diseases may be confused with leprosy. The fact remains that in Europe there was an epidemic during the Middle Ages, which peaked in the twelfth and thirteenth centuries and declined from the fifteenth century onwards. The last case from the

epidemic in Britain was recorded in the Shetlands in 1728 (Browne, 1977). It persisted longer in northern Europe (Richards, 1977). A resurgence of leprosy during the nineteenth century created a chronic problem in Norway, where Danielson and Boeck described the disease accurately in 1847 and Hansen identified the causative agent in 1873. The last indigenous cases in Norway were diagnosed in the mid-twentieth century (Vogelsang, 1975).

Leprosy in the New World

The early history of leprosy in the American continents is obscure. A pre-Columbian skull, for example, found in Mexico, was thought by Goff (1967) to have the characteristics of leprosy described by Moeller-Christensen (1967). However, no other evidence has been found in Peruvian mummies or skeletal remains. According to Wells (1964), the theory for the existence of pre-Columbian leprosy is largely based on the facial deformities, superficially similar to those found in advanced leprosy, which appear on old water jars from Peru, Bolivia and Ecuador.

If leprosy did not exist in the New World in pre-Columbian times, it must have been introduced by migrations from the Old World. From the fifteenth to the nineteenth century, leprosy could have been introduced by various European groups: the Spanish and Portuguese to the

West Indies, southern United States, Central and South America; the French to Canada and the southern United States; Germans to the Mid-West, Venezuela and Argentina; Central Europeans to South America; and Scandinavians to Minnesota and Missouri (Browne, 1980; Skinsnes, 1973). Slaves brought from West Africa may well have brought leprosy, and Chinese immigrants may have brought leprosy to California and the west coast of Canada (Ackernecht, 1964; Browne, 1980). Certainly the Chinese in California had the reputation of being leprous and were avoided (Kellersberger, 1951). Again there is the association of a "foreign" disease associated with a visible immigrant group. The first indigenous case of leprosy recorded in Canada was that of a New Brunswick woman in 1815. Two of her seventeen siblings also contracted leprosy. The first Canadian leprosarium was opened at Sheldrake, New Brunswick in 1844, and moved to Tracadie in 1849. Patients were admitted until 1937 and the last surviving residents were discharged in 1965 (Whitehead, 1967).

Leprosy in Africa

With the exception of Egypt, little is known of diseases in Africa before European colonisation. Suggestions have been made (Pacha, 1914; Felsenfeld, 1968) that Nubian slaves introduced leprosy into Egypt from Central Africa, and that slaves taken from West Africa

carried leprosy to the New World (Browne, 1970; Skinsnes, 1973). Certainly the current prevalence of leprosy in Africa would support the probability that its history pre-dates European contact. Although conditions in Europe at the time of first contact were similar to those in the third world today, providing suitable breeding grounds for leprosy, several factors make its introduction by Europeans unlikely. Leprosy in Europe was declining by the time of the "Voyages of Discovery", and given the negative social reaction toward the disease, anyone suspected of having leprosy would not have been welcomed on ships. Also, the absolute number of Europeans in contact with Africans was small, therefore even if some were infected with leprosy, the possibility of widespread infection from them is remote. A final supporting point for the existence of leprosy before European conquest is that in other areas where there is early evidence of leprosy (India and China), the areas still have a high prevalence today.

Asia and Oceania

From the time of the earliest references to leprosy in India and China, periodic references point to its continuous presence. It was well established in Japan by the eighth century, when numbers warranted the opening of a hospital to deal with the problem (Skinsnes, 1973). Migrations associated with the spread of Buddhism may

account for the establishment of leprosy in Japan. At a later date, Chinese migrant labourers probably introduced leprosy into the oceanic islands and Australia (Browne, 1970). Leprosy was first noted in Hawaii in 1823, in the New Hebrides in 1865 and New Caledonia in 1870, and in Australia in 1908 (Skinsnes, 1973). Davidson (1978), however, traced the introduction of leprosy into Australia to pearling boat crews or Chinese migrants, pointing out that cases of leprosy were noted among Chinese in the 1890s but only later among Australian Aborigines.

Leprosy in the World Today

There may be as many as 20 million leprosy sufferers in the world today, with as few as 20% receiving treatment (The Star, 1983). The W.H.O. Sixth Report on the World Health Situation (1980) notes that there has been no decrease in the leprosy problem in the preceding fifteen years and that to obtain significant results at least 75% of all estimated infectious cases must be treated. The largest number of sufferers is in southeast Asia, estimated at over four million, including 3.2 million in India alone. The highest prevalence is in Africa, where some areas have a rate of over 40 per 1000 population, and most of tropical Africa has a prevalence rate between 10 and 40 per 1000 population. A similar high prevalence rate is found in

Burma, Thailand, parts of Indonesia, especially Irian Jaya, the western half of the island of New Guinea, northern Australia, New Caledonia and isolated pockets in South America. Throughout South America, with the exception of mainland Chile, there is a significant leprosy problem with prevalence rates between one and 5 per 1000 (see Fig. 1).

There are an estimated 50,000 leprosy sufferers in Europe, mainly in the countries bordering the Mediterranean and in the islands, four thousand known cases in the continental United States and about 400 in Canada, where there were 23 new cases in 1983 (Inqura Canada, 1984). In North America, leprosy is only endemic in Florida, Louisiana, Texas and California. Although there has been an increase in the number of sufferers in the United States, the increase is chiefly attributable to immigrant sufferers, and no increase in incidence has occurred in the indigenous population (Levis *et al.*, 1981). It has been pointed out that despite migrations of guest workers from southern Europe or third world countries where leprosy is endemic, there has been no re-establishment of foci of leprosy in European countries where it had previously been endemic but had ceased to be a problem (IDL 46 (1978):442).

The purpose of this chapter has been to demonstrate that although leprosy has been known for about 2500 years, it seems to have made its appearance in new areas as

Fig. 1. Distribution of Leprosy Throughout the World

Source: World Health Organisation
(in Browne, 1970:15)

populations have conquered new territories. It is not a tropical disease, but is more prevalent today in third world situations where living standards are lower and conditions overcrowded, facilitating its transmission. Fear of the disease and myths and misconceptions surrounding it have warped the historical perspective. This geographical and historical overview has been an attempt to set aside beliefs and attitudes and to present the evidence of leprosy's existence in different eras and areas. Now that we have a general idea of where and when leprosy was present (chapter 5), the nature of the disease (chapter 4), and how various cultures have responded to disease (chapters 2 and 3), we are in a better position to analyse leprosy's unique position in the history of disease. In chapter 6 social attitudes toward leprosy and its victims in the western world will be discussed, and in chapter 7 the attitudes in non-western societies will be examined. These chapters will provide insight into the process of stigmatisation cross-culturally.

CHAPTER 6

LEPROSY: A DISEASE APART I

LEPROSY IN THE WESTERN WORLD

"What strange ideas people have about leprosy, doctor".

"They learn them from the Bible. Like sex".

Graham Greene (1961:29)

In the previous chapter, the historical and geographical distribution of leprosy was presented. Prior to that, in chapter 4, it was shown that leprosy shared with other diseases the uncertainties about causation, progress, treatment and prognosis that accompanied the slow development of medical understanding prior to the nineteenth century. Only since that time, and more especially since the middle of the nineteenth century, has it been possible to diagnose accurately specific diseases, a procedure which is increasingly improved by technological advances. Leprosy, however, is unique among diseases in the degree of social opprobrium it has attracted.

Since the time of Confucius, until the present day leprosy has been treated differently from other diseases. Even in technologically and scientifically advanced

societies today, non-scientific notions about leprosy are retained. The aim of this chapter, therefore, is to explore in detail how the treatment of leprosy victims in the western world has differed from the treatment of people suffering from other diseases. In chapter 7, the social response toward leprosy in the non-western world will be examined.

It has already been stated (chapter 2) that in the author's opinion the social response to leprosy and its victims at various points in time is determined by a complex amalgum of prevailing ideas - religious, medical, legal and social. This collective response has been termed "stigma" when these ideas combine to identify a condition which discredits the individual and prevents that individual's full participation in social intercourse (Goffman, 1963). Where stigma exists, therefore, religious, medical, legal and social ideas are frequently inter-related. Especially in the western tradition, religious attitudes toward "leprosy" have strongly influenced the medical, legal and social responses to the disease. This influence is still apparent. The western tradition will consequently be examined in the first instance, to afford a basis for comparison with other cultures, to be discussed in chapter seven.

The Religious Approach to Leprosy

The quotation from Graham Greene's novel A Burnt-Out Case, quoted at the beginning of this chapter, cannot be taken as proof that the source of the stigma associated with leprosy is to be found in the Bible. Rather, it reflects the tremendous influence that the written word, especially that regarded as holy, or sacred has on society as a whole. Direct Biblical influence was originally limited to the literate few, whose learning was seen as preparation for Bible study - the highest branch of learning in the Middle Ages (Smalley, 1983). Nevertheless, even the largely illiterate populace was influenced by others reading from the Bible. As the written word was made available to a wider population via the medium of printing and the education of the masses, literacy was regarded as the means by which people could read for themselves the holy word. The first and sometimes only reading material was the Bible, "...the study of the Bible becoming the national education in the seventeenth century in England" (Trevelyan, 1966:50). When reading "leprosy", it was literally interpreted as leprosy the disease, rather than as the "impure state" that was represented. The idea associating leprosy and impurity therefore became deeply ingrained early in literate times.

In chapter 5, it was shown that the Hebrew word *tsara'ath* which in English versions of the Old Testament was translated as "leprosy", was used to define a condition considered ritually unclean and had no implicit clinical meaning. The purification rituals and the observation of isolation procedures were religious in nature, and similar to those required in any society where a ritually impure condition is considered a threat - menstruating women for example. There is no indication that the condition, or the isolation, in the case of Biblical "leprosy", was permanent. The observable signs come and go in a short period of time and are certainly not characteristic of chronic or incurable diseases. None of the signs mentioned could lead even the most experienced leprologist to a categorical diagnosis of leprosy as we know it today. As we have seen (chapter 5) that leprosy, the disease caused by *M. leprae*, is not specifically identified in the Old Testament (Browne, 1970, 1975, 1979; Wilkinson, 1977, 1978). Although palaeo-pathological evidence does not support the idea (Møller-Christensen, 1967), the possibility remains that leprosy did exist, but probably only as one among a number of skin conditions which cannot readily be differentiated.

When, in 300 B.C. the Hebrew *tsara'ath* was translated as the Greek *lepra*, a clinical term already in use and applied to a group of skin diseases characterised by

peeling or scabiness, a clinical element was superimposed on the religious concept of ritual impurity. As a consequence of replacing *tsara'ath* by *lepra* throughout the Old Testament, identifiable clinical conditions became associated with ritual uncleanness, because both aspects were encompassed in the one term. It is suggested here that since true leprosy was known in Alexandria at the time of the Septuagint translation, being referred to by Erasistratos as *elephas* or *elephantiasis*, the two conditions *tsara'ath* and leprosy were not directly associated at that time. If such an association had existed, one of the Greek terms would have been used. *Lepra*, therefore, was, as suggested by Wilkinson (1977, 1978), an attempt to generalise rather than to be specific.

The condition *tsara'ath* made one unfit to enter the temple, until the necessary time had elapsed and the correct sacrifices and rituals had been performed. The condition could arise through divine intervention, as punishment for sin. "Sin" in Old Testament times was any act of disobedience or failure to fulfill obligations set down in the Torah or Law. Thus, Miriam, the wife of Aaron, was smitten with "leprosy" for challenging the authority of Moses (Lev. 12:1-12). Sin, therefore, takes on a moral connotation. Warning of a similar fate was given on other occasions (Deut. 26:8-9). Once God's wrath was evident in

the appearance of "leprosy", the "sinner" was excluded from religious ceremonies.

In the Old Testament, therefore, "leprosy" is a condition which God can inflict and remove. As stated elsewhere, the clinical manifestations of Biblical "leprosy" do not correspond to those of true leprosy. Neither is the sudden appearance of these characteristics symptomatic of leprosy. On the other hand, a specific physical condition is said to be the result of sin. It is possible to see in some references, therefore, how Biblical "leprosy" might at a later date have been considered true leprosy. In Numbers 12:12, for example, we read: "Let her [Miriam] be as one dead, of whom the flesh is half consumed when he cometh out of his mother's womb". Also, in Deuteronomy 24:8: "Take heed in the plague of leprosy, that thou observe diligently and do according to all that the priests the Levites shall teach you". There is in the first quotation a possible basis for equating Biblical "leprosy" with true leprosy, given that the advanced stages of untreated leprosy can create the impression of a body being eaten away. The reference to "plague" is traditionally a generic term used in connection with epidemics in which large numbers of the population are affected. In the absence of an identifiable cause such epidemics appear to be sent by God.

It was indicated in chapter 3 that the sin-punishment concept of disease acquired prominence as the concept of the leprosy became purer. This process was fostered by the commentaries and interpretations of the ancient teachings, including oral traditions which facilitated the adaptation of the written tradition to changing circumstances. Such commentaries are found in the Talmuds and Midrashim. Also included, however, were legends and folklore which the Rabbis transformed to reinforce their teachings. Among these legends were embellishments which directly linked "leprosy" with sin, specific sins being identified in different commentaries (Brody, 1974). One commentary on Leviticus lists seven sins which result in "leprosy" - pride, lying, murder, scheming, erratic ways, false witness and trouble-making (Midrash Rabbah IV:100). In another instance ten sins are listed, including blasphemy against the Divine Name, gross unchastity and evil eye (preediness) (Midrash Rabbah IV:215).

The commentaries therefore furnish evidence of leprosy as punishment for sin, and provide the foundation on which Christian allegorical tradition was built (Fletcher, 1964). The concept of sin at this stage, however, identifies specific transgressions. One legend states that all diseases were removed from the people before God gave them the Torah, not wanting "a race of cripples" to receive

the Law. Diseases returned as punishment for idol worship. Later God separated the "unclean" (i.e. *tsara'at*) from the "lepers", the "lepers" being the "very ones who had worshipped the Golden Calf". They were excluded from the camp, whereas the unclean were only removed from the sanctuary (Ginzberg, 1911:212-213). By this interpretation, therefore, "lepers" were those being punished for their sins, and the implication is of a permanent state of exclusion, rather than the temporary state associated with *tsara'at*.

The commentaries, begun in the second century A.D., were frequently revised and expanded until the twelfth century. Later Jewish exegetes emphasised the rabbinical tradition, which identified "leprosy" as the external manifestation and punishment of a spiritual evil. Thus sin results in "leprosy", which is a sign that God has withdrawn his favour. The inter-weaving of myth and legend in the interpretations of the Scriptures provides continuity of traditions within Jewish beliefs. The frequent dispersal of the Jews has spread these ideas and influenced traditions in areas where Jews have settled (Smalley, 1937).

At the same time that the Mishnah was being compiled, the first books of the New Testament were being written. It is hardly surprising, therefore, that the oral traditions which formed part of the Mishnah should also have

been incorporated into Christian teaching, which itself grew out of those traditions. The Old Testament was accepted as an integral part of the new religion, which began as a Jewish sect. One particular common element significant to the present study was that the "leper" was singled out for different treatment.

In the New Testament, is it also possible to find ideas that could have inspired the notion expressed by Greene's characters?

The terms "leper" and "leprosy" appear only in the synoptic gospels (Browne, 1979), which are accounts of the works and teachings of Jesus Christ. The society in which these activities took place was Jewish, hence the prevailing beliefs were those found in the Old Testament. Therefore, although the gospels were written in Greek, the concept of tsara'ath was part of that tradition, and the term lepra would on that basis retain the notion of ritual uncleanness. Such an argument would be supported by references to the "cleansing" of lepers (Matt. 8:2-4; 11:5; Mark 1:41; Luke 5:12-14; 7:22; 17:10-15) who were charged to go to the priest and show themselves. Similarly, Christ's command that his disciples should heal the sick and cleanse the lepers (Matt. 10:8) indicates that lepers were not considered sick, being placed in a different category. There is a departure from the Old Testament tradition in Christ's

attitude toward sickness, however. When questioned by disciples, Christ indicates that sickness is not the result of sin of either the individual or the sufferer's parents, but is an indication that one has been singled out to receive God's revelations (John 9:2-3). Christ's association with all social outcasts, however, angered the religious leaders and He also was rejected.

Interpretations of the Old and later the New Testament in the Christian tradition followed a similar allegorical approach to that found in the Jewish tradition. It has already been noted that the Mediaeval Christian allegorical tradition was influential in communicating ideas to an illiterate and ignorant population. The teachings and interpretations of the Church Fathers, to whom later commentators turned for their information, certainly did not ignore "leprosy", but did apply a literal use of the term, although it was originally borrowed from the allegorical tradition. Gregory the Great (540-604) and Isidore of Seville (560-636) both saw leprosy as symbolic of heresy and the sufferers as heretics. Others associated leprosy with various sins. Different forms of the disease were associated with various sins by St Jerome, and in the twelfth century, Richard of St. Victor made leprosy the symbol of all the vices by which man is spiritually defiled. Examples are found in the Old Testament to support such

interpretations (Arody, 1974). Lust frequently becomes identified with leprosy. Several examples of leprosy as a metaphor for cardinal sins are provided by Bloomfield (1967) from Mediaeval sermons. Thus, by the time of the Crusades, the association of leprosy and sin was firmly established. Goffman (1963) emphasises the importance of visible discrediting characteristics in stigmatised conditions. Such characteristics are evident in untreated leprosy. By identifying leprosy as sinful, society found justification for discrediting its victims. Leprosy is sin when seen through the eyes of these exegetes, and those afflicted with the disease should therefore be excluded from society.

The Church Fathers consulted Jews to get a better understanding of the Old Testament. The practice of focussing on the Old Testament in biblical study persisted until the later Middle Ages (Smalley, 1983). The New Testament was seen as fulfilling the prophecies made in the Old. Hence, Christianity inherited from the Jewish tradition the Hebrew Bible or Old Testament, and moral ideals. To this was added the new doctrine of salvation. The moral ideal was stressed in the emphasis on healing and making whole. Providing care became an integral part of Christian practice. How religious beliefs influenced medical attitudes and treatment of leprosy in the western world is the topic of the next section.

The Medical Approach to Leprosy Sufferers

In preceding chapters, the close relationship and frequent overlapping of religious and medical practices were discussed. In primitive societies, the priest and healer were often the same person. This dual role is also evident in early Christianity, where the followers of Christ were charged to go out and heal the sick. The cures effected were often miraculous, the efficacy of the cure depending on the faith of the victim. Usually the sick were cared for rather than treated. Constantine issued an edict in 335 A.D. for the establishment of "hospitals" to facilitate the care of the sick and needy. The distinction between the sick and "lepers" made in the New Testament was apparent in the early treatment of leprosy sufferers. The earliest record of a hospital built especially for the care of leprosy sufferers was in Rome during the reign of Constantine. Other leprosy hospitals were established in Caesarea (372 A.D.), in France (460 A.D.) and in England (625 A.D.) (Browne, 1980). The Synods of Orleans (549 A.D.) and Lyons (588 A.D.) expressed concern about leprosy victims and recommended that they should be fed at Church expense (MacArthur, 1953). Meanwhile, miraculous cures of leprosy sufferers were reported in Belgium in the fourth and sixth centuries.

All early hospitals were ecclesiastical, not medical institutions, providing care, not cure, relieving the physical discomfort if possible, but primarily concerned with strengthening the soul for a future life (Clay, 1966). Apart from monastic institutions, a sense of Christian responsibility and charity led to the establishment of other "hospices" for travellers, the needy and leprosy victims, all being intimately associated with the Church. One feature that sets leprosy apart from other diseases is that it was the only disease for which institutions were specifically designated. Clay (1966) notes that in mediaeval English towns, a hospital or almshouse on the main street provided relief for the needy, and near a main gate would be a hospice for travellers. Outside the town, however, would be located an establishment where those afflicted with leprosy could be isolated from healthy townspeople. Such a practice was widespread in Mediaeval Europe and reinforces the Old Testament notion of placing "lepers" outside the camp. Leprosy was therefore treated differently from other diseases. It was shown in chapter 2 that European medical thought remained stagnant from the fourth century until the eleventh century. Care was in the hands of the Church, but there was no real treatment of the disease. The Church was therefore able to reinforce misconceptions such as the association of sin and leprosy.

Just when the practice of excluding individuals suffering from a disease which was possibly leprosy first occurred is not clear. (The exclusion of "lepers" in Jewish tradition is, as noted above, a religious exclusion permitting purification and not necessarily associated with a particular disease). What is clear, however, is that in mediaeval Europe, formal social sanctions were administered against victims of leprosy. This notion of "containment" was discussed by Goffman (1971) with reference to mental illness, and similarly recognised by Foucault (1965).

The earliest known example of segregation of people suffering from a disease identifiable as leprosy is found in "On the Causes and Symptoms of Chronic Diseases" by the second century A.D. Greek physician Aretaeus. Born in Asia Minor and having studied in Alexandria and Rome, it is quite possible that Aretaeus' observations relate to practices among Christian people.

There is a danger also from the communication of the ailment. Many, therefore, have exposed their most beloved relatives in the wilderness and on the mountains, some with the intention of ministering to their hunger, but others not so, as wishing them to die.

(from a longer extract cited by Mettler, 1947:245)

An extract from the same work cited by Mettler (1947) and confirmed by Browne (1975) and Kalisch (1975) leaves no doubt that the disease described is leprosy, and that the

population was concerned about it. There was, therefore, at an early stage, evidence of social exclusion, whether on the basis of fear of moral contagion, or on the grounds of non-aesthetic appearance described by Aretaeus. The Greek emphasis on physical beauty and physical fitness would provide an argument for the latter explanation, whereas religious beliefs would support the former.

Other early European evidence is sparse, but a sermon by St. Gregory of Nazianzus, given in 379 A.D. implies that the practice was well established by the end of the fourth century. He describes victims as "men already dead, except to sin...horrifying spectacles of human ruin" who are "driven from the house, the marketplace, the village and the fountain" and "persecuted even by their own parents" (Brody, 1974:79). The use of leprosy in the sermon impresses the image in the minds of the public, reinforcing the religious beliefs of the period. The limited evidence in the following centuries is suggestive of the developing social response which was prevalent in the later Middle Ages. A reference was made by Pope Gregory II, early in the eighth century, to the "Leper Mass" - the religious service which stripped the victim of all rights and made him "dead to the world". In later years, this was widespread use Europe, although less so in England (Feeny, 1964). The idea of Christian charity made it fashionable in Europe to endow

"leper houses", and many were established in France between 751 and 987 A.D. (Zambaco Pachas, 1914), and in England (Richards, 1977). Establishments usually consisted of a chapel, with an annexe where care could be provided. The bigger the hospital the greater the glory for the benefactor and the more assured his heavenly reward (Richards, 1977). Also, the benefactors who exposed themselves to the worst possible cases and hence the greatest danger of contamination, could be seen as "martyrs", and hence could expect to reap the highest reward.

These efforts on the part of individuals must reflect a perceived need for leprosy sufferers to be cared for, and confirms that the victims were regarded as social outcasts for such a need to arise. Other diseases did not receive the same attention. The concern expressed in the Synods of Orleans, Lyons and Worms in the fifth and sixth centuries indicates that the Church had recognised leprosy as a problem. The appearance of "leper houses" across Europe at this time (cf. chapter 5) shows that provision was made for the segregation of victims from society. By that time, however, the Church had also definitively equated leprosy with sin and communicated the idea to the illiterate masses in sermons. At the same time, the disease was becoming increasingly evident in the societies which the Church served, and acted as a constant reinforcement of the

church's teaching.

There is no doubt that to have leprosy gave the victim a distinctive status, more pronounced than that associated with other diseases. It forced its victims to withdraw from normal obligations. Zambaco Facha (1914) cites the cases of two virgins who successfully prayed that they would get leprosy so that they could avoid human marriage and devote their lives to God. A similar action was taken by a girl in the eighth century who did not want to marry the man chosen by her father (Feeny, 1964). It is also reported that Viking raids on Ulster left untouched the house of prayer where the "men of God and the lepers stayed" (Richards, 1977; Vogelsang, 1975). As churches attracted frequent attention on such raids (Lindisfarne and other monasteries on the English east coast, for example), the presence of "lepers" would seem to have been the cause of the fear on the invaders' part.

Thus by the end of the tenth century, there existed in Europe a widespread fear of the disease, but also a certain ambivalence about it. Leprosy was seen as God's recognition of both the sufferer's sin and his assured redemption. The victims were consequently despised and at the same time almost envied. They were outcasts, yet they afforded the opportunity for charitable deeds, and the pious sometimes even prayed for leprosy as a sign of grace

(Zambaco Pachar, 1914). This ambivalence may well have been fostered by the random nature of the disease, which made it difficult to explain in terms other than divine intervention.

In the centuries which followed, leprosy's position in society is well documented. Leprosy was already well established across Europe by the time of the First Crusade in 1095. However, the disease does seem to have experienced a significant rise in its prevalence during the twelfth century. Foucault (1965) and Feeny (1964) estimate that there were 2000 houses for the care of victims in France and Clay (1966) and Bayliss (1979) stated that there were nearly 300 in England. These figures, however, do not give an accurate picture of the epidemic, as many were small establishments and some were temporary. What it does reflect is a renewed interest in the disease.

It was perhaps natural that the increased incidence should be attributed to contact with the "Infidels", but the contraction of leprosy by the Crusaders posed a problem for the Church. The Church had played on the fear and ignorance of the masses and explained leprosy in terms of punishment for sin. It was emotionally unacceptable, therefore, to consider men who had taken part in the Crusades, Holy Wars, as sinners. Hence, it was necessary to reinterpret Isaiah's prophecy "yet we did esteem him stricken, smitten of God"

(Isaiah 53:4) to mean that Christ would be deemed leprous (Feeny, 1964:31-32; MacArthur, 1953:11). Jesus thus became associated with leprosy in sermons and the disease came to be viewed as a sacred disease, and the sufferers being "stigmatised" by God, as was St. Francis of Assisi, rather than stricken. Leprosy was thus, at the religious academic level, identified as a mark of God's grace.

For a time this change in religious views on leprosy led to a new wave of religious hysteria, as people tried to emulate Christ's example and not reject those suffering from leprosy. Eminent personages humbled themselves and washed the sores of the victims and even embraced them to demonstrate their virtue. This activity is a striking contrast to the practice of segregating the victims from the healthy population. Either these individuals did not feel threatened by the disease, or they felt that they were immune from it by virtue of their charitable actions. The number of leprophiles, however, was insignificant compared to the number of leprophobes.

The Third Lateran Council of 1179, however, made a clear pronouncement on the segregation of leprosy victims. The sufferer was charged not to mix with others, nor to share the same church, and they should be buried in sites separate from the general population. The Order of the Knights of St. Lazarus was established to provide and

maintain hospitals for leprosy victims throughout Christendom. Once established, such Orders had a vested interest in perpetuating the stigma of leprosy.

Richards (1977) draws attention to the fact that isolation as mentioned in the Lateran Council did not mean that victims had to go into hospital. They could only be forced to enter an establishment, by Writ of *De amovendo leproso*, if they failed to maintain voluntary segregation, and when disfigurement definitively confirmed that they had leprosy. The judgement which enforced segregation was thus based on visibility, and sanctioned by religious ritual, reinforcing a belief in the disease being punishment for sin. The "comforting words" with which the priest was advised to conduct the separation ceremony must have seemed terrifying to the victim. The priest shovelled earth on to the feet of the one to be secluded, saying: "Be thou dead to the world, but alive again unto God." The instructions state that: "the priest must lead him to the church and from the church to his house as a dead man" (Clay, 1966:273). Such words were hardly likely to encourage an individual voluntarily to go to the priest to have his self-diagnosis confirmed. How then did the diagnosis and the commitment to isolation, either at home or in an institution, come to be made? Medical practitioners were only found in large urban centres and even there diagnosis

was frequently left to the priest. In some areas committees were set up to decide on the diagnosis. Even when medical opinion was sought, medical knowledge remained vague and confused, and although some symptoms of leprosy are accurately described, moral evaluations often entered into the diagnosis. Thus, thirteenth century descriptions included a "burning desire for coitus" among their symptoms (Brody, 1974). The moral evaluation in the medical diagnosis again emphasises the association between the disease and past sins.

In England there was no universal practice of strict segregation. In fact, the regulations of the hospitals at that time allowed visitors and permitted excursions at the discretion of the warden (Richards, 1977). The ultimate punishment for disobedience was expulsion from the "hospital". Thus, although segregation would suggest that the disease was thought to be highly infectious, before the concept of disease transmission had been established, lack of enforcement of isolation implies that religious contagion rather than clinical contagion was at its base. In continental Europe, and especially in France, however, the practice of segregation was somewhat stricter. The office of separation required the victim to kneel at the altar under a black cloth, and in some places to stand in an open grave during the ceremony. It also included more

prohibitions than its English counterpart (Colgoul, 1943). The prohibitions in the office of separation indicate a concern for the transmission of the disease which was inconsistent with the medical understanding of the period and therefore emphasises the notion of religious impurity of the disease. The prominence of religious practices in connection with leprosy, where they did not occur in association with other diseases, helped to distinguish leprosy as a disease apart, necessitating special treatment for its victims. That is, they were stigmatised at this time as a consequence of the confluence of beliefs regarding sin and disease.

Richards (1977) provides evidence of stricter controls over leprosy victims in Scandinavian countries from the later Middle Ages until the nineteenth century. Visitors were forbidden in the fourteenth century leprosarium at Enköping, Sweden, and the settlements for sufferers were frequently on remote islands. The victims had to take with them to their isolation their moveable possessions and provide wood and nails for their own coffins, emphasising the finality of their situations. Care remained in the hands of a priest/warden. Although in Stockholm, from at least 1482, medical examinations had been customary for confirming the diagnosis, in the Åland Islands, in the northern Baltic, medical examinations were

not recorded until the seventeenth century, when it became the usual procedure. Before the seventeenth century, Aland islanders suspected of having leprosy were isolated at home for observation. Examination of the suspected leprosy sufferers by the parish council took place annually outside the church. Thus, medical examination resembled the Old Testament examination for ritually impure conditions. A diagnosis of leprosy led to mandatory confinement in hospital. A certificate of freedom from leprosy allowed the suspect to be cleared of the charge. If no conclusion was reached, the victim continued his isolation at home for another year. The whole process of assessment thus took on the appearance of a religious court. The use of the terms "suspect" and "charge" immediately indicates wrongdoing and furthers the association of sin and punishment and disease.

Leprosy and the hospitals in Scandinavia from the fifteenth century onwards are well documented. It is therefore possible to see how, while the same religious control was present, new medical evidence was incorporated. The concept of disease transmission, that is, infection, although not well formulated, was developing (see chapter 3). A document authorising the founding of Sjahlo hospital in Finland in 1619, when leprosy hospitals in other parts of

Europe had largely ceased to be active, demonstrates a belief in the infectious nature of leprosy, despite its association with sin:

...the infectious plague and disease of leprosy, which is a divine punishment for sin, is spreading and becoming common in Finland, and not least because those who are afflicted with it mix carelessly with those who are healthy and live amongst them, thus the disease must be prevented or retarded in as far as it is humanly possible. In order to separate those poor miserable people from the healthy a measure which is considered wise, we have...ordered that a hospital should be built for them on a remote island...

(Richards, 1977:149)

What had been isolation on the basis of religious impurity, in the fifteenth and sixteenth centuries, clearly becomes quarantine of an infectious disease.

The development of trade in the later Middle Ages and the epidemics of plague which were associated with ships from the Far East, led to the development of a quarantine period for ships from distant ports. Although plague was the first disease identified as "infectious", the first detention centre, established in 1423 on an island near Venice, was called a lazaretto. Although the term "lazaretto" had been used for places of segregation for leprosy victims, the term was then attached to quarantine stations for ships in European ports. (Encyclopaedia Britannica, 1975). Thus, before any medical theory of

isolation had been developed, the place for isolation ships for plague was given a name commonly associated with leprosy hospitals. Not until the sixteenth century were diseases other than plague quarantined at ports (Encyclopedia Britannica, 1975). Prior to the establishment of quarantine for cases of leprosy, leprosy was kept in the general leprosy hospital or leprosarium, treated as a highly infectious condition, and as such there was no concrete theory of disease transmission from one individual to another.

From the middle ages on, the contagious nature of leprosy received more attention from the medical standpoint. Leprosy hospitals were built, and after the hospital at St. George, England was visited by Pope Sixtus IV, 1472.

After European settlement in the New World, the isolation of leprosy victims became more necessary. Settlements were again to be found in lands or remote coastal areas. The first in Canada was near Fredericton, New Brunswick in 1794, and another was established on Beothick Island off the west coast of Vancouver Island in 1894. Gallup Island in Boston harbor was used for leprosy victims, mainly seamen. However, when local residents were found to be afflicted, attempts were made to get them admitted to State institutions. However, Tewksbury hospital for tuberculosis patients refused to accept them. When a safe out location

was selected, residents protested that the tourist trade would be adversely affected. Finally, in 1905, Pekinese Island was purchased for the purpose (Sabin 1981). Even at the end of the nineteenth century medical opinion was divided. Controversy raged between Danielson who first described leprosy as a disease entity but believed it to be hereditary, and Hansen, his younger colleague and son-in-law, who identified the bacillus which showed it to be an infectious disease.

This is an important issue in its consequences for leprosy patients. When a health condition is hereditary, there is no possibility of transmitting it to others through contact, therefore segregation cannot be justified on medical grounds. The discovery of the bacillus would provide adequate grounds for isolation. However, leprosy patients had been segregated, even though in medical circles leprosy had generally been considered hereditary. Stigma must therefore have been the reinforcement of the religious notion of contagion.

Several cases of leprosy in the United States during the first part of the twentieth century demonstrate the lack of medical understanding of the disease in modern times. The best documented is the case of John Early (Kalisch, 1972). John Early was a veteran of the Spanish American War, with service in the Philippines. Several years later

he developed a rash for which he sought medical attention. Over a period of thirty years, from 1908 to 1938, Early was quarantined in various locations, released and re-quarantined, as medical opinions differed on laboratory test results. A prominent dermatologist refused to see him, fearing that his practice would be adversely affected if other patients knew that he had been in contact with a suspected "leper". Early was transported to New York for assessment in a locked baggage car and charged for its fumigation afterwards. With the discovery of *M. leprae*, the disease was known to be infectious. The over-reaction demonstrated by the Early case, in that leprosy was thought to be a highly contagious disease, was almost certainly occasioned by the knowledge of a bacillary basis, coupled with the Biblical concept of contagion.

While John Early's case is extreme, other twentieth century victims have faced similar experiences (Burgess, 1940; Stein, 1964; Anon, 1983). Even after the second world war, medical opinion held that leprous fingers dropped off, and only the type of observation carried out by Dr. Paul Brand in India revealed that many patients lost insensitive fingertips to rats during the night (Wilson, 1965). Further observations showed that burns and other trauma were also responsible for the loss of insensitive fingers. Even today there is a lack of awareness among medical practitioners in

non-endemic areas. A prime example is the report of a recent visit to India by a U.S. physician who felt it necessary totally to disinfect himself after visiting a leprosy hospital (Crawshaw, 1982). This emphasises the difficulty of integrating treatment programmes into general hospitals or clinics.

The spread of European influence in the nineteenth century identified new endemic areas of leprosy. Again Christian missionaries were frequently in the vanquard of this discovery, and followed their traditional practice of providing care for the sick. The isolation practices of the Middle Ages provided the model on which such care was provided for leprosy patients. Remote islands, such as Culion in the Philippines and Molokai in Hawaii, were preferred locations. All were governed by the western understanding of leprosy and its treatment. Evidence of this practice remains in the many leprosaria and leprosy settlements established by religious orders around the world. Perhaps the most famous missionary priest to be associated with leprosy care was Father Damien, who, the same year that Hansen identified ~~Ma~~ leprosy, committed himself to caring for the leprosy victims of Molokai. At that time, controversy about causation centred on heredity and diet, but was generally believed, in medical circles, to be hereditary. However, the idea that leprosy was

punishment for sin also remained prominent. Fr. Damien having contracted leprosy some years earlier, died in 1889, at which time, the Rev. Hyde, head of the Presbyterian Mission in Honolulu, asserted that "he was not a pure man in his relations with women" and that the "leprosy of which he died should be attributed to his vices and carelessness" (Feeny, 1964:88-89). Such a malevolent pronouncement from a religious authority reinforces any notions linking moral transgressions with physical manifestations, which the laity might have about leprosy's sexual transmission, and reaffirms the mediaeval associations of leprosy with cardinal sins, especially lust. Thus, despite the scientific advances in the understanding of diseases in general, there remained at the end of the nineteenth century, some areas of disagreement in medical circles, and the persistence of religious notions, misconceptions and ignorance about leprosy among the general population.

Religious beliefs influenced the medical treatment of disease, because of the earlier close relationship of religion and medicine. Thus, the influence of religion on medicine caused leprosy to be treated as "a disease apart", resulting in the disease being stigmatised and its victims being isolated and segregated.

Having seen how the earlier close relationship

between religion and medicine fostered the stigma of leprosy, we will now see how civil legislation as it applied to leprosy was similarly affected.

Legislation in the Treatment of Leprosy.

In the previous section we saw how individuals said to be suffering from leprosy were treated or cared for medically, but did not consider the legal measures taken against them. Although legislation is implied in the segregation practices, it is often difficult to disentangle civil law from canon law. The influence of canon law is evident, but what is set down as civil law often reflects the perceived need to legalise what is customary practice. Thus, civil law follows social practice rather than determining it.

One of the earliest decrees concerning leprosy was made by King Pepin of France in the middle of the eighth century. He made it illegal for leprosy victims to marry, and at the same time made leprosy grounds for divorce (Feeny, 1964; Skinsnes, 1973). Pope Etienne III threatened to ex-communicate Charlemagne (Emperor 800-814) if he married the daughter of the Lombardy king and thus mixed noble French blood and leprous Lombardy blood (Zambaco Pachau 1914). Whether or not "leprous" in this instance implies the disease, or is a moral evaluation of the

Lombards whom Charlemagne had conquered for Christendom, the association of leprosy with moral corruption is reflected.

The Third Lateran Council (1179) which advocated the isolation of leprosy victims, at the same time recommended more humane treatment with regard to marriage. The Council recommended that leprosy should no longer be considered a cause for divorce (Feeny, 1964), which suggests that before that time it was the usual practice. It also advised that a leprosy victim could marry a willing, healthy wife, and expect full conjugal rights (Brody, 1974). If the Church advocated a more tolerant attitude toward leprosy during the Crusades, leprosy sufferers appear to have had only a temporary, if any, respite from the general persecution. When the Lateran Council was recommending a more humanitarian treatment of leprosy victims (1179), Henry II, of England, reigned 1154-1189, is alleged to have replaced the religious office of separation, a symbolic ritual, with a simple civil ceremony in which the victim was burnt at the stake (Roueché, 1953:117). Feeny (1964) however, argues that Henry II's edict that men should be "burned if leprosus - that is to say a beggar or a tramp" has been erroneously interpreted to mean that leprosy sufferers should be burnt. (The semantic confusion in Mediaeval English surrounding leprosy the disease and leprosus the condition of vagrancy is one of the factors which make it difficult to identify

accurately the magnitude of the leprosy problem. Although restricted, vagrants had more freedom of movement than leprosy victims). Clay (1966) cites several examples of Henry II as a benefactor, founding leprosy hospitals both in England and France. Richards (1977) similarly notes the provision of supplies and bequests, in repentance for his murder of Thomas Beckett. Edward I of England, ruling 1272-1307, permitted "lepers...the comforts of a Christian burial. They were led down to the cemetery and buried alive" (Roueché, 1953:117). Roueché also states that Philip V of France, who ruled 1314-1322, replaced the symbolic ritual with a burning ceremony similar to that of Henry II. Philip was also responsible for the massacre of many leprosy victims accused of poisoning wells across France (Clay, 1966). Thus, leprosy victims became scapegoats for extreme reactions from high-ranking leprophobes.

During the thirteenth and fourteenth centuries restrictions were more strictly enforced. Feeny (1964) cites edicts in 1242 and 1269 enforcing segregation and in 1283 statutes in Berwick on the Scottish border excluded leprosy victims from the town. Legislation concerning the movement of leprosy victims was widespread. In the 1340's they were banned from London and Bristol (Richards, 1977), from Glasgow in 1350 and Perth in 1427 (Feeny, 1964). The ban in London came under a royal mandate of Edward III in

1346 because:

"...those bearing the blemish of leprosy, do publicly dwell among the other citizens and sound persons, ...endeavouring to contaminate others with that abominable blemish, (that so, to their own wretched solace, they may have more fellows in suffering), as well in the way of mutual communications, and by the contagion of their polluted breath as by carnal intercourse with women in stews and other secret places, detestably frequenting the same, do so taint persons who are sound, both male and femaleall persons who have such blemish, shall, within fifteen days...quit the city and the suburbs, and betake themselves to places in the country, solitary and notably distant....no persons shall permit such leprous people to dwell within their houses and buildings in the city...on pain of forfeiture of their said houses and buildings, and more grievous punishment on them by us, to be inflicted if they shall contravene the same"

(from a quotation by Brody, 1974:97-98)

However in 1375 Edward again found it necessary to ensure that leprosy victims did not enter the city, threatening that gate porters who did not enforce the law would be pilloried (Brody, 1974). Such extreme reactions reinforced the stigma of leprosy.

Similar actions were taken in Paris where in 1371 Charles V ordered the expulsion of all leprous non-native Parisiens. Between 1388 and 1413, no fewer than six further decrees were enacted to forbid the entry of those afflicted with leprosy (Brody, 1974:98). The "persistent wandering and mingling" of leprosy sufferers with other people was a constant problem in France, such that in 1490 rituals for their separation were still in force (Cougoul, 1943:130).

Threats of punishment made to leprosy victims who did not abide by the local bye-laws included the burning of their clothes, and their expulsion, naked, in Berwick in 1283, the pillory in London in 1372, prison in Bristol, forcible confinement in hospital in Copenhagen in 1443, burning the cheek and turning out of town in Edinburgh in 1530, and forcible confinement in Finland in 1670.

As indicated above, the practice of forcible removal of leprosy victims was never undertaken on a national scale in England, but was under the control of local authorities (Clay, 1966). However, in 1315, national laws were enacted to ensure that hospitals established for the care of leprosy victims should be devoted to that purpose and the admission of other people refused (Clay, 1966). Edward VI⁴ in 1547 similarly advocated the continued treatment of leprous inmates and permitted a proctor to gather alms to support them. This law stands in contrast to pronouncements in 1357, 1369, 1383, 1388, 1495 and 1503 prohibiting begging (Clay, 1966).

Other "privileges" which were granted to leprosy sufferers in England by local legislation included the holding of fairs and markets, some of which continue today as annual events, although their original purpose of fundraising no longer exists. At Shrewsbury, victims were allowed a handful of corn from the market, while at Chester

a toll on salt, fish, grain, malt, fruit and vegetables went to them, together with one cheese or salmon from each load and one horse from the horse fair (Clay, 1966). This practice was not confined to England. Bakers in Copenhagen who sold bread illegally in 1443 had to forfeit it to the leprosy hospital. In Scotland, the "leper men" were entitled to food too rotten to sell or wild beasts found dead or wounded (Richards, 1977).

If such "privileges" helped to supply the sufferers' physical needs, other legislation removed their rights. Norman law in England removed the right to inherit or bequeath property, but appears to have died out later (Clay, 1966). In France, however, the law was usually much stricter. Sometimes all the property went to the institution wherein the victim was confined, regardless of whether or not the victim had family (Cougoul, 1943). In Scandinavia too, the victim's family was deprived of any rights of claim (Richards, 1977). When the secluded person was "dead to the world" there were no rights, and the rights of dependents were also affected. A result of this was a change in the rules governing marriage. Although in the twelfth century spouses were expected to take vows of chastity when one of them was admitted to a leprosy hospital, that practice also seems to have changed later. Richards cites examples of spouses seeking permission to

re-marry, while the first partner was still alive, although it seems to have been easier for a man to remarry than for a woman. In 1691, the Bishop of Abo felt that the separation was so total that the purpose of marriage could not be fulfilled and therefore the spouse should be allowed to re-marry to prevent hardship (Richards, 1977). Marriage laws were enacted elsewhere too. In Iceland marriage was forbidden to leprosy sufferers in 1776, but in 1898 a more humanitarian approach recommended that husband and wife should not be separated when one became leprosy, if they desired to stay together. Although in Norway a Bill to prevent marriage of leprosy victims was rejected in 1855, in 1918 another Bill permitted marriage if the partner was aware of the danger. The second Bill suggests that there had developed a *de facto* prohibition on marriage. This latter Bill was in effect until 1969 (Richards, 1977). Thus, although some scientific knowledge was considered during the past hundred years, old ideas were not totally rejected.

During the latter part of the nineteenth and the first half of the twentieth centuries, legislation concerning leprosy was largely consistent with its consideration as a public health problem. As a communicable disease, and a potential threat to the healthy population, quarantine/isolation measures were considered necessary.

Smallpox, diphtheria and scarlet fever were all similarly quarantined. In the case of leprosy, however, the relative non-virulence of the causative agent was not recognised. In 1856, the leprosy register became the first national patient register in Norway, and is credited with helping to bring the disease under control in that country (Irgens and Bjerkegal, 1973). When diseases are notifiable it is possible to observe trends in those diseases, but the restrictions pertaining to leprosy were more far-reaching than those of other infectious diseases. The campaign by Stanley Stein, a patient at Carville, U.S. Public Health Service Hospital, to repeal some of the restrictions in the 1940s and 1950s reflects this. He fought successfully to abolish the Louisiana law which designated leprosy a quarantinable contagious disease with mandatory segregation, and to repeal the inter-state ban on the use of public transport by patients and the ban on marriage between patients (Irgens, 1968).

Reporting on the current legislation pertaining to leprosy, Doull (1950) indicated that in the United States, infectious diseases were generally covered by State legislation. Although ten states reported no specific regulations for leprosy sufferers, in all except New York and Vermont leprosy was a reportable disease. Section 332 of the Public Service Act (1944) however, allowed the

Surgeon General to provide regulations for the apprehension, detention, treatment and release of people with leprosy. Once again, the terminology suggests punishment for crime. Escapees from the U.S. leprosy hospital at Carville used to be punished before Stein's crusade for reform. At the present time, a hole in the wire fence symbolically indicates that leprosy patients are no longer mandatorily confined.

In England, leprosy was made notifiable in 1951, all information going directly to the Chief Medical Officer, Ministry of Health. New regulations in 1967 placed the patient under the care of the Medical Officer of Health of the local authority, who then forwarded the information to the Chief Medical Officer. Leprosy thus came under the general health service (I.J.L. 1967). At the present time, therefore, in western societies where leprosy is non-endemic, official recognition of the disease as expressed in legislation is determined by the current medical understanding of leprosy as a mildly infectious, controllable disease. At the same time, it retains a mystique which sets it apart, even today. This mystique is based on the retention of the image it had in the past together with the associated social attitudes. Myths and misconceptions propagated by literary and visual media representations of leprosy continue in western society,

remove it. Not only was it incurable, it could be seen as getting progressively worse, and although the victim was pronounced "dead to the world", his earthly presence persisted.

The regulations pertaining to the movements of leprosy victims varied in severity, and in degree of enforcement, as shown in the previous section. However, standards of behaviour were laid down, and normal rights and privileges were forfeited. People knew how to treat those with the disease and how they would be treated if they should be afflicted. The response to the disease was thus determined by fear: fear of the disease itself, both because of its association with moral depravity and because of the resultant deformities; and fear of social rejection and ostracism, as well as loss of rights. With such a prospect, any early signs would be hidden, until suspicious neighbours made the accusation (Cougoul, 1943; Roueché, 1953). Once the diagnosis was made, the victim's fate was sealed. Clothing and warning devices proclaimed the condition, even if the physical signs were concealed. The regulations of St. Alban's leprosy hospital (1344) leave no doubt about the leprosy victim's place in society.

Amongst all infirmities, the disease of leprosy may be considered the most loathsome, and those who are smitten with it ought at all times, and in all places, as well in their conduct as in their dress, to bear themselves as more to be despised than pitied.

(Richards, 1977:149)

The victim was thus expected to abase himself. The fact that some leprosaria punished inmates by expulsion suggests that in the Middle Ages, life inside was preferable to life outside for a recognisable victim exposed to open hostility. He was denied the usual legal privileges and protection and was considered dangerous. Outside the sheltered environment, victims were avoided, pitied, despised and vilified, regarded as outcasts by other members of society.

The mediaeval populace thus understood leprosy as a disease with physical manifestations which were both long-lasting and progressively deforming, and at the same time it was associated with immorality. Although the incidence of the disease declined from the fifteenth century onwards, that double image was perpetuated in literature and art (Bloomfield, 1952; Brody, 1974; Sigerist, 1943). Shakespeare provides several examples which reflect the social conception of the disease in his time: in *Hamlet* (I.v.41-91), Banquo's ghost relates how his brother, lusting after his wife, poisoned him with a "leprous distillment", which made him "lazar-like, with vile and loathsome trust" and brought about his death; leprosy is used as a curse in

Amleth and Cleopatra (III.2-15) and Hamlet (IV.1). The images of punishment, curses, and just associated with leprosy are thus incorporated into Shakespearean drama. Similarly, Prender (III.1) and Faerie-Queene links leprosy to sin. The particular sin in that case being envy (I.iv.101-102).

'Such imagery was not confined to medieval or Elizabethan literature.' Even in the twentieth century, in literate societies, old beliefs and attitudes are perpetuated in literature (Gunn, 1977; MacLure, 1977; Donaldson, 1977). Zappa stresses the association of leprosy and illicit sexual activity. He also takes up the suggestion cited earlier that sufferers deliberately try to infect others so as to have companionship in their misery. More recently, in his novel Hawaii, Michener (1953) similarly stresses old ideas by describing fingers, toes and noses falling off, and giving accounts of licentious sexual activity. In The Chronicles of Thomas Covenant, a comprehensive four volume fantasy, compared in reviews with the works of J.R.R. Tolkien and C.S. Lewis, the main character is a leprosy victim whose disease is brought under control by modern therapy. However, the descriptions given of the disease, the man's divorce, attempted suicide, and solitary life, and the ostracism by residents of the small town in which he lives, all portray the old image

(Donaldson, 1977).

The most sympathetic account of a leprosy victim's ordeal is given by the Yugoslavian author and activist Djilas, (1957). In one short story, "The Leper", he captures the suffering and anguish of the victim, the insidious development of increasingly severe isolation, encouraged by the head man of the village, the rejection of his daughter in marriage, the shooting of his dog which visited him, the building of ever higher walls so that he cannot see his family home, and finally, when he can no longer be heard and is presumed dead, his house of isolation is burnt to the ground. All this took place in the early twentieth century. If Djilas is using leprosy as a metaphor for dissidence in the story, it is a striking example of how deep-rooted beliefs can be harnessed and stimulated wherever stigma is concerned. Another such example is given by Ellison (1982). The fear and horror of leprosy is indicated when "leprosy" is used as one of a series of "plaques". All have emotional connotations: frogs, floods of blood, dust storms, spiders, snakes, locusts and bats. Leprosy, however, is the only disease used to conjure up terror.

If literature perpetuates such out-moded perceptions of leprosy, the visual medium is even more prone to do so. In the award-winning film *Bog-Huc* (1959), leprosy sufferers were vividly portrayed. The physical appearance presented

was not leprosy, but the social stigma presented was accurate. This film reached a wide audience. A similar effect is created by lesser films, such as *The Egg* (1980), in which the fear of leprosy is used as a theme, and has no other purpose in the film than to cause alarm. Such then are the images to which the modern population is exposed and upon which current impressions are based. When these visual images from both film and popular literature are coupled with Biblical images of leprosy, it is not surprising that old beliefs persist. Most people in non-endemic societies have not encountered the disease personally, and respond to the idea of it with impressions gained from an earlier age when the social stigma first developed.

The outcome of such frequent repetition of leprosy's bad image is that in modern western society the idea still persists that leprosy is a highly infectious, disfiguring, incurable disease associated with a licentious lifestyle. A recent study in the United States indicates that most Americans have a limited knowledge of leprosy. Ten per cent of those sampled, for example, thought that leprosy had been totally eradicated, whereas the World Health Organisation places it with tuberculosis and malaria as one of the three major health problems in the world today. It was the less educated and lower income groups which still perceived leprosy as a major world health problem (Gallup, 1982).

Perhaps these groups are most influenced by the popular images presented by visual media and literature, and also by religious teaching. The findings of the Gallup study reflect the fact that those not directly affected by the disease in non-endemic countries, tend to regard it as either an ancient, therefore no longer relevant disease, or as a tropical disease with which they need not be concerned. At the same time, those with the disease are very much afraid of disclosure. The decision in 1981 to close most United States Public Health Hospitals where leprosy patients were treated, brought that treatment to an abrupt end. It also caused concern that the confidentiality they had experienced in recent years would be eroded. It was this fear of social rejection and ostracism which led Stanley Stein to assume that name to protect his family, and other leprosy patients to tell their stories anonymously (Anon, 1983).

In recent studies in Israel, leprosy patients were found to have negative perceptions about themselves, expressing shame and despair (Meisels, 1979a, 1979b). These feelings were more pronounced among in-patients than out-patients, and strongest amongst those with severe deformity. They were under a constant burden of secrecy and fear of disclosure. Relatives of patients and hospital workers were similarly conscious of the stigma, again trying

to conceal their association with the disease. Junior hospital staff avoided telling people where they worked for this reason. Of those not directly associated with leprosy, 80% thought that victims should be isolated, but did not react to the word "leprosy" with stereotypic notions. Verbal assurances were given that treated patients would be accepted and that care would be given to a relative with leprosy, but whether or not such was the case in practice was not assessed. The conclusion was reached that the patients conceived of the stigma as more severe than it really was.

It has been demonstrated in this chapter that, in the western world, leprosy has been treated differently from other diseases. Leprosy has been, and still is, a disease apart. Both the disease and its victims have been, and are, stigmatised. The western world has been influenced by Judaeo-Christian religious teaching. A direct link is apparent between beliefs in disease as punishment for sin, and the stigmatisation of the disease, leprosy, which visibly, but mysteriously, deforms its victims. As such, the stigma of leprosy may be seen as a mechanism of social control, ensuring adherence to religious teaching and the pursuit of a moral lifestyle.

The following chapter will examine the

- socio-historical position of leprosy and its victims in non-western societies. This will afford the opportunity to compare the social reactions toward leprosy in areas influenced by other religions, and hence confirm or refute the assertion of this study, that leprosy is universally stigmatised.

CHAPTER 7

LEPROSY: A DISEASE APART II

LEPROSY IN THE NON-WESTERN WORLD

"What a dreadful fate!

That such a man should suffer such an illness!"

Confucius (6th. century B.C.)

It has been suggested by some authors that the stigma associated with leprosy was introduced into non-western societies with European expansion (chapter 2), and especially with the introduction of Judaeo-Christian religious ideas (Rotberg, 1978; Shiloh, 1965). Others, notably Kellersberger (1951) and Skinsnes (1964a, 1964b, 1964c, 1968, 1972), argue that evidence of social opprobrium related to leprosy can be found in societies before they came under European influence. In this chapter, it will be shown that both these claims have some validity. Areas which came under direct Christian European influence, where both the disease and the stigma may well have been introduced, will be discussed first. Then areas with long-standing traditions which can be traced back to eras before European influence will be considered.

3

The Spread of Western Influence

There is no doubt that the mediaeval European perception of leprosy was introduced directly into some subjugated areas. Most notable in this respect is the area now termed Latin America, which was settled soon after discovery by the Spanish and Portuguese, who imported their European values. Aboriginal cultures flourished in small isolated pockets, but essentially, the society which developed throughout Latin America was European. There is no evidence that leprosy was present in the New World before Europeans arrived (Wells, 1964). Europeans, therefore, introduced the disease, either directly through infected Europeans, or indirectly through the slave trade (see chapter 5). They also introduced the social response to it. Thus, Latin America inherited leprosy and all the ideas of the mediaeval European Church. It was then little affected by the events of the Reformation in Europe, from which it was relatively isolated.

The stigma remains strong in Latin America today. Rotberg, a Brazilian leprologist, has for this reason been campaigning against the name "leprosy" for years, because of its long-standing pejorative associations. He argues that the population learns to fear and repel leprosy in early childhood, through religious texts, forming deep-rooted prejudices which are resistant to future education (1972).

Brazilian dictionaries give as synonyms for leprosy "filth", "vice", "repulsiveness" and "nauseating thing", and the word is used as the strongest of insults. Gonzalez del Cerro (1979) confirms the association of leprosy and social stigma in Argentina. The name "lepero" in American Spanish is used for a Mexican of low social or economic status (Webster, 1971). Thus, dictionaries again reflect popular usage of the term and help to perpetuate the stigma associated with the disease. Latin America consequently presents a modern example of leprosy viewed with the fear and repulsion with which it was associated in mediaeval Europe. Leprosy remains endemic, and attitudes have changed little from those revealed in the edicts of the Middle Ages in Europe. Only in 1956 was legislative reform introduced in Brazil to remove some of the restrictions (ILL, 1957). A direct link with European religious influence is thus observable.

In the islands of the Pacific Ocean, the imported western influence is also obvious. In the Philippines and Hawaii, for example, mandatory segregation and institutional care was instigated under western control during the nineteenth century. In Hawaii, Molokai provides a picture of ostracism, sanctioned by the Territorial Government, in a complex legal leprosy code affecting all areas of life. Isolation was legally enforced, and laws affected marriage, divorce, taxation, property, voting, pension and fishing

rights. Infants were separated from leprous mothers and concealing anyone with leprosy was a crime (Gould, 1969). In Cullion, Philippines, letters and money were fumigated to prevent transmission of the disease with the mail (Burgess, 1940). The afflicted thus had a similar experience to their mediaeval counterparts. At the same time, leprosaria provided a form of protection. As mediaeval victims found a haven in leprosy hospitals, cured victims on Molokai voluntarily remain in the leprosarium in modern times, because of their stigmatisation by the general population (Bloombaum and Gugeluk, 1970).

It is asserted that Australian Aborigines, among whom the first cases of leprosy were reported about 1900 (Davidson, 1978), attached no stigma to the disease until segregation of victims became law, removing them from their families (Medical Journal of Australia, 1977). Victims were reportedly concealed from white authorities, but cared for by their relatives, allowing them to die in their homeland (Australian Dept. of Health, 1970). The same observation is made concerning the native population of Papua New Guinea. Rotberg (1978) states that in the highlands, the last known area to come under European influence, leprosy was a disease like any other until western influence and religious missions brought about the stigmatisation and ostracism of patients and their families.

A similar argument is made by Shiloh (1965), among the Hausa of Northern Nigeria. There, the mainly Moslem population had no clearly defined theories about the aetiology of the disease. A variety of possible causes, from diet or poison to sin were cited, but the disease excited no greater apprehension than any other and little disgust was expressed. Compulsory isolation by Western medical personnel, frequently missionaries, made the disease something to be feared.

Wherever Christian missionaries went, they were responsible for instituting Western education and health services, supplying services which did not exist before their arrival. Unfortunately, as well as the benefits which these services brought, less desirable elements were also introduced. In the case of beliefs about and attitudes toward leprosy, Christian influence may be regarded as an important contributory factor in the development of the stigma, and has certainly helped to sustain negative social attitudes.

As demonstrated above, Western influence has contributed to the stigmatisation of leprosy in many areas. Areas where Western influence has had little effect, or where other major religions have been influential, will now be considered.

Leoprosy in Areas Influenced by Islam

Although Islam originated in the same cradle as Judaism and Christianity, there are some fundamental differences. The Islamic doctrine is more rigidly monotheistic, with an omnipotent, yet just and merciful God. It also incorporates pagan Arab beliefs in a blind inexorable fate over which man has no control. Everything within the universe is patterned and only Allah's power is unlimited. Man exists to submit to Allah's will. Repentance is always possible and removes all sins, returning man to his original sinlessness. Social service to alleviate suffering or help the needy is an integral part of Islamic teaching (Encyclopaedia Britannica, 1975).

Islam, like all religions, is convinced of its superiority over other religions. The Jihad, or Holy War, unlike Christian missionary activity, aimed at gaining political control over other societies, which when run according to Islamic principles would lead to the conversion of individuals. This drive carried the Islamic faith throughout the Middle East, across North Africa to southern Spain, and into northern India. Later waves spread the faith to East Africa and southeast Asia, exerting considerable influence.

Islamic theology provides the basis for the law, which seeks to realise the Islamic system of values. Thus,

moral and legal aspects are not separated, and all acts are governed by Islamic law. It would be expected therefore, that, with the strong fatalistic aspect of Islam, together with the stated concern for the relief of suffering and protection of the weak, the victims of leprosy in Moslem areas would be more readily accepted by the rest of society than those in areas influenced by the Judaeo-Christian traditions discussed in chapter 6 and the first part of this chapter. Opinion on this subject, however, appears to be divided.

Support for the supposition that under Islam leprosy victims are not stigmatised is provided by Shilch (1965) who studied the predominantly Moslem Hausa of northern Nigeria. The Hausa did not appear especially apprehensive about leprosy, regarding it as one of the normal range of diseases they would encounter. Sufferers lived in the family compound, assisted by members of the extended family. Children were not separated from people obviously suffering from leprosy. When the disease reached an advanced stage, the victims exploited their disabilities as beggars. Since the giving of alms is part of Islamic practice, beggars, including those with leprosy, habitually gathered near mosques or in the market place to obtain alms. Leprosy victims in that society were therefore not stigmatised.

The Hausa commonly put forward several possible

causes of leprosy: eating the flesh of certain animals, especially crocodile, rat, chameleon, red monkey, black goat and field lizard; poisons, frequently thought to contain blood from the above animals; and, "sins", such as sexual intercourse with a menstruating woman, or swearing falsely by the Koran. Some idea of contagiousness is implied in a less frequently held belief that washing in the same water as a leprosy victim could result in leprosy. However, sleeping in the same room was considered acceptable, with certain precautions. Disagreement was voiced as to whether the leprosy sufferer should leave the room first, taking leprosy out or last, leaving it behind. Much closer to traditional Moslem thinking was the belief of some Hausa that everyone is born with leprosy, and one's actions in life determine whether or not it manifests itself.

The traditional medical practices employed by the Hausa in treating leprosy are similar to those of many societies in the past. They include: burning the lesions; using herbs in potions or baths; purges and emetics; and writing Koranic verses on a board, washing the board and drinking the water. That is, they are magico-religious in nature. The wide variation in treatment practices suggests that they are unsuccessful.

Christian missionaries provided leprosy care to the Hausa during the 1930s and 1940s, basing their practice on the contemporary medical understanding which required segregation of sufferers. Shiloh argues that the removal of members of the community, by members of another religion and race, made the disease one to be regarded differently - and hidden. (Similar fears were expressed when Inuit and Indians suffering from tuberculosis were sent to southern Canadian hospitals for treatment). Thus, despite the Christian role in providing treatment for leprosy sufferers, the Christian influence also made it a "disease apart" for the Hausa. Only when the patients could again receive treatment locally, from their own people, did leprosy return to its more acceptable status.

A different picture is presented by Kahout et al (1973). In a city hospital in Iran, as late as 1963, patients awaiting transportation to a leprosarium were locked in a room, and following their departure, everything in the room was burnt. The authors also report that historically, sufferers in the southern part of the country were sent into the desert because fear of contracting the disease was so great. A Persian source is cited indicating that because bad spirits were believed to cause the disease, victims were banished to cemeteries, forests or islands. They had to keep their mouths closed, or speak from a

distance, and if approached, had to call out naiss (unclean). They were not allowed in public places or cities. This practice clearly mirrors that in Mediaeval Europe. Unfortunately, no indication is given of the date when such practices were common. Kahout et al (1973) state that although changes have taken place, victims are still ostracised by society and separated from their families. Even doctors and nurses may refuse to have contact with them, and in leproseries, door handles are avoided for fear of infection. At the same time, patients isolate themselves from other people. When cured, patients cannot obtain employment, are unable to find marriage partners, and their children cannot attend school with other children (Eshraghi, 1969 (in Persian) cited by Kahout et al, 1973). Since Iran was greatly influenced by western ideas, although retaining its Moslem status, prior to the overthrow of the Shah, it may not be truly representative of Moslem attitudes toward leprosy. It would be interesting to find out if attitudes are changing now that Iran is a fundamentalist Islamic state.

It was reported (ILL, 1938a) that in Turkey, the presence of a leprosarium near town caused panic among the local townspeople, therefore it was proposed to establish a larger leprosarium in a more isolated location. Richter and Tat (1958), however, argued that the Islamic Code, which

requires members to support and help the weak and sick, and also the population's indifference toward disfiguring skin diseases, allowed people with leprosy unrestricted participation in community life. Only at the extreme stage, when victims were blind and totally crippled, would they perhaps be taken to a doctor and then sent to a leprosarium. Levin (1984) commented on the exploitation of all types of deformity in Turkey, noting that in the past, children were sometimes maimed by relatives to make them better beggars. If society does not react emotionally against either physical deformities or disfiguring skin diseases, it suggests that the physical manifestations of leprosy are not the reason for any ostracism which occurred in the past. Both Turkey and Iran are close to the Judaeo-Christian influence in the Middle East, and Islam incorporated Arabic folk beliefs into its doctrine. Perhaps in this area, therefore, these attitudes may be the result of an underlying, pervasive, folk influence.

Leprosy in the Indian Sub-Continent

As indicated in chapter 4, the earliest references to a disease identifiable as leprosy are found in the Vedic literature of the first and second millennia B.C. The descriptions in the Susruta-Samhita, incorporating traditional knowledge from earlier times, clearly indicate

that the population was familiar with the disease. Once again, linguistics produces difficulties, but there is a suggestion that a disease, or diseases, stimulated a negative social response. The Sanskrit terms traditionally translated as "leprosy" in English are *kustha* and *kilasa*. As indicated in chapter 4, *kustha* was considered the worst of diseases, being carried into future incarnations. Jolly (1951) suggests that *kustha*, a dangerous skin disease, with gross deformities, was, according to Indian law writings, the punishment afforded the worst sinners in a future incarnation. The afflicted were not allowed to inherit property, unless they did penance to remove the sin. Treatment of the afflicted included strict diet, piety and penance, and the avoidance of over-exertion, sexual intercourse and excessive eating and drinking (Siderist, 1964b). There appears to have been some degree of segregation, with huts set up outside the village (Siderist, 1961), but medical texts do not mention this. Siderist also notes that people did not marry into families where leprosy occurred. Two thousand years later, this remains true among Hindus, who also regard it as a legitimate reason for breaking a contract of betrothal (Reade, 1983). One observer noted that leprosy victims are often relegated to a caste-like pariah status, regardless of their natal caste and leprosy has thus become known as "the disease of

untouchability" (Berreman, 1983:22). The author takes care to point out that the designation does not imply that only "Untouchables" are afflicted, but that the disease confers untouchability on its victims. Leprosy causes them to be outcasts. Thus, once again, there is the implication of impurity applied to one specific disease: leprosy. However, personal observations confirmed by local professionals, indicate an ambivalence in the social response which is more negative towards those of lower castes. At the same time, the local population gives alms to leprosy beggars, thereby salving the conscience.

As India has the largest number of leprosy victims in the world today, leprosy is an ever-present problem. Leprosy has existed in India for at least two and a half millennia, and has been recognised throughout that time as a very serious condition - the worst of diseases. Limited evidence (Sigerist, 1961) suggests that leprosy victims may have been segregated in ancient times, but there is no continuous record of such treatment afforded leprosy victims since those times. Updated versions of the Vedic literature retain references to the disease (Kutumbiah, 1962). The belief in an underlying supernatural cause of disease, evident in the earliest literature, persisted, even when diseases were classified as resulting from environmental or hereditary causes, worms, sorcery or demons and spirits

(Kutumbiah, 1962). Ayurvedic medicine, still practised in India, provides a prescription for healthy living. In this respect leprosy was not specially treated, although mention of it specifically indicates that in the past it was considered serious. In a seventeenth century dramatic allegory, "Jivananda", the body is attacked by diseases attempting to drive out the soul. Leprosy (*kustha*) is the leader of the army of diseases (Zimmer, 1948:61-75).

These sporadic references to leprosy make it impossible to give a comprehensive account of its treatment prior to this century, but abundant evidence is available for recent times. This evidence shows that leprosy victims frequently suffer more from the social reaction they experience than from the effects of the disease itself, although the latter may be considerable. Children may be refused admission to schools unless a certificate of fitness is provided, and doctors have been known to consider education a useless investment for leprosy victims (Wilson, 1965). Rejected by friends and avoided by strangers, frequently barred from public transport and refused service in eating places, denied employment even when able to work, and treated in clinics set apart from the rest of the hospital, sufferers withdraw from society to the greatest extent possible. So strong can the impact of leprosy be that euthanasia of leprosy victims has occurred (ILL, 1936a,

1938b), and suicide is not infrequent (Wilson, 1965). By 1949 a voluntary isolation village had been established where the victims at least had the company of others similarly afflicted, and such centres became a standard form of controlling leprosy in India (ILL, 1950). The Gandhi Memorial Foundation was established in 1951 with the aim of bringing about a more humanitarian treatment of leprosy victims.

Leprosy and social isolation are not confined to members of low socio-economic status, although they do provide the stereotype of leprosy victims in India. Even in professional occupations, sufferers find themselves ostracised. For example, a Calcutta lawyer, who had undergone treatment at his own expense, was the victim of a complaint laid by his colleagues. They objected to the sight of his badly clawed hands in court. Fortunately, surgical treatment restored normal function and appearance before the hearing, and the charges were dropped (Wilson, 1965). The stigma, in this case, among professional peers, was in the "disgrace" he brought to the profession by practising law with the visible deformities occasioned by leprosy, although he was known to be cured. Removing the offending stigmata removed the objection. On the other hand, similarly successful operations may have unforeseen consequences. The first attempts to straighten fingers were

made on hands which could not be made worse by the procedure. After surgery, hands which were no longer deformed lost their utility for begging, although other signs of leprosy prevented their owners from obtaining employment (Wilson, 1965).

Chatterjee (1958) traced the customs and practices associated with leprosy in India in modern times to erroneous ideas perpetuated from ancient times. According to Ancient Hindu Law, disinheritance was based on the virulence and incurability of a disease, which made a person unfit to make offerings to the ancestors. Before the passing of the Hindu Succession Act in 1956, leprosy was considered "of such a virulent form that it was incurable and rendered the individual unfit for social intercourse" and disqualified a person from inheriting. When the Hindu Marriage Act of 1956 was projected in 1953, it was protested by the Indian Association of Leprologists (IIL, 1953). The Act passed into law in 1956, however, allowed "a virulent form of leprosy" and a "virulent and incurable form of leprosy" to be grounds for separation and divorce respectively.

Restrictions also affect other areas of daily life for leprosy sufferers. Under the Railway Act of 1890, people suffering from some infectious diseases, including leprosy, were banned from travelling in a compartment with

others. Concessions were made at various times for the sufferers of other infectious diseases, such as that for tuberculosis which came into effect in July 1957. Leprosy, however, remained a ground for exclusion. Under the Motor Vehicle Act of 1939, leprosy disqualified absolutely a person from obtaining a licence to drive a public vehicle. Life insurance rules deny acceptance to a person with leprosy. Military service rules bar a leprosy victim from joining, or necessitate his discharge, as soon as the diagnosis is made. Thus, the stigma of leprosy, as translated into laws, acts so as to remove the victims from all facets of "normal" social life.

Chatterjee argued that ancient terminology is copied verbatim (for example, "virulent and incurable") even when it is no longer relevant as a description of leprosy. Medical understanding of leprosy has progressed, but the law has not taken note of such changes. He points out for example, that the Indian Divorce Act of 1869, which applies to Christian marriages, does not consider leprosy a ground for divorce. Despite Chatterjee's call for reappraisal of the obsolete terminology which allows leprosy to be separated from other infectious diseases in law, lawyers were still being asked to assist leprosy patients with problems such as wife abandonment some years later (ILL, 1964).

With the expansion of medical and education programmes in India, an improvement in social attitudes could be anticipated. On a positive note, Madras State government sanctioned the payment of allowances equal to half pay for public servants who took leave to obtain treatment for leprosy (IIL, 1967). Other employees were less fortunate. A study of 128 industrial establishments in Bombay found widespread prejudice. Employers were apprehensive of the reactions of other workers if former leprosy patients were hired. Only 15% agreed to employ or train them (IIL, 1969). An outstanding exception was that of Tata Industries, which employs ex-patients, and provides monetary assistance when patients are unable to work. After resumption of work, patients are monitored to ensure that treatment is continued (IIL, 1971).

Studies undertaken specifically to assess the popular understanding of leprosy found a low level of knowledge among both rural and urban respondents. (Selvapandian et al, 1972; Selvapandian, 1975; Matthews, 1978). The majority attributed its transmission to sexual intercourse, but also thought that heredity played a role. Some of Matthews' (1978) respondents thought leprosy was a later stage of venereal disease. Respondents in all studies exaggerated the infectiousness of leprosy, saying they would avoid even casual contact with leprosy patients. In

Selvapandian's (1975) study, most respondents thought that leprosy victims are incapable of working, that they should be treated in hospital and that employers would not employ patients, especially those with deformities. From this study it is obvious that the general population associates deformities with infection. Matthews (1978) found a reluctance among some members of the population to discuss leprosy at all. Early symptoms were treated at home, and only when deformities occurred was the disease considered to be leprosy requiring treatment from a doctor. Thus, public opinion again associates deformity with leprosy, despite the fact that most badly deformed victims are no longer infectious.

Deformities, ugliness and ulcers were the most frequently mentioned signs of leprosy in a study comparing the knowledge and attitudes of patients and the general population (Matthews & Jesudasan, 1978). Nearly half the general population and 38% of patients did not know the first sign. (Given the magnitude of the problem in India, this finding is disquieting). While 63% of patients claimed not to know the cause, sexual immorality was cited by 18% of the general population but by only 6% of the patients.

Although Matthews and Jesudasan found some, albeit limited, improvement in knowledge and attitudes among patients, other recent studies reflect the persistence of

old ideas and beliefs. Vyan *et al.* (1982) found that 70% of leprosy patients asked had no idea of the cause. Infection was recognised by only 3.5% - the same number as attributed it to punishment for sin. Seventy per cent left home for fear of losing family prestige or to hide their disease. Among patients studied by Kushwah (1981), males and those of lower economic and social classes more frequently reported being stigmatised, confirming personal observations (1985). The greatest aversion, reported by 63%, was against their touch.

In South India, Berreman (1984) found that leprosy was known in the local language as *hgrl-hang* (big disease). Leprosy is believed to come from the local goddess Yelloamma, whose help is also sought in its treatment. Childhood leprosy, which resembles many other skin diseases, does not seem to be recognised as leprosy, although the marks are referred to as Yelloamma's flowers. It is referred to as "pre-leprosy", the treatment of which will prevent the development of leprosy.

- Although the author reported that stigma was slight in the area under study, where all treatment was provided on an out-patient basis, and patients were open about their treatment, the observed behaviour suggested an underlying stigma: workers in the government hospital were reluctant to examine suspected cases of leprosy, referring them to the

private hospital; the more visible the condition the more likely were the victims to withdraw from society; people were reluctant to discuss the subject when other people were able to overhear; facial deformities were rarely seen in public, as people with facial deformities secluded themselves. Occasionally, women who contracted leprosy were sent away by their husbands, and leprosy was considered adequate ground for divorce. Thus, despite frequent verbal denials of fears about the disease, behaviour with regard to leprosy and its victims contradicted the statements.

Using the term "pre-leprosy" in relation to childhood leprosy, suggests a tacit understanding of the true nature of the disease, but a reluctance to be confronted with such a diagnosis. Such a subtle change may well help in bringing early cases to treatment if early signs are considered "pre-leprosy" and not subject to negative social reactions. Nevertheless, it seems that a strong negative social reaction still exists in India and is present among Hindus, (the vast majority of the population) Moslems and Christians, and in different social groups and occupations.

Waxler (1981) supported the findings for India, but suggested that Sri Lanka presents a different picture of the social response to leprosy. She argues that the general population, as in India, fears leprosy, thinks it very

contagious and associates it with hideous deformities. Leprosy patients interviewed remained at home and continued their occupations. But, she states that most "withdrew from society to some extent, they stigmatize themselves" (1981:174). There was a general agreement not to tell non-family members, to avoid the anticipated rejection. This indicates that they are aware of the stigma. The author acknowledged that her study of Sri Lanka drew on out-patients attending a clinic and an estimated 50% of victims remain untreated. Since those who do attend express shame and fear, the fifty per cent who do not come forward for treatment are merely confirming the presence of stigma in the opinion of the present author.

At the other end of the sub-continent, in Nepal, also mainly Hindu, leprosy is also regarded as "the big disease" (Murray, 1981). Nearly half of 1280 people questioned attributed leprosy to "karma", and even among those who thought it was acquired through contact, 58% regarded it as a curse from the gods. Rehabilitation and resettlement into the community were only successful if the patient was highly motivated and physically able to work his land. Over 70% of respondents stated that they would neither help a victim on his own land nor hire him to work on theirs. Nearly as many (69%) thought victims should not participate in pilgrimages or enter places of worship.

There is in Nepal, therefore, a similar deep-rooted dread of leprosy, which is fostered by ignorance of the scientific facts and religious beliefs associating sin with the disease.

It seems that in India, among Hindus, the stigma of leprosy is incontestable. The studies discussed here imply a similar response among Muslims and Christians, who make up a small minority of the population. The population is very much aware of the disease and is confused about its causation, with beliefs in its origin in heredity, sexual intercourse and past sins, mingling with more accurate statements of infection. It is identified with deformities and the large number of untreated victims helps to sustain the belief that it is incurable. The overall social attitude which responds to victims with prejudice and repugnance, rather than sympathy, does not seem to vary significantly in different parts of the country.

Leprosy in the Far East

In the preceding sections it has been shown that a high degree of negative social reaction is experienced by leprosy victims as members of many different societies with very different backgrounds. Other different social systems are encountered in China, Japan and other parts of South East Asia. In contrast to the societies discussed earlier,

Christian missionary activity was late in making its entry into these societies, therefore written records which pre-date that period provide us with some indication of attitudes prior to the introduction of western influence.

China

Leprosy existed in China at least as early as the fifth century B.C. The earliest Chinese literary references to leprosy, from about that time, using the terms *g chi*, *li*, *lieh* and *lai* indicate that it was an "evil" disease. Improper activity was that deemed inappropriate to the place or season. This activity disturbed the natural equilibrium, bringing disasters. Leprosy was considered a disaster, and thus was seen as punishment for a moral transgression - a disregard for the proper time and place for activities to take place (Skinsnes, 1964b). Deities provoked by such impropriety were believed to cause leprosy through evil air or wind. By the seventh century A.D. a whole chapter of the *Thousand-Golden Remedies* was devoted to the "loathsome sickness of leprosy" (Skinsnes, 1964b).

As indicated in chapters 4 and 5, there is no doubt that the disease described in these early works was leprosy. Although environmental factors were considered part of the aetiology, the entry of "evil air" was thought to be facilitated by sexual and dietary excesses. In this belief

there is a similarity to the Hindu and Buddhist doctrine of avoidance of all forms of excess. Even during the Ming dynasty (fourteenth to seventeenth century), abstinence from eating meat and rich foods, and control of sexual desire were recommended to give the sufferer, a chance of recovery (Skinsnes, 1964b).

A seventh century Chinese legend attributes the origin of leprosy to illicit sexual activity, implying that leprosy is contracted venereally. Other traditional explanations for leprosy consider it congenital or hereditary, resulting in the avoidance of marriage into a family where leprosy exists. Indeed, in rural areas, the whole clan is stigmatised by its presence (Skinsnes, 1964a).

Other legends refer to the horror of leprosy, portraying it as a great calamity, considering it incurable, except by magic. Stories tell of leprosy sufferers being sent into isolation in caves and other remote places. In southern China such folklore exists in modern times. A proverb states that "if leprosy can be cured, salted fish can live again". Even priests and gods are believed incapable of curing leprosy. If oracle bones produce a favourable response, then the disease is deemed not to be leprosy. According to folklore the best that can be hoped for is amelioration - either by "selling" some of the leprosy to a healthy person, or by eating the flesh of a

dead infant (Skinsnes, 1964b).

The proposed construction of a leprosarium in Hong Kong was regarded as a major calamity such that marriage partners would not be sought in the villages near which the leprosarium would be sited. However, when a temporary centre was established, there was a fatalistic acceptance by the Chinese neighbours, who sold vegetables to patients and bought rabbits and ducks from them. When a permanent site was chosen, some Chinese stayed to work in construction and maintenance. It was then nearby European residents who objected to having the dangers of leprosy so close (Skinsnes, 1964a).

It is interesting to note that in Hong Kong the "Leper Laws" of 1933 treated all cases of leprosy as "foreign". Victims were given \$1.00 and taken by boat to leprosaria on the mainland. By 1935 however, it was necessary to provide facilities for the segregation and treatment of indigenous cases, who were, of course, British subjects. Contravention of the Ordinance was punished by fines or imprisonment (ILL, 1935).

Although Skinsnes notes a basically non-violent response to those suffering from leprosy, he does report stories of occasional violent incidents in which victims in areas outside Hong Kong, were burnt or shot. Other earlier reports indicate that leprosy was considered very infectious

in China and leprosaria were not allowed in cities. Sixty leprosy victims condemned to be drowned by a local council in southern China were saved and given asylum by Roman Catholic priests (IJL, 1936b). Care was usually provided by private charitable organisations with little support from government. Because of the supposed risk involved, a witness was excused from testifying when it was found that he had leprosy (IJL, 1937a). In the same year, soldiers attacked a leprosarium on the southern China coast, bound, shot and buried 60 patients before looting and burning the institution (IJL, 1937b). The officer responsible for the massacre was later found guilty of being a spy and shot (IJL, 1938c).

The horrors of leprosy seem to be instilled into children at an early age. Victims are often portrayed as evil monsters (Skinsnes, 1964a). Thus leprosy victims could be regarded as a threat comparable to that of the "bogeyman" in western society. The effect of such "education" can have a lasting impact. As a result, accurate self-diagnosis, even among illiterate peasants, is usual in people presenting themselves at the leprosy clinics. In Hong Kong, however, twenty-three patients, with no evidence of leprosy, presented themselves, convinced that they were so afflicted (Skinsnes, 1968). Skinsnes concluded that the dominant basis for what he termed "lepra-angst" was a combination of

fear and guilt about sexual misconduct and the retributive consequences. Sixteen of the 21 males cited relations with prostitutes, and only two explicitly denied extra-marital intercourse. Both were private tutors and therefore perhaps reluctant to admit such associations. Several had previously received treatment for venereal diseases and thus considered leprosy as distinct from venereal disease. One of the women cited intercourse with her husband during menstruation as the "dirty behaviour" which could have given her leprosy. The other woman, a student, denied any sexual relationships. The explicit denial of sexual relationships by the three most educated respondents suggests the strength of a belief in sexual immorality in the aetiology of leprosy. The notion that those who contracted leprosy were "bad" people, guilty of some immoral behaviour, was predominant in the minds of the 23 "lepra-angst" patients. It emphasises the underlying concepts and beliefs which Skinsnes (1964a, 1964b, 1964c) has shown date back to ancient times.

Whenever the topic of leprosy was raised, Skinsnes (1964a) found it received with horror, fear and disgust, and he expressed opinion that its victims should be driven away. Even today, there is a marked reluctance to discuss the subject, even among professionals. Leprosy is not considered one of the normal range of conditions to be

treated, but is consigned to "special" centres, "because of contagion" (personal observation). One informant reported that as late as November 1984, he had seen leprosy victims in northern China transported in caged wagons, with long poles ensuring that they were totally separated from the driver of the vehicle. This reinforces Skinsnes (1968) study, and emphasises the underlying concepts and beliefs which Skinsnes (1964a, 1964b, 1964c) has shown date back to ancient times. This clearly demonstrates that the stigmatisation of leprosy in China pre-dates European influence, and has continued through the development of the Marxist state.

Japan

Leprosy existed in Japan before the eighth century. A study of leprosy in Japan by Weith (1947) revealed that early Shinto priests stressed ritual purity and combatted everything considered polluting. Impurity was considered the tangible manifestation of sin and could be incurred in many ways. Acts such as murder, desecration of corpses, and incest, and afflictions such as leprosy were all considered tsumi or "sin", and the offenders were considered taboo. Shinto purification rituals eventually cleansed sinners of their impurity. However, leprosy sufferers, whose impurity was concrete in nature, could not regain a state of ritual

purity as long as they had the disease. Veith concluded that this reaction to leprosy pre-dated western influence. As in China, leprosy in rural communities stigmatised the whole clan. It was considered hereditary and stringent efforts were made to ensure that no history of leprosy existed in a family where marriage was being considered.

Japan came under the influence of China, Buddhism and Christianity at various times, the Buddhist influence being greatest. The full extent of such influences is uncertain, given that Japan remained a "closed" community from early in the seventeenth century until the middle of the nineteenth century. Only then did the rigid feudal system begin to break down. Information on leprosy in Japan is scarce prior to the 1930s, when mandatory segregation of leprosy victims was practised, even when they were considered cured (Wilson, 1936). Healthy children removed from leprous parents had difficulty in entering society (IJL, 1937c). It was reported that in Osaka "leper bands" terrorised shoppers and shopkeepers by threatening to infect them if goods were not handed over. Police were afraid to take action (IJL, 1939b).

Mandatory sterilisation was rejected in 1941 on the ground that sterilisation would give the impression that leprosy is congenital (IJL, 1941). In 1948, however, legislation was passed to permit abortion on certain

grounds, including "families with hereditary insanity or leprosy" (IIL, 1949b). Such legislation reflects the retention of old ideas about the hereditary nature of the disease, seventy years after its bacteriological cause had been identified. A paper presented at the Xth. International Leprosy Congress stressed that prejudice and stigma is common in older people, while lack of interest and indifference among the young was said to be marked (Satto, 1978). Perhaps the most telling information about recent attitudes to leprosy comes from survivors of the atomic bomb attack on Hiroshima, who report being shunned by others who fear contamination. "We now know how lepers feel", they stated (IIL, 1958).

Other parts of South-east Asia

In other parts of southeast Asia, similar patterns can be seen. Legends about leprosy, the isolation of its victims and cures resulting from the consumption of the products of the tree from which chaulmoogra oil is obtained, come from Cambodia (Burgess, 1940;; Skinsnes, 1970, 1972), indicating that leprosy was viewed with horror and those who suffered from it were avoided.

Although in more recent times these views have been influenced by western ideas, and care and treatment of leprosy sufferers has generally been undertaken by Christian

missionaries, deep rooted fears which go back to earlier times are evident. In Thailand, in 1920 for example, there appeared a "Lepers Wanted" advertisement in a newspaper. Taking advantage of the widespread fear of leprosy in the population, creditors employed leprosy victims exhibiting the most repulsive deformities to collect debts (ILL, 1936c). The use of leprosy victims to guard fields and scare away marauders in southern China was noted by Skinsnes (1964a). In both cases the worst visible manifestations, but those most usually associated with the disease and most stigmatised, were used as a threat, the threat thought most likely to be successful. The fear of the disease and the deformities must therefore be great. Currently, in Thailand, stigma seems to occur only when the deformities of leprosy appear.

Thus, it seems that throughout southeast Asia, in societies where western influence has had relatively little impact, there is a history of widespread social opprobrium directed toward leprosy.

Leprosy in Africa

As indicated in chapter 5, there is no definitive evidence that leprosy existed in the African continent before the sixth century A.D. (Moeller-Christensen, 1967). It is, however, a major problem at the present time,

especially in sub-Saharan Africa (see Fig. 1). Reports on leprosy in African countries give conflicting opinions on the degree of stigma associated with the disease, and personal experience confirms that there is a variation.

The case of the Hausa, in northern Nigeria, was discussed in the section on leprosy under Islamic influence. Shiloh (1965) argued that before Christian missionaries introduced segregation treatment for leprosy, the Hausa did not treat it differently from other disease. From personal experience of leprosy work in East Central State, Nigeria, it can be confirmed that in areas which were predominantly Roman Catholic, leprosy was greatly stigmatised, and religious institutions resisted the introduction of modern treatment programmes. The use of English as the lingua franca, as well as the extensive European influence in the past two centuries, makes it difficult to determine the extent of the indigenous reaction, but the stigma certainly seemed to be less strong in non-Catholic areas.

Brown (1937) studied leprosy in the folklore of southern Nigeria. His findings showed a general and intense fear of the disease. Its native name, *ggg*, was seldom used, since it was believed that repetition of the name would attract the disease to the speaker. Descriptive terms were used as euphemisms, but it was generally known as the "big disease". Even interpreters avoided the English word and

referred to "the sickness". Opinions on causation included supernatural actions, heredity and poisons, or a combination of all three.

When the disease was seen as punishment for deliberate sacrilege or omissions in rituals, it was believed to pass through generations until the disease died out. Since leprosy was seen as being latent in all off-shoots of the family, it could skip generations. Any idea of contracting leprosy through contact was secondary. Thus, not only a prospective bride, but all her forebears must be clear of the disease. In villages where there are many leprosy victims, the proportion of unmarried people was high. When leprosy was attributed to poison, it was believed curable by scarification and cauterisation of the lesions.

Some degree of isolation was reported. It was thought unlucky for a leprosy victim to be the first person seen in the morning. They were therefore supposed to stay indoors, in a hut outside the village, until the morning was well advanced. Because of fear of the disease, elders held periodic inspections. Anyone fully clothed was suspect, as normally, when working in the fields in a loin-cloth, the presence of signs would be obvious. It was preferred that victims did not die in the town, and there were reports of victims near death being taken outside and pushed into a

grave. Then, when the victim was dead, the grave was filled, and a fire built to trap the leprosy as it escaped.

A similar mixture of responses was reported from Senegal (Senkale et al, 1977). Fear was expressed about the "great disease", seen as the result of a curse or as punishment by 43%, and as hereditary by 29% of respondents. Seventeen percent attributed it to diet, especially goat, fish and milk. At the same time, many thought it contagious, needing segregation, but curable. Even when it was thought hereditary, it was deemed necessary to avoid victims. Thus, once again there is a mixture of sophistication and ignorance about the disease. The influence of traditional beliefs similar to those in southern Nigeria, and European religious influence while a French colony is also apparent.

Giel and Luijk^e (1970) found that the majority of patients in Ethiopia did not initially try to hide their disease from relatives, but about 25% of these were later rejected. On the other hand, 75% of victims who attempted to hide the disease from spouses were later rejected or divorced. Nearly half the patients who were married before they were aware of the disease had been divorced. Of the patients still married, about one third abstained from sexual intercourse for fear that it would increase the symptoms, although venereal transmission was not mentioned

as a reason. Of 49 patients giving such information, only seven males still visited prostitutes. Half the respondents reported being avoided and insulted, taunted as "leper" or "mutilated one", or told to go away as they would spread the disease, indicating a general belief in contagiousness. Although 83% of the respondents were Orthodox Christians, the authors noted that attitudes among Muslims was not markedly different.

Another study of Ethiopian leprosy up to 1935 indicated more tolerant attitudes toward leprosy victims than in western societies (Pankhurst, 1984). Although largely isolated from the rest of the population, they were permitted to beg at court and near churches, even accosting or threatening the public with impunity. They were also allowed to accompany the army on expeditions - a factor which could have contributed to the spread of the disease. Traditionally there seemed no awareness of contagion, leprosy being thought hereditary, curable by prayer, amulets, vapour baths, internal and external medication. Miraculous cures were frequently mentioned in old legends. One possibility is that the Arabic influence in this area, especially in relation to giving alms, was a factor in leprosy's tolerance, as was shown by Shiloh (1965) among the Hausa. It is postulated here that where there is a strong Arabic influence, attitudes are mixed. The practice of

punishing by amputating hands, for example, provides a permanent mark or stigma on such individuals. The manifestation of deformities due to leprosy, therefore, need not be differentiated from punishments for other "sins". They were, nevertheless, marked for life, but where Islamic influence is strong, repentance brings automatic absolution.

In northern Tanzania, van Etten and Anten (1972) studied the effects of health education on the population in three areas, one of which had been subject to an intensive campaign for five years, and the other two with incidental or irregular education on leprosy. They found that in the areas where it was irregular, health education was of little benefit, and that it may be negated by tribal attitudes. The best educated, that is, schoolchildren in the area with a long-standing education programme, were most knowledgeable. However, overall, 25%-30% attributed leprosy to insects, 25% to heredity, while a belief in witchcraft being the cause was held by about 20% of both the less educated groups. Only 15% said they did not know the cause. In the less educated groups there was a belief in adultery as the cause. When leprosy appeared in someone with no family history, the person was deemed to be illegitimate. Thus, the stigma of leprosy was used as a mechanism for social control and as a means of limiting sexual promiscuity or adultery. If leprosy was caused by witchcraft, it was

believed that it could only be cured by witchcraft, and then only if not advanced to the stage of disfigurement.

Although the authors found the attitude toward leprosy victims "rather benevolent", they noted that people hide the signs as long as possible, treating them at home. Once diagnosed, most sufferers are generally accepted, and even carry out duties as political leaders, but there is some evidence of stigma. Leprosy victims were usually buried outside the family compound. Those with obvious signs had less chance of marriage, and those seeking transport to receive treatment sometimes found drivers unwilling to take them. An incidental reverse effect of health education on schoolchildren was that having been told leprosy was infectious, they naturally drew the conclusion that it was to be avoided, the opposite of the intent of the education programme. In the adult population, the message of contagion had led to some market sellers being asked not to sell their wares, although previously they had not been restricted. Thus, the authors concluded, even in the most successful area there was a need to tailor education more closely to traditional institutions and structures.

From personal experience in southern Tanzania (1967-1969) it can be stated that the treatment programme was well established and very well received. Health education was part of the overall programme, and the whole

programme was supported by local leaders. Victims were encouraged, cajoled or coerced into seeking treatment. Provided treatment was sought and maintained, victims were accepted in their communities. Even so, a survey of remote villages in the area found that 40% of those with the disease had not come forward for treatment (Wheatley, 1970). This suggests that even though there is no strong social reaction against leprosy and its victims in this area, some underlying fears remain.

From the material presented here, it is clearly evident that leprosy attracts a negative social response. Waxler (1981) concluded that leprosy was not universally stigmatised but that a moral definition of the disease led to its stigmatisation in some societies. The present author agrees that moral definitions are part of the process of stigmatisation, but considers the stigmatisation of leprosy to be an almost universal phenomenon.

The case studies cited by Waxler to show the absence of stigma also in fact provide examples of stigma. Waxler found little overt rejection in Sri Lanka, and concluded that there was a general acceptance of leprosy victims. However, the perceived need of leprosy victims to withdraw and to keep their disease "secret" demonstrates that stigma did exist. Waxler stated that in Nigeria the Hausa attached

no stigma to leprosy, whereas the present study has shown that a stigma did develop among those same Hausa.

This study has shown leprosy to be stigmatised almost universally, but the degree of stigma is greater in some societies than others. In societies where leprosy is endemic, the degree of stigma attached to it seems to be determined by a combination of the nature of disease itself, and the social definition of disease. The disease presents a variety of signs depending on the type of leprosy with which an individual is afflicted. The ratio of lepromatous leprosy to tuberculoid leprosy cases, and consequently the presenting signs, varies from one society to another. The degree of stigma attached to the different deformities is therefore determined by the social definition of "acceptable" or "unacceptable" characteristics. For example, loss of eyebrows, characteristic of lepromatous leprosy, is not stigmatised in China where the plucking of eyebrows is common, whereas in India it is a much more serious problem. Based on such social definitions of acceptability, moral definitions of the disease, determined by the society's theodicy (Berger, 1969), then give the disease meaning for that society.

It was postulated in chapter 2 that a disease which is mysterious, and apparently uncontrollable, is more likely to be a candidate for stigma than diseases which are readily

explicable. It was also postulated that, when the nature of the disease is such that as it progresses it deforms, but does not kill its victims, the evidence remains to sustain the stigma. Leprosy was taken as a case study because it fulfilled all these characteristics. The resort to religious or magical explanations about the cause, or the reason why specific individuals are afflicted may result in identifying the cause as "sin". Thus, the disease acquires a moral connotation.

In chapter seven, it has been shown that societies influenced by Islam, Hinduism, Buddhism, Taoism, Shintoism, and animism, respond similarly to leprosy. Even when the stigma is relatively slight compared to that of western societies, it seems to be present in nearly all societies. Stigma occurs whatever the type of leprosy, and is often strongest in response to the visible deformities of non-contagious tuberculoid leprosy. These findings support the postulations set out above. The only exceptions noted were groups which remained isolated, or relatively isolated, until modern times: the Hausa in northern Nigeria; the natives of Papua New Guinea; and, the Aborigines of northern Australia. All were simple societies, in which the concept of sin does not imply deliberate violation of norms. Hence, no moral definition of the disease is found. It is only in more complex societies, apparently in all, that a moral

definition of leprosy occurs.

These anomalies bring into question the assumption that cultural development leads to a more rational understanding of disease. In simple societies, all "disease" is a shared responsibility. Groups are small and all members are known to each other. In larger, more complex societies, relationships are less personal, and the deformed less acceptable, rejected as being of no personal concern. In response to the physical repulsiveness of leprosy, religion explains it in moral terms and provides a justification for the rejection of its victims. This explanation helps to account for the fact that almost universally, with varying degrees of severity, leprosy is stigmatised in the non-western world. Again, it is a disease apart.

CHAPTER 8

"DISEASE AND STIGMA"

"Nothing is more punitive than to give a disease a meaning...
that meaning being invariably a moralistic one"

Sontag (1978)

The purpose of this study, as set out in chapter 1, is to obtain a better understanding of the stigma associated with certain health conditions, which results in those so afflicted being isolated or segregated and rejected by society. Whether victims are institutionalised as a group, or ostracised as individuals, they are denied access to full participation in everyday social affairs by other members of their society. The questions raised, therefore, were: how and why do some, but only some, health conditions and diseases attract a negative social response (stigma); how is this stigma perpetuated or maintained once established; and, how can the stigma be modified - that is, alleviated or preferably eradicated.

Chapter 2 presented a theory of stigma of disease, bringing together ideas about stigma (Foucault, 1965; Goffman, 1963, 1971), disease causation (Malinowski, 1961; Katz, 1981), acceptability (Shears & Jensema, 1969; Tringo, 1970), abnormality (MacGregor et al, 1953), stereotypes

(Klineberg, 1964) and religious influence (Berger, 1969; Bloomfield, 1967; Davis, 1961; Weber, 1963). It was postulated that there is a complex interaction of a number of factors, the most important being the concepts of health, illness and disease, abnormality and acceptability, religion and sin. Using these concepts, a theory of stigma was proposed.

In chapter 3, historical and cross-cultural variations in beliefs about disease causation were examined. It was shown how the human understanding of health problems has varied over time and space, but also that there has been a steady advance in the scientific understanding of diseases and their aetiology, and an associated improvement in techniques for preventing and treating them. Therefore, it was asked why, despite these advances, do some, but only some, conditions continue to attract social opprobrium which is inconsistent with the scientific advances.

Leprosy was selected as an extreme example of the problem, because of the almost universal negative social response to it over many centuries. Before examining the stigma of leprosy, however, it was necessary to present leprosy as just another disease - a disease like others. Thus, chapter 4 provided the medical history of leprosy to the present, and chapter 5 provided an account of the historical and geographic distribution, culminating in an

estimate of the current world problem. Leprosy was therefore considered solely on known and estimated facts consistent with the epidemiology of all diseases with which its history was shared.

Chapters 6 and 7 then presented leprosy as a case study of a stigmatised condition - a disease apart. In these chapters, it was shown that throughout history, in the western world and in most areas of the non-western world, leprosy has been stigmatised and its victims have been subjected to medical, legal, ecclesiastical and social treatment which has deprived them of their right to inherit and marry (India, mediaeval Europe, Hawaii), raise children (India and Japan), work and move freely (in most areas), and in extreme cases has led to death (China, France and England). Even without actual clinical death, the deprivations were such that the victims were "dead to the world", and in many cases clinical death would have been preferable to the life they were forced to lead. It was thus firmly established in chapters 6 and 7 that leprosy is a prime example of a stigmatised condition. It was suggested that leprosy came to be so stigmatised because it fulfilled all the conditions set out in the theory of stigma: the disease is mysterious; reasons for it afflicting specific individuals were sought in supernatural explanations linking disease to sin; the intrinsic nature of

the disease is such that as it progresses, it is increasingly deforming, but does not cause death, therefore victims remain in evidence to demonstrate that it is "incurable". The confusion between Biblical "leprosy", a state of ritual impurity, and true leprosy, a concrete disease entity, has served to perpetuate the association of sin and disease, and hence stigma, in parts of the world influenced by Judaeo-Christianity. However, there is evidence that even in non-western areas sin and leprosy are associated. It is now necessary to re-examine the theory of stigma proposed in chapter 2, to see how it can be applied to disease in general, but especially to other conditions which carry a stigma, so as to identify possible courses of action to rectify the situation.

It was also shown in chapters 2 and 3 that socialisation leads to social definitions or constructions of health, illness, disease, abnormality and acceptability, and hence, stigma. The historical and cross-cultural variations were discussed in these chapters. It was shown that populations are socialised to cope with health, not "un-health". An unhealthy (unwhole) state is perceived as a threat by the individual, the family and the society. It creates anxiety and uncertainty which in turn affect the normal functioning of the individual and the group. The level of anxiety varies with the intensity of the perceived

threat, or degree of uncertainty (Malinowski, 1961). Thus, all diseases, have the potential for being stigmatised, but many debilitating conditions are short-term, and are experienced by many members of the group - childhood infectious diseases in the past, the common cold, influenza, or broken limbs, for example. These conditions are accepted, the causes are recognised and the general social reaction is one of sympathy and encouragement for anyone could fall victim to the same condition. This tolerance, however, is usually limited to a time considered reasonable by society. Parsons (1951) noted that the victim is expected to co-operate to regain health, and be able once again to fulfill the obligations from which sickness excused him. Frequent absenteeism is discouraged, and habitual hypochondriacs and complainers are treated less sympathetically. When the condition is not short term, as in chronic diseases and conditions where disability is permanent (physical and/or mental handicap) or recurring (epilepsy, asthma), the situation is considered differently. These conditions are mysterious and thus constitute a bigger threat, greater anxiety and uncertainty, or fears. Fear will be used to categorise this complex of reactions, to convey the acute response which occurs.

In this author's opinion, fear is not only an important, but a necessary factor in the development and

persistence of stigma. Many situations are mysterious, uncertain and cause anxiety; anxiety, like uncertainty, is vague and non-specific, and it is chronic and usually difficult to pin down. Fear on the other hand, is more pressing and acute, and more specific than anxiety. It relates to some particular cause of uncertainty or anxiety. Similarly, terror is an exaggerated form of fear, and occurs less frequently. In relation to the present study, anxiety is not sufficient to produce stigma, although anxiety provides fertile ground for its development. The more defined the feeling becomes, the greater the likelihood of stigma emerging. The social reaction, particularly as it pertains to leprosy, is one of fear not anxiety. Reluctance to discuss the subject, for example, is a result of fear in the individual. Terror is not the usual response, since that would lead to flight. A more controlled physical withdrawal is more representative of a fear reaction. Thus, admitting that there are gradations in the level of fear felt and exhibited, fear can be identified as a common theme in the origin and perpetuation of stigma:

- (a) fear about how the condition occurs and why certain individuals are afflicted;
- (b) fear of contamination, or of being in that condition;
- (c) fear in varying degrees of severity of how to cope with someone in that condition; and,

(d) fear and repulsion at the actual or potential physical manifestations (incapacities) or about the outcome (death). The behaviour of individuals or groups in response to these fears and their coping mechanisms determine the acceptability of common situations. These coping mechanisms will be analysed as they apply to the origin, maintenance and potential for modification of stigma.

Origin

Individuals' reactions to the fears outlined above are largely determined by the prevalent societal response (see chapter 2). In the past, very little was known about disease (chapter 3), and those which were most puzzling created greatest anxiety (Malinowski, 1961). As noted in chapter 7, the societies which appeared to attach no stigma to leprosy were simple societies, with small family groups, which expressed personal concern for diseased victims. Today, even when a scientific explanation is available, such as viruses or bacteria or "germs" in lay terminology, the mode of attack and the selection of victims may still appear to be unexplained. The greater the mystery surrounding the disease and the more ephemeral the details, the more likely the effort to find answers: "There must be a reason"; "Why me?" ; or, "What have I done wrong?" in non-scientific spheres. Fear of the unknown, combined with guilt about

unacceptability on the part of the victim, leads to explanations being sought in transgressions of the individual afflicted (Davis, 1961). This response is reflected in the attribution of the term "curse", applied selectively and not to all diseases, and by its use implying divine intervention, either as an expression of the power of the deity or as the retributive consequence of displeasing divine authority. Disasters and plagues have frequently been attributed to divine displeasure which is visited on society as a whole. Everyone in the group is subjected to the punishment. In the case of diseases such as leprosy, however, individuals are the foci of the punishment, and therefore it is the sin of the individual (or his family) which is marked out. Thus, there develops an association between the manifestation of the disease and the supposed guilt of the victim. Sin leads to punishment which is manifested in disease. This provides the mark - "stigma" - of guilt to the observers and justifies their explanations of the person's affliction. "He must have done something to deserve it"; "There's no smoke without fire". When the condition does not improve, the victim is a constant reminder of divine displeasure and acts as an example of "the wages of sin". Elements of this type can be seen in the present day attitude toward cancer. Many people are reluctant to discuss the subject and employ euphemisms to

avoid using the term "cancer". In recent years, in western society, however, strenuous efforts have been and are being made to change this situation. People are being encouraged to discuss the subject. Tuberculosis drew forth a similar response (Sontag, 1978), in years gone by, when "weak lungs" were discussed in hushed tones. A tendency for familial predisposition which suggested that tuberculosis was hereditary extended the sin-quilt complex from the individual to the family. The successful prophylactic screening and treatment programmes for tuberculosis have largely counteracted this response, although many people today recall such incidents in their own experience.

The sin concept, however, remains. Now twenty to thirty years after poliomyelitis attacked them, many survivors are experiencing mysterious symptoms which are being quoted as "a second curse" (McNeilly, 1984). Thus, emotive language is once again used in association with symptoms which are bewildering or inexplicable. Other "new" diseases, such as AIDS and Herpes, share the mystery of causation, and because cases have been identified among members of society who follow unconventional lifestyles which are stigmatised, victims have tended to become labelled as "sinners" who have been punished. Thus labelled, society knows how to respond. It seems that people in conditions which are stigmatised are not viewed as victims

or sufferers but stand as accused, subject to trial by society, judgement and sentence. Historically, those who have suffered, especially from mental illness and leprosy, have found denial futile, having been convicted in advance and sentenced, usually to confinement which removes them from society. The fact that such confinement was in an "asylum" - a place of refuge from which they could not be forcibly taken - suggests that such institutions were for their own protection. In reality, however, these institutions were prisons, institutions of segregation, surrounded by high walls with spikes on top or barbed wire fences, protecting society from these undesirable members, who were often condemned to serve "life sentences" (Foucault, 1965; Goffman, 1971).

Thus, society, having provided the social definition of what is acceptable, sets out criteria by which to measure deviation from acceptability and the degree of abnormality to be tolerated. Waxler (1981) concluded that the stigma of leprosy is not universal and that the moral definition of leprosy may arise from particular historical/social/medical circumstances, different in each society. The present study was based on factors which are deemed to be necessary, cross-culturally, for the development and persistence of the stigma of leprosy: mystery concerning the disease; abhorrence of its advanced stages when untreated; religious

beliefs which link sin and guilt to disease; and the notion of contagion as impurity. Contrary to the findings of Waxler (1981), on the basis of these criteria, leprosy was found to be almost universally stigmatised.

When the cause of a non-acceptable condition is not immediately identifiable, there is a tendency to seek answers in supernatural explanations (Berger, 1969; Malinowski, 1961), which, as Davis (1961) pointed out, cannot be verified nor refuted. The explanations depend on uncritical acceptance or faith in their veracity. Such explanations, however, can foster the fear and anxiety already extant. If this disease strikes individuals who have transgressed, and are consequently marked out, association with such individuals makes contacts susceptible to contamination by association. The sick person is therefore "dangerous", considered "taboo" and avoided. The condition is treated as "infectious", even when it is not transmissible, in the medical sense, from one person to another. Guilt feelings among observers may also make them feel vulnerable to similar "punishment", so they feel safer if they stay away from someone already marked out and "punished". Thus the fear of contamination or of being similarly afflicted in some mysterious way justifies any avoidance strategies and emphasises the seemingly uncontrollable nature of the disease.

Chronic conditions do not conform to acceptable temporary deviations from "health". Whereas there are social guidelines, or "norms", for dealing with temporary incapacities, chronic conditions do not revert to normal and frequently the condition deteriorates. There is thus fear of the outcome. Degenerative conditions produce increasingly non-aesthetic, and consequently less acceptable, characteristics. Other characteristics, while not visible, are known to be life-threatening. Therefore, avoidance takes on a new fear - a reluctance to discuss the subject which reflects the inability (or avoidance) of coming to terms with the condition. The lack of guidelines for coping causes frustration, and the victim is blamed for his affliction, temporarily satisfying the frustration, but not displacing the fears of which it was the manifestation.

Maintenance

The social definition of acceptability, as applied to health and disease, also determines at the same time what is unacceptable. Through socialisation, all members of society, including those individuals who become stigmatised, learn how to respond to "unacceptable" conditions. The development of stigma is facilitated by the compliance of the stigmatised with the patterns of action defined by society. Without such compliance stigma could not develop.

The interaction between society and the stigmatised individuals produces feedback which reinforces the definition and thus maintains the stigma once it is established. Feedback comes from formal and informal reinforcement which concentrates on and exaggerates the fears in which stigma took root. Stigma is then fertilised by the continued repetition of the "image", in religious teaching, printed and visual material and the pejorative use in all walks of life, of terms such as "leper".

Klineberg (1964), following Lippmann (1922), defined stereotypes as "pictures in our heads" and showed how they are resistant to change even when all the facts contradict the stereotype. This was shown in the previous chapters to be true for leprosy. Even well-intentioned individuals and groups have, for example, made use of the image conjured up by stereotypes to get financial support. Presenting the worst "picture", in order to get more financial support is a common practice. Waxler (1981) went so far as to suggest that organisations providing care for people with stigmatised conditions actually perpetuate the stigma, because of their need for support. Reluctance of formal institutions to negate such images, either deliberately or unintentionally, encourages the retention of the image by the population as a whole. Thus, religious, legal, medical and social institutions cultivate and preserve stereotypes

which no longer pertain in reality and thereby maintain the stigma.

Much has been said in preceding chapters about the important influence of religion on behaviour associated with disease. It was not until the sixteenth century that medicine became secularised. Even after that time, religious institutions were responsible for the care of the chronically ill. In chronic conditions where medical knowledge could not provide acceptable facts on aetiology, treatment and cure, the conditions remained or reverted to the responsibility of religious institutions. These institutions supplied the basic needs for the comfort of the victims (Clay, 1966). Little was provided in the way of treatment as there was little or no hope for recovery or cure.

Mysterious, chronic conditions failed to stimulate the scientific world, since the reputation of practitioners was tarnished by failure to cure or improve a condition. It is perhaps for this reason that the diagnosticians of ancient India, China, Egypt and Greece assessed the possibility of cure before embarking on treatment, leaving the care of patients with a poor prognosis to magico-religious practitioners. Even today the care of the terminally ill frequently falls to religious institutions. As medical knowledge advanced in most spheres, many chronic

conditions remained enigmatic and uncontrollable. The identification of specific disease-causing organisms, followed by the development of prophylactic and curative treatments, brought many previously perplexing conditions under control. Other conditions, including leprosy, mental illness, and degenerative and congenital diseases, however, remained unsolved. Even after considerable scientific knowledge had been acquired about such conditions, their association with "immoral" practices meant that their victims were still stigmatised.

Technological advances made many aspects of medicine attractive and stimulating to members of the medical profession, whereas stigmatised conditions held little appeal. Life-saving transplant surgery is far more glamorous than the treatment of victims of leprosy, even though the number of potential beneficiaries of the latter is much greater. Medical practitioners are affected by the same social reactions as apply to the population in general.

Medical practitioners may deny such attitudes, but in practice, aversion to entering certain fields of medicine, lack of training in these fields in medical schools, the limitation of funds for research into them, and a certain ostracism by professional colleagues when interest is shown, point to underlying problems in changing the situation. In the case of leprosy, medical acquaintances

report that western medical schools devote little or no time to its study. Even in areas where leprosy is endemic it has a low priority. It was noted in chapter 6 that medical professionals engaged in leprosy research or a practice associated with the disease, in India, Israel and the United States often found it necessary to conceal their place of employment. Among personal contacts, physicians have confessed to an irrational fear of leprosy which would make them avoid any possible contact with leprosy patients. Other professionals also help to perpetuate the stigma. Waxler (1981), using leprosy as a case study in the social construction of illness, reiterates the word "leper" throughout the paper. This use of the deprecatory term in recent professional literature merely inscribed the old image, by using the term synonymously with outbreak.

In recent years attempts have been made to alter the image of stigmatised conditions by changing the name. Thus, the Society for the Deaf became The Society for the Hard of Hearing, blind people became visually impaired, and cripples became handicapped or disabled. Similarly, workers in "stigmatised" occupations, such as garbage collectors and undertakers, have attempted to "clothe their work with some dignity" (McFarlane, 1985), by changing the names to sanitation engineers and funeral directors respectively. In the case of the term "leper", however, the word passed from

being a term to describe a person with leprosy, at which time it acquired all the moral connotations associated with the disease, to being used to identify people who were deemed to be social outcasts or pariahs. Thus, although the medical understanding of the disease has changed, the horror associated with it in the past is transferred to individuals thought despicable in some way. The leprosy sufferer then becomes tainted by the connotations of the term "leper" which have nothing to do with his disease. In keeping with this approach, the Mission to Lepers changed its name to The Leprosy Mission in the 1950s. Also, the International Leprosy Congress in 1948 recommended that the term leprosy be replaced by Hansen's disease. "Idiot" is another example of a term which applies moral judgement to a physical or mental condition beyond the control of the individual.

The positive contribution of religious institutions in caring for the afflicted for whom medical practitioners are unable or unwilling to provide treatment should in no way be disparaged. However, by setting these conditions apart, and making them appear religious rather than medical problems, religious organisations have helped reinforce the stigma. Having these conditions under religious responsibility also fosters the association of sin, guilt and punishment which is found in religious teaching.

In Christian teachings, for example, many of the victims healed by Jesus Christ in the healing miracles suffered from stigmatised conditions: "lepers", as discussed in chapter 6; the palsied man (Luke 5, 18-26); the man with the withered hand (Mark 3, 1-5); the demoniac boy (Mark 9, 14-27); the blind (Mark 2, 46-52; 8, 22-26); and the raising of Lazarus from the dead (John 11, 44). All were conditions which had not responded to medical treatment. By emphasising Christ's concern for those rejected by their society, attention is directed to such conditions as being in need of "special" attention. The acts may thus be seen not as symbolic acts of "loving thy neighbour" but as acts of sacrifice. Christ associated with sinners, "lepers", menstruating women, and the dead, all considered taboo in Jewish society. Sacrifice then becomes a central theme in stories of martyrdom, and also in the activities of public benefactors and missionaries who provided for the needs of similar unfortunates. On the one hand, the activity which subjects the individual to the dangers of contamination is praised. Unfortunately, on the other hand, the association of "martyrs" with conditions considered taboo helps to reinforce the stigma.

An example of the important influence of religious teaching comes from personal experience in Nigeria. After several years during which the East Central State Government

had implemented the WHO policy of treating leprosy on an outpatient basis, a delegation to the Commissioner of Social Health and Welfare, including a Roman Catholic Archbishop, an Anglican Bishop, a Methodist minister and a Salvation Army officer, among others, "...deplored the new method...and emphasised the need to segregate leprosy patients for effective treatment and control" (Daily Times, Nigeria, June 29, 1972). In most areas, patients discharged and certified "cured" were re-integrated into the community. In the predominantly Roman Catholic villages along the Niger River, however, their return was vigorously opposed.

Legislation also helps to strengthen what society has decided is unacceptable. Although asylums are intended to protect the victim, individuals so confined are kept there by decrees, regulations or laws, providing overt approval for segregation and deprivation. When legislation does not modify to reflect changes in factual knowledge, as happens in stigmatised conditions, stigma is further maintained. As social norms are modified, legislation usually changes gradually to reflect the practice. Abortion law reform and changes in laws relating to sexual activity in private are modern examples of this. However, even when legislation is changed, failure to implement new provisions sustains and reinforces the stigma. Thus, in Canada, the "old" Immigration Act (1952) denied entry to

people with certain health conditions, including leprosy and epilepsy. It was proscribed for conditions seen as a threat to society. Under the new Immigration Act (1976, Part III, Section 19), potential immigrants are excluded from admission to Canada if (a) they are likely to be a danger to public health or public safety, or (b) their admission could cause an excessive burden on health or social services. The majority of leprosy sufferers should therefore not be affected by the provisions of the Act. The exclusion criteria should apply only to certain categories of leprosy sufferers, such as lepromatous cases not on treatment and people with advanced, untreated leprosy, which has made the victims dependent on welfare services. Despite this fact, no leprosy patients are knowingly admitted to Canada. In administering the Act, federal-Provincial agreement is necessary because immigrants take up residence in the Provinces, which then become responsible for the provision of services. Although most Provinces accept that leprosy victims need not be excluded by Section 19 of the Act, one Province, Quebec, has refused to agree (Leslie, 1984). Despite the secularisation of the Province of Quebec in recent years, this decision may well be a reflection of deep-rooted religious influence. As a result, no person known to have suffered from leprosy, even those who have been treated and cured, is admitted to Canada, although this

is contrary to the spirit of the 1976 Immigration Act. This illustrates graphically how stigma can cause discrimination. At the same time, these actions also reinforce the stigma, clearly demonstrating and supporting Klineberg's (1964) assertion that stereotypes are retained counter to all the evidence, even in a liberal society such as Canada.

The stigma of disease also receives deliberate and accidental social reinforcement. As indicated earlier, literature of all kinds helps to perpetuate erroneous images. The Oxford English Dictionary, for example, gives the image official support through the retention of out-dated terms and definitions of leprosy as "a loathsome disease", while other infectious conditions, such as syphilis or tuberculosis, are defined in biomedical terms. As noted above, dictionaries reflect common usage. However, they also help to perpetuate out-dated images, since they lag behind changes in usage.

The earliest manuscripts were copied in religious institutions, remaining unchanged in content for centuries. Popular literature adopted a moralistic pseudo-religious approach, presenting the foibles of human nature in drama and romance. Stigmatised conditions were used to enhance characters deemed to be "evil". Richard III's alleged deformity and Lord Chatterley's paraplegia have already been cited as examples. Villains have been portrayed not only as

evil-minded but as physically or mentally incapacitated. Curses and threats use stigmatised conditions to arouse fear in the character cursed, and also in the mind of the reader. Any misconceptions in the author's mind are transmitted to the public by the descriptions given, and perpetuate the public stereotype and the stigma. Prime examples of this are the descriptions of victims of leprosy, with "rotting flesh" which were cited in chapter 6.

Whereas popular literature paints vivid verbal pictures using emotive language, the medium of film employs visual images to even greater effect. Lighting and make-up facilitate the creation of human figures characterised as "monsters" - Quasimodo, the hunchback of Notre Dame, for example. The shock with which the audience makes the first encounter enables the viewer to participate as a member of the crowd. Modern space fiction and fantasies challenge the imagination and make almost anything credible. Reality and fantasy become confused, therefore any misrepresentation of reality, whether or not intentional, sustains erroneous notions and perpetuates stigma. When stigmatised conditions are erroneously presented in literature, films and on television, as in "The Fog", "Ben Hur", "Hawaii" and "Lord Foul's Bane" for example, they appear as realistic representations to the consuming public. A non-discriminating acceptance, therefore, not only allows

misconceptions to become accepted as fact, but reinforces previously held notions on the subject which have become out-dated. These notions are further reinforced when pejorative terms such as "leper", "cripple" and "bastard" are used out of context, especially when used by prominent members of society.

Another factor which functions to perpetuate the stigma of these conditions is the behaviour of the victims themselves. As noted earlier, their acceptance of their social status helps to sustain the idea of their unacceptability. Initially this acceptance stems from their socialisation in the same milieu as other members of the society of which they are part. As a result, they feel a "dis-ease" greater than the usual discomfort experienced by people temporarily incapacitated by disease. Because they feel uncomfortable with "normal" members of society, they seek solace either in isolation, or in the company of those who share their affliction. They may also feel comfortable with people who provide their care or treatment. With these people there is no need for secrecy, they have a sense of belonging, and in this group do not feel outcasts (Goffman, 1963; Gussow and Tracy, 1968; Boombaum & Gugelyk, 1970). Social interaction with family, friends and colleagues is strained. While the victim tries to present himself as normal, concealing information which may hinder the

interaction, the non-afflicted are uncertain of the appropriate behaviour. Does one ignore the visible evidence, such as a wheelchair or facial disfigurement which cannot be concealed, or try to avoid contact? If others know of a problem but see no visible evidence (cancer, for example), they may react with condescension, pity or exaggerated cheerfulness. Interaction between the ill and the well becomes tense because of anxiety about coping on the part of both. Thus victims become dependent on the support of their group and the institutions which provide their care. Chronic disease victims stay on what Sontag (1978) termed "the dark side" of life, and as time passes they feel divorced from the "light side". Some victims, such as present-day cancer patients and leprosy sufferers in the past, do not expect, and are not expected by others to return to the light side. Dependence helps to sustain the stigma because it makes return to society difficult. After a long absence, re-entry into the non-sheltered society poses problems which they cannot or do not wish to overcome.

Institutionalisation of victims of stigmatised conditions made the problem less visible by removing the evidence. The tendency to institutionalise all those with marked physical or mental abnormality, with the assertion that "it is for the best" or "in their best interests" reinforces the stigma. Parents who have undertaken to care

for their afflicted offspring at home have been viewed as martyrs and their decision has been met with a negative social response from neighbours. The recently reported incidents of healthy children being withheld from schools when victims of herpes attended (Ottawa Citizen, Jan. 11, 1985), confirm the assertion that even today fear may prevent full acceptance of scientific facts. People believe what they want to believe.

When the disease causes physical disability, the visible deformity strongly upholds the stigma. The physical disability is equated with the disease. Even when the disease is no longer active, as in cured polio~~myelitis~~ or controlled leprosy, there is an assumption that the disease still exists because the disability remains - a serious problem in rehabilitating leprosy victims. Corrective surgery can improve or remove some physical disabilities, but permanent visible disabilities help to perpetuate the stigma.

Whether victims are set apart from society as a result of religious, medical or legal action, or the separation is self-imposed by the victims, the activities of both parties help to sustain the stigma. It is now necessary to consider how the undesirable fact of stigma can be modified.

Modification

There is a general assumption among behavioural scientists that unacceptable social practices can be changed by educating people to "know better" and consequently reform their behaviour. This "solution", however, is too simplistic when applied to stigma, although education has a crucial role in the process. It has been shown that stigma relating to disease rests on social definitions of acceptability and abnormality, anxieties and fears about the cause and outcome, and repulsion toward the possible physical manifestations or fear of death. The first step in modifying stigma, therefore, must be to re-define acceptability. It is in this respect that education can have greatest effect. The declaration of the International Year of the Disabled in 1981 by WHO was instrumental in bringing to public attention the fact that physical disabilities do not necessarily prevent people from participation in society, and that the disabled should not be set aside as "useless". Public education of this nature provides factual information which should result in a greater awareness and better understanding of the problem. It has been argued above, however, that stigma is resistant to facts and is maintained by clinging to old ideas, even when they are in contradiction of the facts. How then can such an education programme be successful?

The considerable change in social attitudes toward sexual activity that has occurred in recent years provides an example. In western society thirty years ago, the subject of sex was taboo, certainly in mixed company, and all sexual activity outside of marriage was considered, at best, questionable. Promiscuity and homosexuality were deemed immoral. The more permissive social attitudes now extant have resulted from various factors, but one fact seems particularly relevant to this study of stigma. "Immoral" sexual activity, especially homosexual practice, has come into the open. Although there is still a stigma associated with homosexuality, the subject is no longer secretive, seedy and discussed only by innuendo. When some homosexuals came "out of the closet", openly declared their sexual preferences, and demanded that their rights be considered, they opened avenues for change. They refused to be considered unacceptable and sought redress for discrimination against them in "Gay Rights" amendments. Whether or not one empathises with the orientation of this group, the fact that the problem is now being discussed openly is a sign of changing social definitions of acceptability. Nevertheless, the publishing of names of people "caught" in this activity in St. Catharines, Ontario, and the resulting suicide and personal problems experienced by those cited (Ward, 1985; Macleans, Jan. 23, 1985),

demonstrate that a stigma still exists, despite the progress made. The latter group had not come out of the closet, but had secret and impersonal relationships which they thought kept them anonymous. They recognised their activity as socially unacceptable, but retained their respectability through anonymity. Exposure brought repercussions which, as in all stigmatised conditions, seem to be out of all proportion to the "transgression". Thus, as with disease, fear, sin and guilt are closely related.

Social attitudes toward homosexuality in western societies seem to have been modified by what at first seems to be a contradiction. Usually, visibility of a stigmatised condition increases the degree of stigma (Goffman, 1963; MacGregor *et al.*, 1953; Richardson, 1961, 1971; Shears & Jensema, 1969; Tringo, 1970). Support for these findings comes in the present study, which indicates that people are repulsed by the visible deformities associated with advanced, untreated leprosy cases, which are probably "burnt out" and consequently no longer infectious. In the case of homosexuality, however, stigma has been reduced by making the object of the stigma more visible. Well known personalities, such as singers and actors, who were famous for their professional performances, have acknowledged their preferred lifestyles, and campaigned to make it more generally acceptable. They have been able to demonstrate

that their homosexuality is only one facet of the whole person, and should therefore be accepted in the same way as hair colour and height. Their actions have enabled lesser known homosexuals to feel more comfortable about their sexual orientation because they have role models who seem to be accepted despite their homosexuality. Bringing homosexuality into the open and making it "visible" has made something which was secretive, more, although by no means universally, acceptable. Can the experience from homosexuality be translated to the stigmatisation of disease?

It was postulated that mysteries about diseases and fears about their consequences have encouraged people to cling to unscientific explanations which are frequently linked to religious beliefs in sin, guilt and punishment. While the mysteries surrounding disease cannot be made visible, the problem of stigma can be brought into the open. A return to the case study of leprosy may provide insight into how such a scheme could work.

In endemic areas, despite education campaigns to increase public awareness of the disease and encourage treatment at the earliest possible stage, in India for example, myths and misconceptions persist and stigma remains. Even in northern Tanzania where stigma is relatively slight, schoolchildren who were knowledgeable of

the basic facts, showed concern about transmission because it had been spoken of as an "infection" (van Etten & Anten, 1972). This finding suggests that the point of emphasis in education programmes was wrong. Informing people that their ideas are wrong does not necessarily change the ideas. It is necessary not only to educate about the "scientific facts" but also at the same time to dispell myths and misconceptions by identifying and illustrating how these notions come about. Thus the stigma of the disease can be brought into the open and discussed, along with the medical facts. When the afflicted are in asylums they are hidden, and being invisible, fertile imaginations create their impression of the manifestations of the disease, based partly on past evidence, and partly on the misconceptions which have been passed down through generations. The disease should therefore be made visible and explained at the same time, demonstrating the reality rather than merely presenting the scientific facts. Initially, patients who have the disease but who look "normal" should be presented. Once these are accepted, there should be a gradual introduction of others with increasingly marked deformities to demonstrate the result when the disease is left untreated. In this way it is possible to illustrate the medical facts: by getting treatment at the earliest possible time, there is less likelihood of the deformities

occurring. The greater the number of patients who seek treatment, the fewer the deformities which will occur, thus removing visual effects which help to maintain the stigma. Information can be transmitted that fears of the disease had some foundation in the past, but with modern scientific knowledge of the disease, such fears are groundless, if treatment is sought early.

In providing the factual information, there is a need to re-iterate that "sin" has no place in the aetiology, that the disease is not something to cause shame, that it can be treated, and if treated will not result in deformity. Education must take place at all levels, so that religious and political leaders can reinforce medical teaching. Such a programme was already well-established in southern Tanzania in the 1960s. A good treatment programme had been in place for 20 years, and the co-operation of 10 house leaders and chiefs encouraged or coerced suspected leprosy victims to seek treatment. Provided they did seek and continue to obtain this treatment, they were accepted in their own communities (Wheatley, 1970). This is in sharp contrast to the Nigerian example cited earlier. Education alone cannot be responsible for this difference. That area of Tanzania had a high literacy rate, although it was a largely peasant population. In Nigeria, the population was more "sophisticated" and "westernised". Could the

difference perhaps be attributed to the different social organisation in the respective areas, or to the different religious influences on each group? The population of southern Tanzania is closer to the pastoral-agricultural social organisation of small family groups, whereas the Nigerian population is more socially organised. The population of southern Tanzania has also had more mixed religious influences, including Moslem, but had predominantly been under the influence of University Missions to Central Africa (UMCA) established by Livingstone. The Roman Catholic influence was less than in Nigeria. In Nigeria the denser population had largely been sectioned off, with Roman Catholics predominant in some areas, while American Baptists and British Methodists "controlled" others. A detailed comparative analysis might be rewarding but is beyond the scope of the present study.

Whatever the past influence of missionaries, they must now accept responsibility for many misconceptions, however well-intentioned, and religious teaching must strive actively to counteract those misconceptions. Once having admitted that they are part of the problem, their part in the solution becomes simpler. They must endeavour to divorce disease from its long-standing association with sin, which makes it unacceptable on moral/religious grounds. When all diseases are considered as medical rather than

religious problems, social definitions of acceptability/unacceptability will be modified because the religious influence is less important.

The removal of the underlying association of moral connotations of diseases, however, really only copes with limiting the development and perpetuation of stigma. It was postulated in the theory of stigma in chapter 2 that certain types of disease lend themselves to becoming stigmatised. Mysteries about the disease which are explained in an extension on animistic beliefs, can be overcome by combining modern medical knowledge - scientific fact - and the recognition that religious beliefs have helped to sustain old ideas. Efforts can then be concentrated on treating such conditions to prevent further degeneration. Education must show that it is not unacceptable to have the disease, but not to seek treatment is unacceptable, as was the case in southern Tanzania.

The redefinition of acceptability will help to reduce the stigma, but will not eradicate it. Individuals will continue to discriminate. However, once society agrees that stigmatising people who suffer from diseases which are beyond their control is wrong, two possibilities arise: individuals who persist in stigmatising victims are themselves deemed guilty of unacceptable behaviour, and, at the same time, victims of stigma reject their formerly

"unacceptable" status and assert their rights as human beings and citizens.

Goffman (1963) and Gussow and Tracy (1978) studied the behaviour of stigmatised individuals, but in each case the stigma was accepted as fact. Taking "discreditable" status as given, Goffman developed a theory of impression management, whereby stigmatised individuals employed various strategies and techniques to present themselves as acceptable, rather than rejecting the fact that they were unacceptable. The "career patients" in Gussow and Tracy's theory of stigma are a few of those resident at Carville Public Health Service Hospital, Louisiana, who undertake to enlighten the public by themselves demystifying leprosy. They expose themselves as victims of the disease, but return to the shelter of the institution afterwards. There is thus an understandable ambivalence as they educate the public about erroneous ideas on the one hand, but, on the other hand, they appear to accept the stigma by doing so from their protected environment. Neither theory alters the fact that the individuals are "discreditable" as far as public opinion is concerned. The self-assertion of stigmatised individuals or groups has to come in association with changing definitions of acceptability, supported by legislation which protects victims rights and makes discrimination against them socially, morally and legally

unacceptable.

Not only should individuals be made to feel guilty about their negative reactions toward the people they stigmatise, but also, derogatory references in literature and films should be avoided. Literature and films have contributed to the maintenance of stigma through the use of stereotypic characters. These same media could therefore be instrumental in helping to develop a more tolerant attitude, through sensitive portrayal of stigmatised conditions. Focus might even be concentrated on non-acceptable social behaviour, such as discrimination. Kellersberger (1951) argued that the problem of leprosy cannot be beaten until the stigma of the disease has been removed. Long (1965) on the other hand, argued that eradicating the disease would remove the stigma. As was shown in preceding chapters, the stigma of leprosy persists today in areas where the disease is no longer obviously present. Indeed, a non-random, casual sample of educated acquaintances, including graduate students, academics and professionals, showed a disturbing ignorance of the subject. It was most commonly believed to be either a tropical or an ancient disease, while many believed it to be a myth. Only one person questioned had heard of Hansen's disease. The words most frequently associated with leprosy were "ugly", "deforming", "very infectious", "ulcers", "sores", "fingers drop off", "Ben

Hur" and "The Bible". The image that remains is thus that created when the stigma and the disease were both very evident in the western world.

Understanding why certain conditions have attracted stigma and the factors which have helped to perpetuate the stigma will not only help to overcome the problem of leprosy, but should help also to tackle other problems of stigma and disease. It is not, however, a problem of stigma or a problem of disease that has to be overcome. The two are inter-related and cannot be separated. Kellersberger and Long were both right, and both wrong. The solution of the medical mysteries of stigmatised diseases will increase the confidence of its victims that they can be cured or controlled. If at the same time these victims are sustained by family, community, religious and legal recognition of their acceptability, both disease and stigma can be addressed. The example of leprosy has been used in this study, but it demonstrates that in tackling the problem of stigma and disease, it is necessary to seek the root cause of the stigma and identify the process by which the stigma is maintained even when scientific facts contradict the information on which the stigma is based.

The greatest advance in this problem, however, will be made through the combined efforts of communities and affected individuals. Whatever the stigma, whether race,

religion, disability or poverty, the victims of that stigma must be made to feel accepted. The re-definition of acceptability will then work to eradicate stigma if those who are stigmatised actively accept their new status of acceptability.

REFERENCES

- Ackerknecht, Erwin H.
1965 History and Geography of the Most Important Diseases.
New York: Harper Publishing Company, Inc.
- Alexander, A.B.D.
1920 "Seven Deadly Sins" Encyclopedia of Religion and Ethics XI: 426-428.
- Andersen, John G.
1968 "Studies in the Mediaeval Diagnosis of Leprosy in Denmark"
Danish Medical Bull. 16, Suppl. IX.
- Annandale, W.
1903 "The Primitive Beliefs and Customs of the Patani
Fishermen". Fasciculi Malayenses Anthropology pt.1:73-88.
- Anonymous
1983 "The Monkey on My Back". The Star 43,2:2-5.
- Austen, A.B. & Draper, D.C.
1981 "Peer Relationships of the Academically Gifted:
A Review". Gifted Child Quarterly 25,3:129-133
- Australian Department of Health
1970 Leprosy in Northern Territory Aborigines.
Canberra: Australian Department of Health.
- Aycock, W.L. and Gordon, J.R.
1947 "Leprosy in veterans of American wars" American
Journal of Medical Science 216:329-339.
- Barker, R.G. et al.
1953 Adjustment to Physical Handicap and Illness: A Survey
of the Social Psychology of the Disabled New York:
Social Science Research Council.

Bayliss, J.H.

- 1979 "Domus Leprosae - community care in mediaeval England"
Nursing Times 75:62-67.

Berger, Peter.

- 1969 The Sacred Canopy Garden City, N.Y.: Doubleday
& Co., Inc.

Berreman, G.D. (Ed)

- 1981 "Social Inequality: A Cross-cultural Analysis"
Social Inequality: Comparative and Developmental
Approaches New York: Academic Press.

Berreman, Janet M.

- 1984 "Childhood Leprosy and Social Response in South
India" Social Science & Medicine 19, 8:853-865.

Black, W.G.

- 1970 Folk Medicine: A Chapter in the History of Culture.
New York: Burt Franklin.

Bloomfield, Morton W.

- 1967 The Seven Deadly Sins. Michigan: State University Press.

Boombaum, Milton and Gugelyk, Ted.

- 1970 "Voluntary Confinement Among Lepers" Journal of Health
and Social Behaviour 11(March):16-20.

Brandon, S.G.F. (ed)

- 1970 Dictionary of Comparative Religions New York:
Charles Scribner's Sons.

Brock, Arthur J.

- 1929 Greek Medicine. London and Toronto: J.M. Dent and Sons, Ltd.

Brody, Saul Nathaniel.

- 1974 The Disease of the Soul... Leprosy in Medieval Literature.
Ithaca and London: Cornell University Press.

Brothwell, D.R.
1958 "Evidence of Leprosy in British archeological material".
Medical History 11:287.

Brothwell, D.R.
1962 "Palaeo-pathology of Early British Man". Journal of the Anthropological Institute 91:318-324

Brothwell, Don & Sandison, A.T. (eds)
1967 Diseases in Antiquity. Springfield, Illinois: Charles C. Thomas, Publisher.

Brown, J.A.K.
1937 "Leprosy Folklore in Southern Nigeria"
Leprosy Review 8:157-160.

Browne, Derek.
1963 "The Stigma of Leprosy - a Reproach and a Challenge".
JAMA 186:67.

Browne, S.G.
1970 Leprosy. Basel, Switzerland: J.R. Georgy S.A.

Browne, S.G.
1975 "Some Aspects of the History of Leprosy: The Leprosy of Yesterday". Proceedings of the Royal Society of Medicine 68:485-493.

Browne, S.G.
1979 Leprosy in the Bible. London: Christian Medical Fellowship Publication.

Browne, S.G.
1980 Leprosy in England - Yesterday and Today. London.

Bruhaker, M.L., Binford, C.H. & Trautman, J.R.
1967 "Occurrence of Leprosy in U.S. veterans after service in endemic areas abroad". Public Health Report 84:1351-1358.

Burgess, Perry.

- 1940 Who Walk Alone. New York: Holt, Rinehart & Winston.

Campbell, J.K.

- 1964 Honour, family and patronage: a study of institutions and moral values. Oxford: Clarendon Press.

Carling, F.

- 1962 And Yet We Are Human. London: Chatto & Windus.

Carlowitz, Hans (ed).

- 1913 Der Lepraanschmitt aus Bernhard von Gordons "Lilium medicinae" in mittelalterlicher deutscher Uebersetzung. Leipzig: Peter. (cited by Brody, 1974).

Cartwright, F.F.

- 1972 Disease and History. London: Rupert Hart-Davis.

Chatterjee, B.N.

- 1958 "Customs, Laws, Acts and Rules Affecting Leprosy Patients of India". International Journal of Leprosy 26,2:127-133.

The Citizen, Ottawa

- 1995 "Boy afflicted with herpes again attends classes alone" Jan. 11:A11.

Clay, Rotha Mary.

- 1966 The Mediaeval Hospitals of England. 2nd Impression. London: Frank Cass & Co. Ltd.

Clements, Forrest E.

- 1932 "Primitive Concepts of Disease" American Archaeology and Ethnology 32 (2):185-252

Cochrane, R.G.

- 1961 Biblical Leprosy - a Suggested Interpretation. London: The Tyndale Press

- Cochrane, R.G. & Davey, T.F. (eds.)
1964 Leprosy in Theory and Practice. Bristol: John Wright & Sons Ltd.
- Contreras, Duenas, Felix, M & Miguel y Suarez de Inclan, Ramon.
1973 Historia de la Lepra en España. Madrid: Giatrias Hergen
- Cougoul, J-G.
1943 La Lepra dans L'Ancienne France. Bordeaux: Delmas.
- Crawshaw, Ralph.
1982 "Leprosy: a Disease of the Heart" JAMA Vol. 248, No. 5:573-576
- Creighton, C.
1965 A History of Epidemics in Britain. London: Frank Cass (orig. 1898).
- Danby, H.
1933 Mishneh. London: Oxford University Press.
- Davidson, W.S.
1978 Havens of Refuge: A History of Leprosy in Australia. Perth: University of Western Australia Press.
- Davis, Kingsley
1961 Human Societies New York: The Macmillan Press.
- Derry, D.E.
1909 Archaeological Survey of Nubia Bull. No. 3.
- Dharmendra, K.
1947 "Leprosy in Ancient Indian Medicine" International Journal of Leprosy. 15:424-430.
- Djilas, Milovan.
1965 The Leper and Other Stories. London: Methuen & Co. Ltd.
- Dogliotti, M
1979 "Leprosy stigma in Hanseniasis" S. African Medical Journal 1 55 (1979):102.

Dols, M.W.
1979 "Leprosy in Mediaeval Arabic Medicine" Journal of the History of Medicine 34:314-333.

Donaldson, S.R.
1977 The Chronicles of Thomas Covenant the Unbeliever
New York: Holt, Rinehart & Winston.

Doult, James A.
1950 "Laws and Regulations Relating to Leprosy in the United States of America". International Journal of Leprosy 18,2:145-154.

Durkeim, Emile.
1954 The Elementary Forms of Religious Life. (trans. Joseph W. Swain) Glencoe, Ill.: Free Press (Orig published 1912)

Ebel, B.L.
1937 The Papyrus Ebers. London: Oxford University Press.

Ellison, Harlan.
1982 "Djinn, No chaser" Stalking the Nightmare.
Huntington Woods, Michigan: Phantasia Press.

Encyclopaedia Britannica Third Edition.
1975 Chicago.

Eshraghi, R.
1969 "Social Aspects of Medicine". Mashed Med Journal
(in Persian - cited by Kahout et al, 1973).

Etten G.M. van & Anten, J.G.
1972 "Evaluation of Health Education in a Tanzanian Leprosy Scheme". International Journal of Leprosy 40,4:402-409.

Feeny, P.
1964 The Fight Against Leprosy. London: Elek Books.

Feldman, Roger A. & Sturdivant, Marylyn.
1976 "Leprosy in the United States, 1950-1969: an
epidemiologic review" Southern Medical Journal
69:970-979

Felsenfeld, O.
1968 The Epidemiology of Tropical Diseases: Leprosy
(Hansen's Disease). Springfield, Illinois:
Charles C. Thomas, Publishers

Filliozat, Jean.
1964 The Classical Doctrine of Indian Medicine:
Its Origins and Its Greek Parallels. Delhi: Munshiram
Manorial Booksellers and Publishers.

Fitzgerald, C.P.
1941 The Tower of Five Glories. London: Cresset Press.

Fletcher, Angus.
1964 Allegory: The Theory of a Symbolic Mode.
Ithaca, N.Y.: Cornell University Press.

Ford, Clellan S & Beach, Frank A.
1952 Patterns of Sexual Behaviour. London: "The
Practitioner" and Eyre and Spottiswoode.

Foucault, Michel.
1965 Madness and Civilization: A History of Insanity
in the Age of Reason. New York: Pantheon Books.

Frazer, Sir James George.
1935 The Golden Bough Vol. I: The Magic Art and the
Evolution of Kings. New York: The Macmillan Press.

Gallo, R.C. et al.
1984 "Frequent detection and isolation of the cytopathic
retroviruses (HTLV-III) from patients with AIDS and
at risk to AIDS". Science 224:500-503.

3410. Organization, Inc.
1992 Attitude of Public Perceptions and Awareness Concerning
LEPROSY. Conducted for American Leprosy Missions,
Princeton, N.J.

Gieda, H. & van Lier, J. A.
1971 "Leprosy in Ethiopia" International Journal of
Leprosy 38:187-191.

Ginzberg, J.
1911 The Legends of the Jews. (Trans. Henrietta Szold)
Philadelphia: The Jewish Publication Society of America.

Ghaliboungi, P.
1963 Magic and Medical Science in Ancient Egypt.
London: Hodder & Stoughton.

Gotal, Tore.
1983 "Mycobacterial Diseases" World Health. (November):4.

Goff, C. W.
1967 "Syphilis". In Diseases in Antiquity. pp. 279-294.

Goffman, Erving.
1961 Asylums: Essays on the Social Situation of Mental
Patients and Other Inmates. Chicago: Aldine.

Goffman, Erving.
1963 Stigma: Notes on the Management of Spoiled Identity.
Englewood Cliffs, NJ.: Prentice-Hall, Inc.

Goffman, Erving.
1971 Relations in Public. New York: Harper & Row

Gould, M. L.
1969 "Hawaii: A Historical Note". International Journal
of Leprosy 37,2:194-196.

1934 "The International Journal of Leprosy"
1934 "The International Journal of Leprosy"

1935 "The International Journal of Leprosy"
1935 "The International Journal of Leprosy"

1936 "The International Journal of Leprosy"
1936 "The International Journal of Leprosy"

1937 "The International Journal of Leprosy"
1937 "The International Journal of Leprosy"
A Review of the International Journal of Leprosy
of View" in "The International Journal of Leprosy"

1938 "The International Journal of Leprosy"
1938 "The International Journal of Leprosy"

1939 "The International Journal of Leprosy"
1939 "The International Journal of Leprosy"

1940 "The International Journal of Leprosy"
1940 "The International Journal of Leprosy"

1941 "The International Journal of Leprosy"
1941 "The International Journal of Leprosy"

1942 "The International Journal of Leprosy"
1942 "The International Journal of Leprosy"

1943 "The International Journal of Leprosy"
1943 "The International Journal of Leprosy"

1944 "The International Journal of Leprosy"
1944 "The International Journal of Leprosy"

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1939 "News and Notes" 7:367

International Journal of Leprosy
1941 "News and Notes" 9:367

International Journal of Leprosy
1942a "News and Notes" 17:491

International Journal of Leprosy
1940b "News and Notes" 17:487

International Journal of Leprosy
1950 "News and Notes" 18:547

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

International Journal of Psychiatry
1977 "News and Notes" 17:1

Jaffe, J.
1977 "What's in a Name? Attitudes toward Disabled Persons"
Personnel and Guidance Journal 45 (6):557-560.

Jellinek, E.M.
1960 The Disease Concept of Alcoholism New Brunswick, N.J.
Hillhouse Press.

Jolly, J.
1951 Indian Medicine. Poona, India: N.D. Gorjan.

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1. Subject: _____
 2. Topic: _____
 3. Author: _____
 4. Date: _____
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 226. Chapter: _____
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 234. Place: _____

"The Social Impact of the Negro", 1944, 21-128-124-101
Academy of Sciences, 1944, 21-128-124-101

1976 The Philosophy of Medicine in the Early Eighteenth Century. Cambridge, Mass.: London, England: Harvard University Press.

Kirchheimer, W.F. 21 21.
1971 "Attempts to establish the Annadillo as a Model for
the Study of Leprosy". International Journal of
Leprosy. 30,7:697-702.

Kirchheimer, R.F. et al.
1972 "Attempts to establish the Armadillo as a Model for
the Study of Leprosy". International Journal of
Leprosy. 40,3:229-242.

Klineberg, Otto.
1964 The Human Dimension of International Relations.
New York: Holt, Rinehart & Winston.

Kuhn, T.

1970 The Structure of Scientific Revolutions. Chicago: University of Chicago Press.

Kushwah, S.S. et al.

1981 "A Study of social stigma among leprosy patients attending leprosy clinic in India". Leprosy India 57:171-175.

Kutumbiah, P.

1967 Ancient Indian Medicine. Bombay: Orient Longman Ltd.

Lawrence, R.H.

1969 Lady Chatterley's Lover. London: Heinemann Ltd.
(First Published 1928)

Lechat, M.F.

1986 "Hansen's Disease (Leprosy) in a Global Context".
The Star 47/6:11-13.

Leslie, P.S.

1984 Personal communication.

Levin, Leah.

1984 "Too Young to Work" World Health (Jan-Feb. 1984):24-27

Levis, W.R. et al.

1981 "An Epidemiologic Evaluation of Leprosy in New York City". JAMA 247:3221-3226.

Lippmann, Walter.

1922 Public Opinion. New York: Harcourt Brace.

Lower, J.

1942 "Comments on the History of Leprosy" Indian Medical Gazette 77:180 Reprinted Leprosy Review 10 (1947):54

Lu Gwei-djen & Needham, Joseph.

1967 "Records of Diseases in Ancient China" in Diseases in Antiquity.

100-443887-1000

[illegible][illegible]

Mileage

Major, Ralph M.
1964 A History of the Police (1st ed.) New York: Charles C. Thomas Publisher.

Mulrowski, Bronislaw.
1941 Arachnids of the Eastern United States New York:
F.P. Butter & Co., Inc.

Waretzki, T.W.
1963 "Tairas: an Okinawan village" In Beatrice S. Whitely (ed.)
Six Cultures:--Studies of Child Rearing. New York:
John Wiley & Sons.

Marx, Karl.
1964 Selected Writings in Sociology and Social Philosophy
T. Bottomore & M. Rubal (ed). Baltimore, Md: Penguin
(orig. 1949).

-Massey, Edmund
1722 Sermon preached at St. Andrew's Church, Holborn,
England on July 2nd. 1722

Matthews, C.M.

1978 Health and Culture in a South India Village New
Delhi: Sterling Publishers.

Matthews, Christine M.E. & Jesudasan, Mangalan.

1978 "A Leprosy Health Education Project" International
Journal of Leprosy. 46, 4:414-425.

McCormack, Thelma.

1981 "The New Criticism and the Sick Role" Canadian Review
of Sociology and Anthropology 18, 1:30-47

McFarlane, B.A.

1985 "Is there a Museum Profession?" in Greg Baeker (ed).
Is there a Museum Profession? Toronto: Ontario
Museums Association (forthcoming).

McNeilly, Anne.

1984 "The curse of polio returns" The Citizen, Ottawa,
Oct. 26:A17.

Mechanic, David.

1968 Medical Sociology: A Selective View. New York:
Free Press.

Medical Journal of Australia

1967 "Exorcising the Leper" (Editorial) Vol2:345-347

Meisels, Liora.

1979a "The Vicious Circle of the Stigma" The Star Vol.39, No.1

Meisels, Liora.

1979b "Socio-psychological Aspects of Leprosy Stigma" Paper
presented at the Fifth World Congress of the International
College of Psychological Medicine, Jerusalem.

Mettler, Cecilia E.

1947 History of Medicine. Philadelphia: The Blakiston Company.

Moeller-Christensen, Vilhelm.

1967 "Evidence of Leprosy in Earlier Peoples" in Diseases in Antiquity.

Mooney, James.

1932 "The Swimmer Manuscript, Cherokee Sacred Formulae and Medicinal Prescriptions". Revised, completed and edited by Frank M. Olbrechts. Bureau of American Ethnology Bull. 29, Washington.

Muller, W.

1910 "Über die Wilderstämme der Insel Formosa". Zeitschrift für Ethnologie. 42:328-341.

Murray, M.A.

1981 "Control in Nepal". The Star 40,3:2-4.

Needham, J., Wang Ling, Ho Ping-Yu, Lu Gwei-Djen, et al.

1954 Science and Civilization in China (7 Vols)
Cambridge: University Press.

Norbeck, E.

1956 Iakashima: a Japanese fishing community. Salt Lake City: University of Utah Press.

Oppenheim, A.L.

1967 "Mesopotamian Medicine" Bull. of History of Medicine 36:47

Pankhurst, R.

1984 "The History of Leprosy in Ethiopia to 1935". Medical History 28:57-72.

Parsons, Talcott.

1951 The Social System. Glencoe, Ill.: The Free Press.

Popovic, M. et al.

1984 "Detection, Isolation and continuous production of cytotrophic retroviruses (HTLV-III) from patients with AIDS or pre-AIDS". Science 224:497-500.

- Pratt, L.
1956 "How do Patients Learn About Disease?" *Social Problems* 4:29-40
- Reade, Fr.
1933 Personal communication.
- Richards, Peter,
1977 Medieval Leprosy and his Northern Heirs Cambridge & Totowa, N.J. D.S. Brewer & Rawson & Littlefield
- Richardson, S.A.
1971 "Handicap, Appearance and Stigma" *Social Science & Medicine* Vol. 5:621-628.
- Richardson, S.A. et al.
1961 "Cultural uniformity in reaction to physical disabilities" *American Sociological Review* 26:241-247.
- Richter, R. & Tat, L.
1958 "Leprosy Problems in Turkey". *International Journal of Leprosy* 26,2:134-143.
- Rivers, W.H.R.
1924 Medicine, Magic and Religion London:Kegan Paul, French, Trubner & Co., Ltd.
- Rodrigues, Dr. (Sr.) Immaculate.
1979 "The Outcaste". *The Star* 39,2:12-16.
- Rotberg, A.
1972 "Education on 'leprosy' is a dangerous myth". *International Journal of Leprosy* 40,1:75-80.
- Rotberg, A.
1978 "A non-stigmatizing Bible". *Hansenologia*
- Rouche, B.
1953 "A Lonely Road" in Eleven Blue Men and other Narratives of Medical Detection. New York: Berkley.

9

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.....

1974 "Notes on Korea and its People". Anthropological
Institute of Great Britain and Ireland 107:209-214.

1975 Selvarandian, A.J. Leprosy Research and Rehabilitation Project. Final Report.
Vellore, South India: Christian Medical College.

1977 Selvarandian, A.J., Richards, J. & Wilson, T.F.
"Comparison of attitude to leprosy between rural and urban
areas." Leprosy in India 44:62-73.

1969 Chears, Loyda W. & Jensen, Carl J.
"Social Acceptability of Anomalous Persons"
Exceptional Children 36:21-24.

Shepard, C.C.

1960 "The experimental disease that follows the injection
of human leprosy bacilli into the foot-pads of mice"
Journal of Experimental Medicine 112:445-454

Skilton, Allen.

1965 "Case Study of Disease and Culture in Action: Leprosy
Among the Hausa of Northern Nigeria". Human
Organization 24:140-147.

Skilton, Allen.

1968 "The Interaction Between the Middle Eastern and Western
Systems of Medicine". Social Science & Medicine 13:225-236.

Sigerist, H.E.

1947 Civilization and Medicine New York: Oxford University
Press.

Sigerist, H.E.

1951 History of Medicine I: Primitive and Archaic Medicine
New York: Oxford University Press.

Sigerist, H.E.

1961 History of Medicine II: Early Greek, Hellenistic, Persian
Medicine New York: Oxford University Press.

Sigerist, H.E.

1970 The Great Doctors: A Biographical History of Medicine
New York: Dover Publications, Inc.

Skinsnes, O.K.

1964a "Leprosy in Society, I: Leprosy has appeared on the face"
Leprosy Review 34:21-25.

Skinsnes, O.K.

1964b "Leprosy in Society II: The Pattern of Conceit and
Reaction to Leprosy in Oriental Society" Leprosy
Review 34:106-122.

4 4

OF / DE

282

Skinsnes, O.K.

1964c "Leprosy in Society III: The Relationship of the Social to the Medical Pathology of Leprosy"
Leprosy-Review 34:175-181

Skinsnes, O.K.

1968 "Leprosy in Society IV: The Genesis of Leprosy-anxiety"
Leprosy-Review 39:223-229

Skinsnes, O.K.

1970 "Leprosy in Society V: 'Leprosy' in Occidental Literature"
International Journal of Leprosy 38,3:294-307.

Skinsnes, O.K.

1973 "Notes on the History of Leprosy" International Journal of Leprosy 41,2:220-238.

Skinsnes, O.K.

1980 "Leprosy in Archeologically Recovered Bamboo Book in China" International Journal of Leprosy 48,3:333.

Smalley, Beryl.

1983 The Study of the Bible in the Middle Ages 3rd. edition.
Oxford: Basil Blackwell Publisher Ltd.

Smith, Wesley D.

1979 The Hippocratic Tradition Ithaca and London: Cornell University Press.

Snyder, M.L. et al.

1979 "Avoidance of the Handicapped: an attitudinal ambiguity analysis" Journal of Personality & Social Psychology (1979) 37:2297-2306.

Sontag, S.

1978 Illness as Metaphor New York: Farrar, Strauss & Giroux.

Stanford University.

1956 China Project--Taiwan (Formosa). (2 vols.) New Haven: Human Relations Area Files.

Storrs, E.E.

1971 "The Nine-Banded Armadillo: A Model for Leprosy and Other Biomedical Research". International Journal of Leprosy 30,3:703-714.

Trevelyan, G. M.

1966 England Under the Stuarts. London: Methuen.

Tringo, J.L.

1970 "The hierarchy of preference toward disability groups" Journal of Special Education 4:295-306.

Veith, L.

1947 "A Japanese Picture of Leprosy". Bull. History of Medicine 21:905-917.

Vogelsang, Th.

1975 "Gerhard Henrik Armauer Hansen 1841-1912. The Discovery of the Leprosy Bacillus. His life and his work" International Journal of Leprosy 44,3:250-372.

Vyan, G.K. et al.

1982 "A Sociologic study of leprosy cases in the Gandhi Kusti Ashram, Jorhpur". Leprosy India 54:324-331.

Ward, Bruce.

1985 "Are Canada's police going too far?" The Citizen, Ottawa, Jan. 12:83

Washington (State) University Far Eastern Research Institute.

1956 A Regional Handbook on the Inner Mongolia Autonomous Region. New Haven: Human Relations Area Files.

Waxler, Nancy.

1981 "Learning to be a leper: a case study in the social construction of illness" in Elliot G. Mishler (ed) Social constructions of Health, illness and Patient Care. Cambridge: Cambridge University Press.

Webster's Third New International Dictionary.

1971 Chicago: Merriam Co.

224

Weber, Max.
1958a The Protestant Ethic and the Spirit of Capitalism.
New York: Scribner's.

Weber, Max.
1958b The Religion of India. New York: Free Press.

Weber, Max.
1963 The Sociology of Religion. Boston: Beacon Press.

Weddell, A.G.M.
1980 "The Teaching of Leprosy in Medical Schools: Four and
One-half Hours in Three Years". International Journal
of Leprosy 48,3:129.

Wells, Calvin.
1964 Bones, Bodies and Disease: Evidence of Disease and
Deformity in Early Man. London: Thames & Hudson.

Wheatley, Brian.
1970 "Pilot Survey of a Group of Remote Villages in Masasi
District, Tanzania" Leprosy Review Vol 41, No. 1:21-24.

Wheatley, M.A.
1978 Mutilation is in the Eye of the Beholder: A Cross-Cultural
Analysis of Personal Adornment.
Unpublished Honours Thesis, Carleton University, Ottawa.

Whitehead, F.L.
1967 "Leprosy in New Brunswick: The End of an Era"
Canadian Medical Association Journal. 97:1200-1202.

Wiedfeldt, O.
1916 "Wirtschaftliche, rechtliche und Soziale Grundtatsachen
und Grundformen der Atayaler auf Formosa" Deutsche
Gesellschaft für Natur- und Völkerkunde Ostasiens

Wilkinson, J.
1977 "Leprosy and Leviticus: a problem of semantics and
translation" Scottish Journal of Theology 30:153-160.

Wilkinson, J.
1978 "Leprosy and Leviticus: the problem of description and identification" Scottish Journal of Theology 31:153-162.

Wilson, Dorothy Clarke.
1965 Ten fingers for God New York, Toronto and London: McGraw Hill Book Company.

Wilson, R.W.
1956 "Marriage and Sterilisation" International Journal of Leprosy 4:441-447

Winstedt, R.O.
1924 "Karamat: Sacred places and persons in Malaya". Royal Asiatic Society (Malayan Branch Journal) 2:264-279.

Wong, K.C. and Wu Lien-Teh.
1934 History of Chinese Medicine (2nd. edition).

World Health Organization
1966 WHO Expert Committee on Leprosy, Third Report
Geneva.

World Health Organization
1970 WHO Expert Committee on Leprosy, Fourth Report
Geneva.

World Health Organization
1977 WHO Expert Committee on Leprosy, Fifth Report
Geneva.

World Health Organization
1980 A Guide to Leprosy Control Geneva.

World Health Organization
1982 Chemotherapy of leprosy for control programmes
Geneva.

Wright, Patricia A.
1960 Physical disability: A psychological approach
New York: Harper.

Yeoli, M.
1955 "A 'Facies Leontia' of Leprosy on an Ancient Canaanite Jar". History of Medicine 10:331.

Zambaco Pacha, D.A.
1914 La Lèpre: travers les Siècles et les Contreées Paris: Masson et Cie.

Zimmer, H.R.
1948 Hindu Medicine Baltimore: The Johns Hopkins Press.

Zola, I.K.
1966 "Culture and Symptoms: An analysis of patients' presenting complaints" American Sociological Review 31:625-630

APPENDIX 1

METHODOLOGY

This research was concerned with a real issue - the problem of stigma related to certain health conditions. Personal experience from working with leprosy programmes in Tanzania and Nigeria suggested that leprosy provided an excellent, albeit extreme, example of a stigmatised disease - a disease which seemed to be almost universally stigmatised. It was decided to approach the problem of stigma using leprosy as the case study.

Because this was an identifiable social problem and not just a theoretical analysis, the project did not fit neatly into any one sub-discipline of sociology, nor was it confined to sociology. It was a qualitative analysis which sought to: (a) identify common characteristics of diseases and conditions which are stigmatised, shed light on the process of stigmatisation and develop a theory of stigma relating to disease; (b) examine the case of leprosy, historically and cross-culturally, to determine the extent to which leprosy is universally stigmatised; and, (c) develop ideas which would contribute to the de-stigmatisation of leprosy, and by extension help to break through the stigma associated with other conditions. It

was, therefore, necessary to explore any avenues deemed potentially useful in understanding the problem of stigma and thereby help to break it.

The study contains three main components: (1) the problem of stigma and disease; (2) leprosy as a case study; and, (3) the application of the findings of the case study to the problem of the stigma of disease.

The Problem of Stigma and Disease

In order to get a better understanding of the problem of the stigma of certain health conditions, a literature search was made using abstracts, periodical indices and subject catalogues, beginning with the headings stigma, disease, abnormality and disability. Wherever possible, items which seemed to have relevance to the stigma of disease were identified, obtained and read, in order to determine what, if any, were common characteristics in stigmatised health conditions. Goffman's *Stigma* (1963) provided a starting point, but led through a vast literature on medicine, disability, deformity and social psychology relating to disabilities. However, from the literature reviewed, certain characteristics seemed to recur: conditions were usually chronic or permanent, deforming and visible, and being frequently difficult to explain medically, were often explained in magico-religious terms or as superstitions.

The next step was to review the literature to identify cross-cultural ideas on health and disease, abnormality, deformity, religion and sin, to see how these could be brought together in a theory of stigma. This included an extensive search of the Human Relations Area Files (H.R.A.F.) under the headings of religious and social sanctions, ostracism, theory of disease, interpretation of abnormality, definitions of sinfulness, avoidance and taboo, purification and expulsion, unusual births and infanticide. The chief problem with the material from the H.R.A.F. is that information in each category varies from one society to another, both in quantity and quality, and is, therefore, only useful as an indication of the range of beliefs and practices, not as a comprehensive cross-cultural comparison. Other information was sought in histories of medicine, encyclopaedias, dictionaries of religion and interpreters' dictionaries, as well as in legends from various parts of the world, and using whatever material was deemed useful, the theory of stigma was proposed.

The Case of Leprosy

A considerable amount of material on the subject of leprosy was readily available, and personal contacts provided assistance in obtaining information. Each issue of the International Journal of Leprosy reviews current literature on leprosy, and in 1975 devoted a whole issue to

an index of leprosy references, dating back to 1233. These provided valuable leads to material on social and historical aspects, laws relating to leprosy in various geographical areas, and on-going research into the clinical aspects. The library at the Department of National Health and Welfare, Canada proved to be an excellent repository for nearly all relevant medical material. The Union List of scientific periodicals helped to locate less accessible material. A general perusal of more recent issues of Journal of Social Science and Medicine and the Journal of Health and Social Behaviour frequently produced unexpected results. The medical facts about leprosy were provided by recognised textbooks on leprosy, Reports by World Health Organisation Expert Groups, and specialist journals.

Applying the Findings

Once the material on leprosy had been brought together, it was obvious that leprosy was indeed almost universally stigmatised. The theory of stigma was shown to stand for the case of leprosy. Suggestions were made on how stigma of disease originates, and the process by which it is perpetuated or maintained. On the basis of these findings, recommendations were made on how it might be possible to break down stigma.

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