

Health-Related Stigma: Rethinking Concepts and Interventions

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Abstract

As a feature of many chronic health problems, stigma contributes to a hidden burden of illness. Health-related stigma is typically characterized by social disqualification of individuals and populations who are identified with particular health problems. Another aspect is characterized by social disqualification targeting other features of a person's identity—such as ethnicity, sexual preferences, or socioeconomic status—which through limited access to services and other social disadvantages result in adverse effects on health. Health professionals therefore have substantial interests in recognizing and mitigating the impact of stigma as both a feature and a cause of many health problems. Rendering historical concepts of stigma as a discrediting physical attribute obsolete, two generations of Goffman-inspired sociological studies have redefined stigma as a socially discrediting situation of individuals. Based on that formulation and to specify a manageable scope of health research interests, a working definition of health-related stigma is proposed. It emphasizes the particular features of target health problems and the role of particular social, cultural, and economic settings in developing countries. As a practical matter, it also considers various strategies for intervention, which may focus on controlling or treating target health problems with informed health and social policies, countering the disposition of perpetrators to stigmatize, and supporting those who are stigmatized to limit their vulnerability and strengthen their resilience. Our review of health studies of stigma indicates the need for, and how to proceed with, disease- and culture-specific studies of stigma that serve the interests of international health.

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Introduction

In recent years the concept of stigma has attracted increased attention among health professionals, the general population, and through the popular press it has entered the vocabulary of public culture to characterize a distinct component of the social impact of illness. Because it contributes to the burden of illness and it influences the effectiveness of case finding and treatment, which are major interests of disease control, stigma has become a matter of particular interest for public health. It is also a matter of particular interest because stigma is such a prominent feature of many tropical diseases in low- and middle-income countries. In addition to stigma targeting particular diseases and conditions, another aspect of health-related stigma concerns processes by which marginalised groups become more vulnerable to health problems, because they are identified with other targets of stigma, such as poverty, ethnicity, sexual preferences, and other factors that may contribute to social disadvantage or discrimination (Parker and Aggleton, 2003).

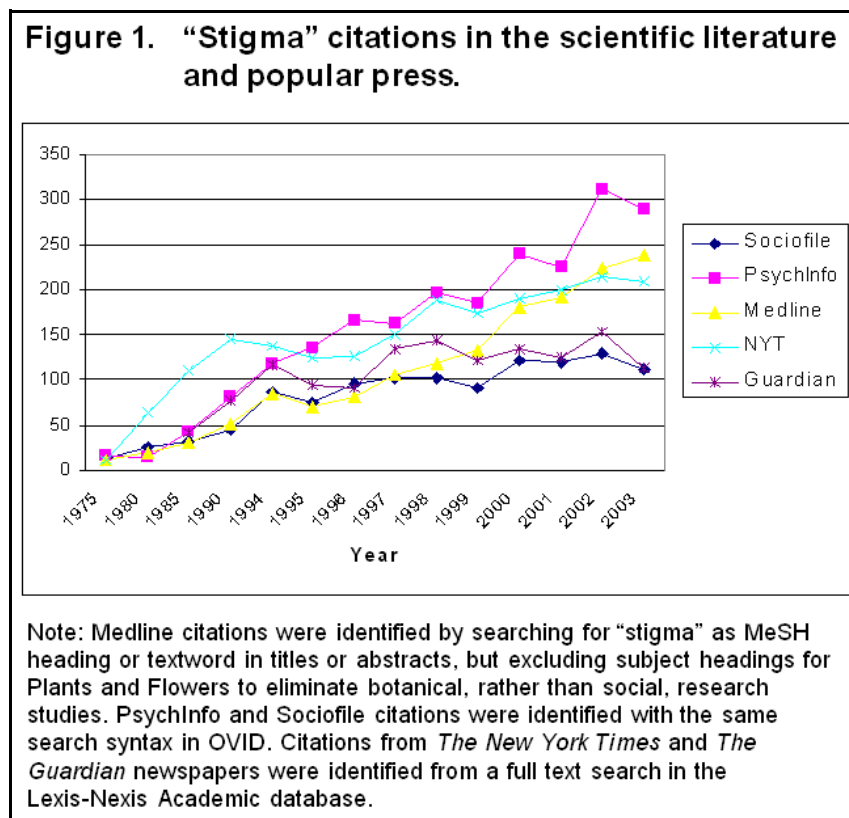
Social studies of stigma since the 1960s have been concerned with many diverse conditions, and the breadth of these interests has both contributed to and confused interests in health-related stigma. Consequently, it is important to specify the scope of our interests at the outset, examining the current social formulation of stigma, its historical underpinnings, and essential features of Goffman's reformulation. Based on that background, we will present a formulation of health-related stigma as a guide to health social science research, policy, and practice, focussing on pertinent diseases and considering implications and needs for research on stigma to guide health policy and clinical practice. Our interest is complementary, but distinct from, social science studies of stigma that set out to examine many diverse conditions for collective insights to explain stigma as a coherent principle of social theory. The aim

here, on the other hand, is to articulate a sufficiently useful formulation that may contribute to the management and control of stigmatized diseases in developing countries.

Concepts of stigma

Current formulation and public understanding

Over the past decade the concept of stigma has become a familiar topic in the English-language popular press and an important research topic with studies reported in the literature of sociology, psychology, and medicine. The American popular press has accepted a revisionist concept of stigma based on social interactions, responsive to developments in sociology and social psychology that emerged from modest beginnings in the 1960s.



Although sociological research interests appear to have begun to plateau in the 1990s, in recent years the increase in practical psychological and health studies of stigma has been

especially striking. Figure 1 indicates a crude estimate of this trend, showing the number of citations concerned with stigma in leading American and British newspapers, and in the databases cataloguing the professional literature of medicine, psychology, and sociology.

Although the term is now widely used and understood with reference to adverse and exclusionary social processes, this current usage is of relatively recent vintage, and the dictionary definition of stigma focussing on a symbolic mark continues to lag far behind current usage. In both popular discourse and research, stigma as a physical attribute has become a rather archaic notion. In large measure, this transformation is the legacy of Erving Goffman's (1963) seminal work on the topic, in which he glossed the term stigma as "the situation of the individual who is disqualified from full social acceptance" (p. 9). This prevailing view of stigma may refer either to an enacted, perceived, or anticipated social judgment.

Goffman's interest in stigma was clearly not primarily a practical matter, and it was not particularly concerned with health problems, even though it recognized them among a broader range of the targets of stigma. The variety of conditions that may be identified as targets of social disqualification is essentially limitless, and the field of stigma studies in the social sciences maintains a broad agenda. Sociological interests in this broad range of targets strives to identify common features and the various manifestations of stigma, delineating a fundamental principle of social theory. For example, a recent book by Gerhard Falk (2001) identifies women, the mentally challenged, homosexuals, single people, prostitutes, African-Americans, the overweight, and even successful people, among others, as targets of stigma. Daunted by the diversity of stigmatized conditions and the heterogeneity of the social responses that are grouped under a common heading of stigma, clarification of what has

become a “vague and uncritical” conceptualization is required to make the concept of stigma a useful focus of applied health research (Stafford and Scott 1986).

Historical

The cultural history of stigma emphasises a mark or brand made on the skin denoting social condemnation and censure. The *Oxford English Dictionary* defines stigmatised as either a literal or figurative marking with a brand to indicate infamy or censure. Stigmatising in the 17th Century by branding appears to have been a common punishment, but one might be stigmatised by other stains, scars or blemishes. Because such a stigma was inflicted as a punishment intended to disgrace the individual, there was no question about stigma being unfair, or identifying stigma as a social problem that policy should aim to mitigate. To the contrary, it was more a solution, imposing disgrace as a punishment and as a means of social control. As the physical mark has become a peripheral consideration, stigma now more typically refers to the process targeting the adverse social situation or condition that brought on censure, rather than the symbolic mark.

The term stigma has been used in several other ways as well. In a religious context, the marks resulting from the crucifixion of Jesus Christ are known as stigmata, and these were thought to be found on the bodies of saintly persons through a kind of supernatural empathic connection with Christ that marked the intensity of their devotion. Though a scar or blemish on the skin, the social impact of these particular stigmata was not disgrace but rather a focus of admiration and awe. Medical texts of about a century ago referred to pathological markings in a socially non-judgmental way; such petechia or lesions of the skin that were signs of a particular disease were identified as stigmata. Stigma is also applied in this descriptive technical sense in zoology and botany to specify particular markings on the wings

of an insect, and to specify that part of the pistil of a flowering plant that is impregnated by pollen.

Cultural context of sociological reformulation

Goffman (1963) noted that research on the underlying concept of stigma, which inspired his monograph, had begun a decade earlier by both sociologists, social psychologists, and clinicians. He especially acknowledged the work of Beatrice Wright on the psychological study of disability, first published in 1960, as an important influence (Wright 1983), and this focus on deformity and disability was also emphasised in Goffman's own work. Other authors he cited had begun studying the underlying concepts, rather than elaborating or reformulating a concept of stigma. Clinical considerations concerned with facial deformities and plastic surgery (Macgregor et al., 1953) also reflected these historical concerns with marks. By the early 1950s Edwin Lemert (1951) had already made a notable contribution to what would become a career interest in criminological study of deviance and social control (See Lemert 2000). Psychoanalytic studies of physical disability (Orbach et al., 1957) and the social impact of psychiatric hospitalization (Greenblatt et al., 1957) were also influential.

Goffman's social interactionist concept of stigma acknowledged the role of context in specifying what was acceptable and what was stigmatised. His formulation of stigma was sensitive to the values and influence of American culture of the 1950s and early 1960s, which was deeply concerned with questions of deviance and normalcy (disparagingly regarded as *conformity*). This was a period when beatnik ideology, unconventional "long hair" of the Beatles, and the social climate that produced the lifestyle of hippies in the next decade were feared as subversive threats.

Such were the times of the 1950s when Goffman undertook his seminal study of stigma. He indicated slight reluctance to define stigma solely with reference to deviance, based on the shared social meaning of conditions that were targets of social disqualification. He questioned whether all forms of deviance could rightly be regarded as a homogenous category. “It is remarkable,” he wrote, “that those who live around the social sciences have so quickly become comfortable in using the term ‘deviant’, as if those to whom the term is applied have enough in common so that significant things can be said about them as a whole” (Goffman, 1963, p. 167n). Nevertheless, he concluded that sufficient common features justified study of stigma with reference to diverse target groups, but he also recommended studying how they differ. This is an especially important consideration for health researchers whose interests reside not so much in developing sociological theories, but rather in a practical appreciation of the impact of stigma and how it operates with reference to particular health problems and in particular settings .

In a society deeply concerned with questions about conformity and deviance, he defined his framework with reference to “the attitudes we normals have towards a person with a stigma, and the actions we take in regard to him” (p.15). Goffman proposed a taxonomy of stigma based on three distinct types, which may be understood with reference to underlying historical concepts of symbolic stigmata and his focus on deviance: (i) “Abominations of the body,” which referred to physical deformities (cf. individual stigmata); (ii) “blemishes of individual character...weak will...passions, treacherous and rigid beliefs, and dishonesty.” Mental disorders, addictions, and unemployment were examples (cf. deviant individuals). (iii) “Tribal identities” referred to stigmatised conditions of race, sex, religion, and national origin (cf. population stigmata and ethnocultural deviance from the majority). His study of stigma was based on examples from a rich catalogue of deformity, disability,

criminality, addictions, mental illness, race and other issues that were concerns of the day and topics of social research.

Goffman's primary interest and the interests of the two generations of sociological studies of stigma that he inspired have reformulated the concept of stigma, recasting it in a model based on social interactions, but more concerned with social theory than social justice. That formulation of stigma has therefore required considerable reworking to make it useful for the practical interests health research. To pursue such aims, stigma research questions focus more on the particular indicators, effects, and practical implications of stigma, and here with more particular reference to the diseases affecting people in low- and middle-income countries. With respect to practical interests, it is not sufficient to ask what are the effects of stigma without also asking and seriously considering what we should do about it.

Clinical practice and public health require thoughtful attention not just to the signs and symptoms, or to the pathophysiology of disease, but also active interest in the social aspects of illness. Recognising that, health researchers have placed greater emphasis on stigma to highlight the importance of the social effects, determinants, and contexts of disease. References to stigma acknowledge the social sources of the pain and suffering of many diseases. Although such social suffering may sometimes motivate treatment, but more typically, because people may also wish to avoid acknowledging a condition that is socially discrediting, stigma may also delay help seeking or lead to discontinuation of needed, effective treatment. The basis and the manifestations of denial of full social acceptance, that is, particular motivations for health-related stigma, may also vary considerably according to the target condition that is stigmatised.

The motives, rationale, and manifestations of stigma that targets HIV/AIDS, schizophrenia, tuberculosis, and epilepsy are distinctive. Furthermore, stigma is more likely to be associated with chronic, rather than acute, conditions, because chronic illness tends to

alter, redefine, or (in Goffman's terms) "spoil" the identity of affected individuals. We may also expect the manifestations of stigma to be culturally determined. For example, in settings where arranged marriages are a major concern of families for their children, the impact of a health problem on the ability to marry is especially troubling.

Because illness identity may interact with social identities based on poverty, gender, ethnicity, sexual orientation, and so forth, it may be difficult or impossible to precisely determine the basis for denial of full social acceptance. The social response to a mix of target identities may be determined by interactions and synergies. For example, although we typically regard tuberculosis and depression as targets of stigma, in selected contexts tuberculosis may paradoxically symbolize style and beauty of the Romantic Age (Krause 1996), and depression as the English malady was similarly regarded as a vulnerability associated with a positively distinguished sensitivity.

Although stigma may often be manifest through interpersonal attitudes and interactions, broader policy issues may also be adversely by stigma, leading to inadequate funding for services and research. Consequently, it is not necessarily clear how to assess and measure stigma. What may we take for appropriate indicators? Insofar as reducing stigma and/or managing its effects becomes a more frequent objective of public health policy, it becomes increasingly important to have some way of assessing stigma reliably to guide effective policy and to assess its impact.

At least three substantial shortcomings limit the utility of Goffman's formulation of stigma for applications to health research and policy, and especially to health problems in low-income countries, which have substantially different cultures from the setting where his concept of stigma was cultivated. From our current vantage point, (i) the language and taxonomy of abominations, blemishes, and tribal identities is antiquated. (ii) The range of phenomena to which the concept of stigma has been applied is so vast that the concept fails

to adequately address health-related interests of social and health policy. A reformulation of the concept is required that is more specific to our interests in health and illness. (iii) Perhaps most important, the conceptual framework based on normalcy and deviance is both inadequate and inappropriate for cross-cultural research and policymaking, and implication of a dominant *normal* runs counter to recognition and appreciation of multicultural societies and multiculturalism. Although innovative and effective in shifting the formulation of stigma from symbols to social processes, viewed from an anthropological perspective, its homogenizing bias limited its practical utility. Modifications in the concept and research agenda are required to serve the practical interests of health research, disease control, and community action.

Stigma and health research

Several reasons explain why stigma is such an important consideration for social and health policy and for clinical practice. The emotional impact of social disqualification adds to burden of any illness in various ways, and as noted already, stigma may delay appropriate help-seeking or terminate treatment for treatable health problems. For diseases and disorders that are highly stigmatized, the impact of the meaning of the disease may be as great or a greater source of suffering than symptoms of the disease. For example, paucibacillary leprosy may present at an early stage as a painless depigmented or anaesthetic patch. Hearing the diagnosis is likely to be far more troubling than these symptoms.

The emotional impact of social and cultural meanings of illness indicates the various ways by which stigma operates. Social science research on stigma regards it fundamentally as a problem arising from social interactions. But Goffman and other researchers have also recognized self-perceived stigma, or the impact of anticipated interactions, which may be as distressing as actual interactions. Each of these various aspects of stigma may impair quality

of life from experiences or concerns about disclosure, and effects on work, education, marriage, and family life. Although its impact is likely to be overlooked in the calculation of Disability-adjusted life-years (DALYs), stigma contributes to what a WHO fact sheet identifies as the hidden burden of mental illness (WHO 2001), and it constitutes a hidden burden for other stigmatized conditions as well. Research also shows that stigma and labelling may affect the course of recovery (Link et al., 1991; Wahl 1999)

Although denial may relieve the emotional discomfort that results from stigma, denial is a problem when it interferes with timely and appropriate help seeking and treatment. The distressing prospect of having a stigmatized condition, which is further associated with stigmatized status in society, may be an inducement to ignore or conceal it and forego the kind of help that one might readily acknowledge as useful if the condition were affecting someone else. The stigmatization of HIV/AIDS and specific groups at risk, such as men who have sex with men and injection drug users, interferes with voluntary testing, counselling and treatment. Timely treatment benefits the individual and society by reducing suffering, improving health and productivity, and limiting opportunities for spread (Chesney and Smith, 1999). For example, leprosy, which has long been the gold standard of stigmatized diseases, may progress late in its course to preventable deformities. Tuberculosis not only becomes more serious for the infected individual, but also poses a threat for contacts and further spread, and it may also promote development of drug resistance. People with untreated mental health problems may potentiate an avoidable progression of symptoms that makes their condition more difficult to treat. For diseases that require a relatively long course of treatment (like leprosy and TB), or chronic disorders that require chronic treatment (like epilepsy), stigma constitutes an obstacle to continuing or remaining in treatment.

Rethinking health-related stigma

In formulating a useful concept of stigma for public health, guided by particular examples of stigmatized health problems and their consequences, it is important to identify salient features, which are amenable to study and potentially useful guides for reducing the adverse impact of stigma. Goffman's ideas about "spoiled identity" and exclusionary social processes remain relevant, but more particular aspects of health-related stigma also need to be considered. We propose such a formulation, as follows, to facilitate action-oriented research on health-related stigma:

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

It is important to note that efforts to distinguish stigmatizing behavior from appropriate precautions for some health problems may require a delicate balance of public health risks and restrictive or exclusionary management based on medical and epidemiological evidence. Though exclusionary, such behavior is different from what we

mean by stigma as the term is understood in the context of public health. For example, measures to protect health personnel from actively infectious patients with tuberculosis may be appropriate, even though the same behaviors would be stigmatizing after treatment has begun and risk of infection from them eliminated. Similarly, health personnel avoiding contact with patients treated for leprosy who are no longer infectious is indeed stigmatizing, inasmuch as such behavior suggests that a conflicting social judgment has inappropriately overridden a medical judgment. Research is concerned with the questions of how much risk to others there may actually be, and how effective or counterproductive any exclusionary measures to deal with that risk actually are. Recent questions about limiting the spread of SARS demonstrate the importance of appraising risk to inform policy that minimizes both the spread of disease and stigma. Exaggerated perceptions of risk in transmission of HIV provide another well-known example.

Health research studies of stigma should also recognize that the manifestations of the “exclusion, rejection, blame, or devaluation” and the nature of the adverse social judgments are likely to vary as they apply to different health problems. For example, isolation of a patient with acute immune suppression may be seen in a positive light as appropriate protection. In formulating objectives and methods for stigma research, the investigator should identify the particular features of the health problem that require attention and motivate study.

Although the cultural patterning of stigma has not been a priority for much of the social research on stigma, the interests of international health require careful attention to how the nature of stigma may vary in different cultures. Such cultural differences affect both what is stigmatized and how stigma is manifest. Although some authors have acknowledged differences in what is stigmatized from one setting to another (Becker and Arnold, 1986), less has been written about cultural differences in the manifestations of stigma, that is, how

adverse social judgments are made and experienced; such considerations are an essential feature of a formulation of stigma that effectively serves the interests of public health.

Studies of its magnitude and nature need to account both for the disease-specific and culture-specific aspects of stigma. A single scale or instrument is likely to be inadequate to fulfill the needs for disease-specific and culture-specific studies of stigma. A cultural epidemiological approach, on the other hand, integrates anthropological and epidemiological frameworks and methods to identify local concepts and categories and to study their distribution and effects. This approach also integrates quantitative and qualitative assessments (Weiss 2001).

Research on disease-specific and culture-specific features of HIV/AIDS is instructive. In the United States this stigma research has produced an action-oriented conceptual framework guiding a multi-pronged agenda for reducing stigma; questions naturally follow about how components of this American framework may be applied in other settings (Herek 1999a; NIMH 1996). Various aspects of HIV/AIDS-related stigma have been considered, such as the interaction of AIDS stigma and sexual prejudice (Herek and Capitano 1999), the impact of policy and law on people with HIV/AIDS (Burris 1999), and others.

Infectious disease-related stigma

Among stigmatised diseases, none have been more closely associated with stigma than leprosy, and the term itself has become a metaphor for stigma. Although the WHO Special Programme for Research and Training in Tropical Diseases (TDR) has been concerned with the impact of stigma for various diseases, leprosy is the only TDR disease for which explicit and exclusive studies of stigma have been supported (Boonmongkon 1994; Paz et al., 1990). Like HIV/AIDS, the motivation for examining the stigma of leprosy has been to help manage the social exclusion, the emotional suffering, and the barriers to

effective health care that follow from local cultural meanings of the disease. The impact of stigma targeting leprosy explains some paradoxical preferences in the utilization of health services. Although the availability of nearby health facilities is usually considered an indication of their accessibility and responsiveness to needs, some investigators have reported concerns about disclosure of the condition may make nearby health services for leprosy too close for comfort. The preference for more distant services has been documented in Nepal (Pearson, 1988), and the director of a large NGO in Ahmedabad, India, has observed a similar preference for more distant facilities among patients seeking treatment for TB (M. Uplekar, personal communication).

Stigma has a substantial impact on the experience of illness, help seeking, and treatment adherence for tuberculosis in various ways. In areas where TB and HIV are endemic, stigma of TB may be enhanced by association with AIDS, which in turn has been shown to contribute to treatment delay for tuberculosis in an HIV high endemic area of Thailand (Ngamvithayapong et al., 2000). TB-related stigma, however, is a matter of much broader significance than just its association with AIDS. From research in Thailand, Johansson and colleagues (1999) distinguish two forms of stigma, based on social discrimination and on fears arising from self-perceived stigma. The impact of TB stigma has also been emphasized in recent reports from low- and middle-income countries in other parts of the world, including West Africa (Lawn 2000) and East Africa (Liefoghe et al., 1997).

The potential for resistance, which increases when control measures fail, makes TB control an ever more important goal. With growing evidence that directly observed treatment (DOT) is effective, questions about the appeal, acceptability, and limitations of DOT programs become more significant. Why do substantial numbers reject the DOT approach to treatment? In a recent study in the Pathanamthitta District of Kerala, Balasubramanian and colleagues (2000) reported that stigma and concerns about not being identified as a patient

with TB was responsible for 28% of patients not being observed in a DOTS program, and this was a substantially greater problem for women (50%) than for men (21%). Another study of social stigma in rural Pune District of Maharashtra showed that stigma interferes not just with participation in DOTS, but more generally with timely help seeking for TB. Morankar and colleagues (2000) found that 38 of the 80 patients they studied (40 men and 40 women) reported taking measures to hide their disease from the community. Social vulnerability contributed to women's reticence to disclose TB, and such women were typically widows or married and living in joint families. Both women and men who hid their disease sought treatment later than others of their respective sex who did not; being female contributed to the delay, and women who hid their disease sought treatment later than men who did not. Such questions about the effects of gender on TB have recently motivated TDR support of a multi-country study in Colombia, Malawi, India, and Bangladesh, in which quantitative and qualitative assessments, and cultural epidemiological study of stigma play an important role (Somma et al., 2004).

Other TDR studies have considered the stigma that comes from the intense itching and socially undesirable scratching caused by onchocercal skin diseases. The itching is severe enough that some people report considering suicide. With the availability of ivermectin for annual treatment to control the disease in affected village communities of 16 endemic African countries, the question arose about whether the disease was a serious enough priority to justify mobilizing the resources needed to reach these people. Studies of illness experience also examined the stigma of the disease, and by documenting its role in the burden, findings helped to motivate establishment of the African Programme for Onchocerciasis Control (Pan-African Study Group, 1995). In this case managing stigma relied on efforts to control and eliminate the disease.

Approach to health-related stigma interventions

Practical implications and the kind of interventions that may be expected to follow from study of stigma may vary considerably from one health problem to another. A framework indicating the focus and approach for interventions to counter undesirable effects of stigma is indicated in table 1.

Focus	Approach	Example*
Health problem	<ul style="list-style-type: none"> • Public health to control the disease • Early recognition and treatment for cure or disability prevention 	<ul style="list-style-type: none"> • Onchocercal skin disease • Leprosy
Stigmatizers	<ul style="list-style-type: none"> • IEC and social marketing to enhance compassion and reduce blame • Correct misapprehensions of risk 	<ul style="list-style-type: none"> • Epilepsy • Various infectious diseases
Emotional impact	<ul style="list-style-type: none"> • Counselling • Peer support groups and therapeutic communities 	<ul style="list-style-type: none"> • Most conditions • Mental health problems
Social policy	<ul style="list-style-type: none"> • Advocacy, lobbying, and legislation • Research support 	<ul style="list-style-type: none"> • HIV/AIDS • Diseases of poverty

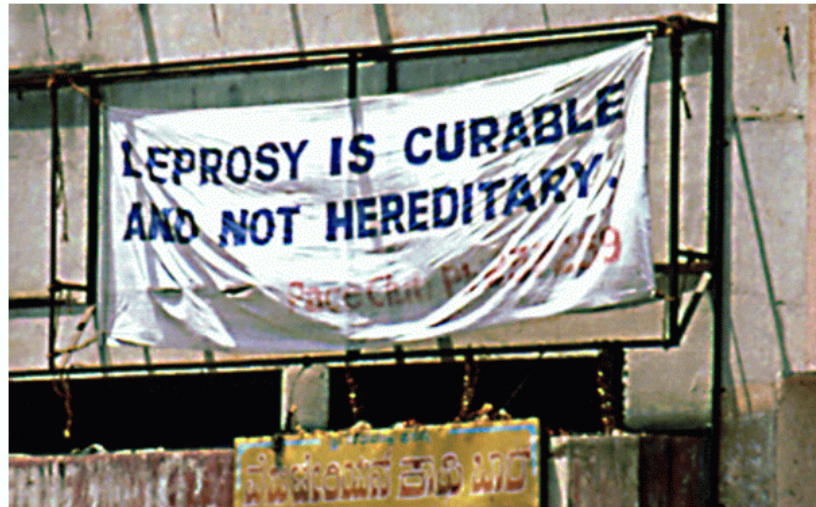
*Examples are illustrative but incomplete. Stigma-mitigating strategies are not limited to a single focus or approach. (See also Miller and Major 2000)

Interventions may focus on support for affected persons, changing behaviour among perpetrators of stigma in the general population (or particular subgroups), and eliminating or controlling the target condition. For many conditions, various combinations of these approaches may be appropriate. Counselling helps people with various target conditions, such as tuberculosis, HIV infection, or mental illness, to protect themselves from the impact of stigma, which they may either encounter or anticipate. Individual and group interventions aim to minimize vulnerability and enhance resilience in response to stigmatizing encounters

or stressful situations. Interventions aiming to reach the general public aim to correct misinformation and unfounded fears about the risks and dangers of people with stigmatized target conditions. Interventions also aim to enhance empathy with affected person by emphasizing the fact that health status is not the only relevant feature of the identity of a person with a stigmatised condition.

Formulating strategies for particular health problems also requires careful consideration of action at global, national, and local levels of intervention (Weiss et al., 2001a). For example, documenting the stigma of onchocercal skin disease (OSD) contributed to establishment of regional intervention strategy to control the disease, as noted above. Using resources to develop counselling or support groups to deal with the personal impact of stigma would be less effective and less culturally appropriate than implementing control strategies in the settings where OSD occurs. Leprosy control programs made effective use of a simple message, "leprosy can be cured," since the early 1980s when the introduction of multi-drug therapy made that a credible claim (Figure 2). As the message became believable, it began to change social perceptions of the condition from an irreversible transformation of personal identity to a treatable disease.

Figure 2. Disease control message helping to reduce stigma by promoting control of leprosy*



*Bangalore construction site, Photo by Mitchell G. Weiss, 1992.

Efforts to alleviate the stigma of epilepsy and HIV/AIDS have focused on helping individuals to acknowledge and adjust to life with a chronic disease, and efforts to acknowledge the personal and social problems of people with HIV infections and AIDS refer to “Breaking the Silence.” A major campaign of WHO and two other global partners to reduce the social barriers arising from stigma and to promote treatment of epilepsy in Africa is called “Out of the Shadows” (WHO 2000). By considering a relevant formulation of stigma and ways of proceeding with field and policy studies, research aims to identify the magnitude and features of the hidden disease burden that stigma imposes, what motivates the social response, and ways to deal with it with various strategies that focus on individuals, populations, and policies. Needs for such interventions define questions and an agenda for studies of stigma.

Approaches to study of health-related stigma

The needs for disease- and culture-specific formulation of such interventions defines questions and an agenda for studies of stigma. Previous studies of illness-related stigma have been concerned with its personal and public health implications. Some of these sociological and social psychological studies have also been concerned with the theoretical formulation of stigma, rather than practical interventions for patients and populations. Stigma research began with mental health studies, but with attention to the social dimensions and implications for control of leprosy, HIV, tuberculosis, and other infectious diseases, the scope of health-related stigma research has expanded dramatically.

Health-related stigma may be experienced and explained differently by people who have a target condition and others who do not, and self-perceived stigma may differ from enacted stigma (Scambler 1998). Effective policy benefits from consideration of these various perspectives. Study of people with a stigmatised health problem provides an account of self-perceived stigma; study of people without that problem in the community clarifies the social context of stigma targeting that condition. Changing health status upon acquiring a stigmatized health problem brings with it a range of social experience and ideas about the implications of the condition from prior life experience.

Assessing stigmatizing attitudes of health care providers indicates the nature of stigma arising from experience in health systems. Inasmuch as health services are supposed to ameliorate, rather than exacerbate, the adverse impact of health problems, it is especially important to identify and correct unintended consequences. It may also be useful to consider the attitudes of key persons or groups within a community, such as political leaders, policymakers, and teachers. Their attitudes are likely to influence the social production of stigma or desirable alternatives.

Families of people with the target health problem are also a specialized group of particular interest for assessing stigma. Like the affected individual, others in the family may themselves be targets of stigma through a process Goffman described as courtesy stigma. Other potential secondary targets of stigma include friends, loved ones, and the health staff and volunteers who work with affected individuals. In some cases, however, family, and sometimes health professionals, may ally with a discriminatory response in the community and become perpetrators of stigma. This puts the person who is a primary target in an especially difficult position. Wahl's (1999) study of the stigma of schizophrenia among recovering patients found that more than a third of respondents identified relatives as perpetrators of stigma.

Mental Health research

In addition to HIV/AIDS studies over the last decade, considerable research on stigma has focussed on mental health problems. This results in large measure from the involvement of social and clinical psychologists in interdisciplinary collaborations with sociologists in studies of stigma from the outset. In the background section of his research report, Wahl (1999) reviews several of these approaches to study of mental illness-related stigma. Questionnaires have been used for studies of patients and the general population. The questionnaires are typically based on key features of stigma identified by the investigators. Vignettes have been used in the general population to compare the responses when the vignette portrays a protagonist identified as a mental patient or not identified as such. Analysis considers how this is related to respondents' rejection, devaluation, and blame of the protagonist. Analogue behavior studies are based on analysis of how people respond in situations where they are led to believe they are dealing with someone who is mentally ill or who has previously been in treatment.

Link's questionnaire for assessing stigma includes items that require scoring along a Likert scale from strongly agree to strongly disagree. These items were formulated under the headings (1) deviation and discrimination and (2) coping orientations that indicate secrecy, avoidance-withdrawal, and education (Link et al., 1991; Link 2001). Link and colleagues have also produced a 20-item scale for studying perceived stigma among people with a psychiatric disorder. This scale has been used by Sirey and colleagues (2001) to assess the impact of perceived stigma on discontinuing medications among groups of older and younger patients with mild depression.

The survey instrument developed by Wahl (1999) included a section on stigma comprising 9 items and a section with 12 items on discrimination experienced by consumers of mental health care (usually identified as patients in other studies). The approach was innovative in several respects. In this NAMI-supported study Wahl involved the consumers at an early stage in the development and design of the research. Consumers helped to identify the relevant indicators of stigma to ensure that the assessment would be responsive to their interests. The study design included both a larger survey (N=1,301) and a subset of respondents followed up with in-depth qualitative telephone interviews, which were transcribed and coded for qualitative analysis. This made it possible to examine not only the frequency of responses from the survey, but also to consider the nature and meaning of response categories.

Each of these 21 items under the headings of stigma and discrimination consisted of assertions about the respondent's experience, which were coded *never*, *seldom*, *sometimes*, *often*, or *very often*. Some items would likely not have been included without the participation and input of the consumers in the study, which is an advantage but also raises some questions. For example, it is not clear how to interpret affirmative responses to such items as, "I have been advised to lower my expectations in life because I am a consumer."

Although this was clearly a stigma-related matter of concern for many respondents, it is unlikely that caregivers who had made the remarks would have characterized their intent or anticipated effects of the remark as stigmatizing. The aim was to protect patients from frustration and disappointment expected to result from unachievable goals. Consequently, the finding offers a useful insight for clinicians who might not have considered sufficiently the impact of such remarks; it also indicates the value of assessing stigma from the vantage points of both consumers and providers.

Survey methods and research on HIV/AIDS

Health research studies of stigma have employed various methods to assess the experience of stigma among target groups and in the general population. Surveys have been widely used in the general population, especially for HIV/AIDS research to study potential perpetrators of stigma. Such assessments range from single-item queries to more complex instruments. For example, an assessment of stigma from households in the general U.S. population queried 5,641 respondents by telephone about HIV/AIDS with one question, asking whether respondents agreed with the following assertion: “People who got AIDS through sex or drug use have gotten what they deserve” (MMWR 2000).

Herek (1999b) has also used a more complex instrument for national telephone surveys in the United States, and a version of that instrument is available on the Internet with a bibliography identifying studies that have used the survey. The extensive interview includes queries about interactions with persons with AIDS, symbolic contact, beliefs about transmission, attitudes towards people with AIDS, trust in authorities and experts, HIV mandatory testing, feelings toward people with AIDS, perceptions of persecution, and the effect of concerns about stigma on HIV testing.

Ethnography and social context

Other approaches for assessing the nature and impact of stigma on people and society are also likely to be useful. Lang (1991) used ethnographic methods to study AIDS-related stigma. Kleinman's (1995) study of the stigma of epilepsy in China critically reviewed concepts of stigma, emphasizing the importance of considering broader social contexts of illness experience. This analysis emphasized the role of stigma as a force both shaped by and influencing the character of local worlds. His formulation also emphasizes the priority of ethnography to study such questions. In that regard, stigma is one aspect of the social experience of illness.

Cultural epidemiology of stigma

Cultural contexts influence both the selection of conditions that are stigmatized, and local manifestations of stigma. Consider, for example, whether concerns about the inability to marry, which is an important feature of stigma in South Asia, are as important elsewhere? Such questions were considered in a comparative study of self-perceived stigma reported by patients with clinical depression in Bangalore and London. Several reports discuss the approach for locally validating features of stigma (Weiss et al., 2001b; Raguram et al., 1996). Raguram and colleagues (2004) have also studied determinants of stigma with reference to cultural epidemiological explanatory variables for illness experience, perceived causes, and help seeking. A similar approach has been used to analyze the determinants of stigma targeting TB, in studies that also considered interactions between role of gender and TB-related categories of experience, meaning and behaviour. This cultural epidemiological approach to the assessment of stigma has been used for studying patients coming for treatment of other mental health and medical problems (Table 2).

Table 2. Selected cultural epidemiological studies of stigma

Country	Citation	Instrument-Target population	Number of items	Response scale	Psychometric properties	Number of subjects
India	Raguram et al., 1996. ²	EMIC interviews: psychiatric outpatients with depression	8	4-points (yes, possibly, uncertain, no) in response to stigma-indicative queries	Interrater reliability; internal consistency	80
Nigeria, Cameroon, Ghana, Uganda	Vlassoff et al., 2000. Pan-African Study group, 1995.	EMIC interviews: Patients with onchocercal skin disease and non-affected general population (vignettes)	13 (Patients); 12 (Gen Popn); 8 (Both)	4-points (yes, possibly, uncertain, no) in response to stigma-indicative queries	internal consistency	468
Bangladesh, India, Malawi, Colombia	Weiss et al., Accepted.	EMIC interviews: DOTS clinic TB patients	17 or 18	4-points (yes, possibly, uncertain, no) in response to stigma-indicative queries	internal consistency	427
India and England	Weiss et al., 2001.	EMIC interviews: psychiatric patients with depression	11 (London); 12 (India)	4-points (yes, possibly, uncertain, no) in response to stigma-indicative queries	Internal consistency; interrater reliability (England)	127
India	Raguram et al., 2004.	EMIC interviews: Family caretakers of patients with schizophrenia	13	4-points (yes, possibly, uncertain, no) in response to stigma-indicative queries	internal consistency	80

To study the stigma of target health problem from the vantage point of people who do not have the condition (rather than patients or others with the condition), analogous EMIC interviews for cultural epidemiological study have been reformulated as inquiries about the problems of persons with the condition portrayed in vignettes depicting a typical presentation. Such interviews may be administered to respondents sampled in the general population, or to special groups, such as health care providers representing various options for health care in the community. In studies of onchocercal skin disease, leprosy, and other conditions, comparing unaffected people in the community with people identified in a clinic,

social stigma reported by the community sample has been higher than self-perceived stigma reported by people with the disorder (Vlassoff et al., 2000).

Policy studies

Complementary research is also needed to guide social policy affecting health-related stigma. Relevant questions in that regard concern access to care, health financing, and support for research, inasmuch as they reflect priorities that are influenced by stigma. Policy affecting people with HIV/AIDS, tuberculosis, and mental illness has also been concerned with human rights questions. These issues are especially important for people with these conditions who come from segments of the population that are already socially stigmatized (Lerner 1996). AIDS-related stigma studies have considered interactions of the disease with minority status or gender, and the need for research in the field to guide policy (Yoshioka and Schustack 2001; Moneyham et al., 1996).

Important questions of social policy interact in subtle ways with questions of scientific evidence and stigma. Diverse issues, such as driving privileges for people with controlled epilepsy, forced isolation of people with active TB, involuntary notification of sexual partners of people with HIV/AIDS, and so forth indicate the need to balance interests of individuals and populations. Balancing these interests may be a complex matter, especially when they appear to be at odds. Focussed studies are need to examine interrelationships between stigma, culture, liability, and ethics, as well as the implications for social and health policy of these interrelationships (Gostin and Lazzarini (1997).

Research Objectives

The above discussion indicates needs for studies of stigma considering points of view of patients, populations, health care providers and other special groups, and general policy interests. The interests of research on health-related stigma aim to guide strategies for mitigating problematic stigma, and to distinguish effective approaches from those that are simplistic, ineffective, or counterproductive. The following six broad aims for such a stigma research agenda may be considered:

1. Document the burden from the stigma of various health problems

Studies of the magnitude and nature of stigma need to address both its disease-specific and culture-specific features. The epidemiology of stigma is concerned with distinctly different questions than the epidemiology of the target condition. In place of a single instrument for assessing a criteria set or a single scale to assess the magnitude of stigma targeting health problems generically, cultural epidemiological approaches are appropriate; they should acknowledge local features of stigma and include both quantitative and qualitative assessments. Such research should clarify the priority of stigma for health policy in the organization of services, public health interventions, training curricula of health care personnel, and for social and economic policy. Qualitative, in-depth narrative accounts are required to develop queries, scales, and instruments at the outset, so that they may ensure the validity of large quantitative assessments of the magnitude of stigma, and the distribution of particular features, the overall impact, and determinants of stigma.

The dimensions of stigma as a framework for assessment should consider the following points:

- Reluctance to disclose the problem
- Exclusion or rejection from school, work, social groups and activities
- Blame and devaluation

- Diminished self-esteem
- Social impact on family
- Economic impact
- Ability to marry and impact on existing marriage
- Other local disease-specific and setting-specific indicators of the denial of full social acceptance

2. Compare stigma for different health problems and in different settings

Motivations and manifestations of stigma vary for different target health problems.

That variation also reflects social and cultural differences in health programs and behaviours of healthcare personnel at different treatment sites. Appreciation of such variation indicates the need for comparative research. Health programs benefit from a comparative account of the role of stigma for different disorders in the same setting. It is also useful to see how stigma for the same disorders varies across treatment sites (eg, government and private clinical services and various complementary and specialist health services). Regional and cultural comparisons indicate how stigma operates in particular settings and provide opportunities to exchange information from experience at different sites confronting similar problems.

3. Identify determinants of stigma, its practical impact on illness experience, and implications for help-seeking behaviour and health policy.

Key indicators of stigma and scales that provide an overall assessment may be used to study and analyse determinants and effects of stigma, testing hypotheses about the particular nature of its impact on health. Stigma may be motivated by exaggerated or inappropriate fears of contagion, moral judgments about persons with the target health problem, magico-religious ideas about the cause, anticipation of burdensome demands for assistance, or other factors. Various hypothesized effects of stigma that merit study include the

magnitude and nature of its contribution to suffering, delay of appropriate help seeking, treatment dropout, and so forth.

4. Evaluate changes in the magnitude and character of stigma over time and in response to interventions and social changes

We expect the level and the features of stigma to vary in response to social changes and in response to interventions. For instance, although it has been assumed that development of efficacious treatment helps to reduce stigma of incurable or difficult-to-treat target conditions, that assumption needs to be documented, and the ways in which this social process operates need to be clarified, noting how such changes vary among different segments of the population. As health policy and program personnel become more aware of the importance of stigma, and as stigma intervention strategies are designed and implemented, evaluation research to track changes becomes increasingly important. Further research is needed to evaluate the effects of social change in general, and stigma interventions in particular, on various segments of the population, both among those with the stigmatized condition and others in the general population. The quantitative and qualitative assessments described above each contribute to the assessment of such changes over time.

5. Improve knowledge about functional impairment and misperceived risk of spreading target health problems, so that laws and health policy may minimize, rather than exacerbate, stigma.

Fears and fantasies provide fertile ground for stigma to flourish. Community understanding and social policy related to stigma need to be informed by research, so that laws and health policy are not influenced by stereotypes, prejudices, and unfounded speculation that magnify risk, or by misguided expectations about the benefits of restrictive policies. Basic health research on particular diseases, disorders, and conditions helps to

minimize stigma or to provide a rationale for restrictive policies, if necessary, based on appropriate evidence.

Examples of stigma-relevant policies that should be better informed include restrictive driving laws for people with controlled epilepsy, popular assumptions about the dangerousness of mental illness, and mistaken ideas overestimating the risk of contracting diseases from noninfective persons. Clinical interactions with patients, public health communications, and scientific writing should each be attentive to ways in which health professionals may contribute to stigma inadvertently and from insufficient self-reflection or consideration of their own prejudices.

6. Develop clear, simple, and unambiguous messages about complicated health problems and strategies to counter health-related stigma.

Inasmuch as health information and programs that aim to reach a large segment of the public must be simple, and because health policy related to stigma may be highly complex, questions about the effectiveness of particular strategies are likely to arise in the course of policymaking. Research is needed to identify and address them. For example, the final report of the an NIH-sponsored AIDS and stigma workshop grappled with "the question of how AIDS educational messages can communicate the importance of taking responsibility for one's own safety from HIV through safe sex without also communicating the idea that people with HIV are blameworthy for their condition" (NIMH 1996). Related questions arise for TB control about precautions to prevent spread of tuberculosis for smear-positive patients, while also trying to promote integration of patients in their family and community. Stigma reduction strategies for mental health adopted by both patient activist organizations and mental health professional organizations emphasize the biomedical basis of mental illness. This approach, however, may promote the idea that "organic" means blameless, and "socially" or "psychologically" based disorders are blameworthy.

Conclusion

Although initially formulated as an area for social science research, stigma has now become an important topic for public health. It contributes to suffering, which may further impair health, and it interferes with appropriate use of health services, even when they are available. The conceptualization of stigma that Goffman developed has guided a wide range of social research studies, and we have suggested ways of rethinking the concept so that it may better guide public health research, policy, and action. Our formulation is rooted in Goffman's view of stigma as disqualification from full social acceptance. Our definition of health-related stigma applies Goffman's concept to international health with reference to particular features of health problems that are targets of stigma.

It is because stigma encompasses so many target conditions that international health research must carefully specify the nature of the interest in the field in the topic. Our review highlights the importance of accounting for particular features of stigmatised health problems and their sociocultural contexts to identify determinants and effects of practical significance for health policy. The priority of studying health-related stigma with reference to particular health problems and cultures, especially in low- and middle-income countries, elaborates and responds to a question originally posed by Goffman about problems he recognized in overgeneralizing common features of the stigma that may result from highly diverse targets. Applied interests and desire for practical benefits from international health research on stigma require attention to that point. With reference to prior work in the field, we present interventions-oriented aims and approaches for research that indicate how a focus on problem- and setting-specific features of stigma may contribute to international health.

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References

- Balasubramanian, V.N.; Oommen, K.; Samuel, R. DOT or not? Direct observation of anti-tuberculosis treatment and patient outcomes, Kerala State, India. *Int J Tuberculosis and Lung Dis* 4(5):409-413, 2000 May.
- Becker, G.; Arnold, R. Stigma as a social and cultural construct. Chapter 3, Pp. 39-57. In: In: Ainaly, S.C.; Becker, G.; Coleman, L.M. (Eds.). *The Dilemma of Difference: A Multidisciplinary View of Stigma*. New York: Plenum Press, 1986.
- Boonmongkon, Pimpawun. *Khi thut*, "The disease of social loathing:" An anthropological study of the stigma of leprosy in rural North-East Thailand. Social and Economic Research Project Reports, No. 16. Geneva: WHO, 1994.
- Burris, S. Studying the legal management of HIV-related stigma. *Am Behavioral Scientist* 42(7):1229-1243, 1999.
- Chesney, M.A.; Smith, A.W. Critical delays in HIV testing and care: the potential role of stigma. *Am Behavioral Scientist* 42(7):1162-1174, 1999.
- Falk, Gerhard. *Stigma: How We Treat Outsiders*. Amherst: Prometheus Books, 2001.
- Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall, 1963.

- Gostin, Lawrence O.; Lazzarini, Zita. *Human Rights and Public Health in the AIDS Pandemic*. New York: Oxford University Press, 1997.
- Greenblatt, M.; Levinson, D.J.; Williams, R.H. (Eds). *The Patient and the Mental Hospital: contributions of Research in the Science of Social Behavior*. Oxford: Free Press of Glencoe, 1957.
- Herek, G.M. AIDS and stigma. *Am Behavioral Scientist* 42(7):1106-1116, 1999a.
- Herek, G.M. AIDS and Stigma Survey Items. Document available on the Internet with reference list including studies based on use of the survey.
http://psychology.ucdavis.edu/rainbow/html/Stigma_items_99.pdf (Accessed 25 November 2004). 1999b
- Herek, G.M.; Capitano, J.P. AIDS stigma and sexual prejudice. *Am Behavioral Scientist* 42(7):1130-1147, 1999.
- Johansson, E.; Long, N.H.; Diwan, V.K.; Winkvist, A. Attitudes of compliance with tuberculosis treatment among women and men in Vietnam. *Int J Tuberc Lung Dis* 3(10):862-868, 1999.
- Lawn, S.D. Tuberculosis in Ghana: social stigma and compliance with treatment. *Int J Tuberc Lung Dis* 4(12):190-1191, 2000.
- Liefooghe, R.; Baliddawa, J.B.; Kipruto, E.M.; Vermeire, C.; De Munynck, A.O. From their own perspective: A Kenyan community's perception of tuberculosis. *Trop Med Int Health* 2(8):809-821, 1997.
- Kleinman, A. The social course of epilepsy: chronic course of illness as social experience in interior China. Chapter 7, Pp. 147-172, In: Kleinman, A. *Writing at the Margins: Discourse between Anthropology and Medicine*. Berkeley: University of California Press, 1995.

- Krause, R.M. Tuberculosis: Romance to reality to resurgence. *Cosmos*, 1996. Web access: <http://www.cosmos-club.org/journals/1996/krause.html>. Accessed 24 November 2004.
- Lang, Norris G. Stigma, self-esteem, and depression: psycho-social responses to risk of AIDS. *Human Organization* 50(1):66-72, 1991.
- Liefoghe, R.; Baliddawa, J.B.; Kipruto, E.M.; Vermeire, C.; DeMunynck, A.O. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health* 2(8):809-821, 1997.
- Lemert, C.C.; Winter, M.F. (Eds). *Crime and Deviance: Essays and Innovations of Edwin M. Lemert*. Lanham: Rowman and Littlefield, 2000.
- Lemert, E.M. *Social Pathology: A Systematic Approach to the Theory of Sociopathic Behavior*. New York: McGraw-Hill, 1951.
- Lerner, B.H. Temporarily detained: Tuberculous alcoholics in Seattle, 1949 through 1960. *Am J Public Health* 86(2):257-265, 1996.
- Link, Bruce G.; Mirotznik, Jerrold; Cullen, Francis T. The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior* 32:302-320, 1991.
- Link, Bruce G.; Phelan, Jo C. Conceptualizing stigma. *Annu Rev Sociol* 27:363-385, 2001.
- Macgregor, F.; Abel, T.; Bryt, A.; Laver, E.; Weissmann, S. *Facial Deformities and Plastic Surgery: a Psychosocial Study*. Springfield, IL: Thomas, 1953.
- Miller, C.T.; Major, B. Coping with stigma and prejudice. Chapter 9. In: Heatherton, T.F., et al. (Eds). *The Social Psychology of Stigma*. New York: Guilford, 2000.
- Moneyham, L.; Seals, B.; Demi, A.; Sowell, R.; Cohen, L.; Guillory, J. Perceptions of stigma in women infected with HIV. *AIDS Patient Care & STDS*. 10(3):162-167 1996.

MMWR. HIV-Related knowledge and stigma—United States, 2000. *Morbidity and Mortality Weekly Review*, 49(47):1062-1064, 2000 Dec 1.

Morankar, Sudhakar; Suryawanshi, Nishi; Kudale, Abhay; Deshmukh, Deepali; Patil, Om Prakash; Rangan, Sheela. Social stigma in tuberculosis. In: Thakur, Arun Kumar (ed.), *Recent Trends in Tuberculosis and Chest Disease*. Patna: Bihar TB Association, 2000; Pp. 41-50.

National Institute of Mental Health. AIDS and Stigma: A Conceptual Framework and Research Agenda. Final Report from a Research Workshop. 12-13 April 1996.

Ngamvithayapong, Jintana; Winkvist, Anna; Diwan, Vinod. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS* 14:1413-1419, 2000.

Orbach, C.E.; Bard, M.; Sutherland, A.M. Fears and defensive adaptations to the loss of anal sphincter control. *Psychoanalytic Review* 44:121-175, 1957.

Pan-African Study Group on Onchocercal Skin Disease. The Importance of Onchocercal Skin Disease: Report of a Multi-Country Study. *Applied Field Research Reports*, No. 1. Geneva: UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR), 1995.

Parker, R.; Aggleton, P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 57:13-24, 2003.

Paz, Consuelo J.; Medina, Isagani R.; Ventura, Elizabeth R. A multidisciplinary study of stigma in relation to Hansen's disease among the Tausug in the Philippines. *Social and Economic Research Projects Reports*, No. 7. Geneva: WHO, 1990.

Pearson, M. What does distance matter? Leprosy control in West Nepal. *Social Science and Medicine* 26(1):25-36, 1988.

- Raguram, R.; Weiss, M.G.; Channabasavanna, S.M.; Devins, G.M. Stigma, depression and somatization: a report from South India. *Am J Psychiatry* 153:1043-1049, 1996.
- Scambler, Graham. Stigma and disease: changing paradigms. *Lancet* 352:1054-1055, 1998.
- Sirey, J.A.; Bruce, M.L.; Alexopoulos, G.S.; Perlick, D.A.; Raue, P.; Friedman, S.J.; Meyers, B.S. Perceived stigma as a predictor of treatment discontinuation in young and older outpatients with depression. *Am J Psychiatry* 158(3):479-481, 2001.
- Somma, D.; Auer, C.; Abouihia, A.; Weiss, M.G. *Gender and Tuberculosis and Research: Status of the Field and Implications for Research*. WHO Department of Gender and Women's Health. Geneva: World Health Organization, 2004.
- Stafford, M.C.; Scott, R.R. Stigma, deviance, and social control: some conceptual issues. Chapter 5, Pp. 77-91. In: Ainlay, S.C.; Becker, G.; Coleman, L.M. (Eds.). *The Dilemma of Difference: A Multidisciplinary View of Stigma*. New York: Plenum Press, 1986.
- Vlassoff, C.; Weiss, M.; Ovuga, E.B.L.; Eneanya, C.; Nwel, P.T.; Babalola, S.S.; Awedoba, A.K.; Theophilus, B.; Cofie, P.; Shetabi, P. Gender and the stigma of onchocercal skin disease in Africa. *Social Science and Medicine*, 50:1353-1368, 2000.
- Wahl, Otto F. Mental health consumers' experience of stigma. *Schizophrenia Bulletin* 25(3):467-478, 1999.
- Weiss, M.G. Cultural epidemiology: introduction and overview. *Anthropology and Medicine* 8(1):5-29, 2001.
- Weiss, M.G.; Isaac M.; Parkar S.R.; Chowdhury A.N.; Raguram R. Global, National, and Local Approaches to Mental Health: Examples from India. *Tropical Medicine and International Health*. 6(1):4-23, 2001a.

Weiss, M.G.; Jadhav, S.; Raguram, R.; Vounatsou, P.; Littlewood, R., Psychiatric stigma across cultures: local validation in Bangalore and London. *Anthropology and Medicine* 8(1):71-87, 2001b.

Weiss MG, Auer C, Somma D, Abouihia A, Jawahar MS, Karim F, Arias NL, Kemp J. Gender and tuberculosis: Cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi, and Colombia. WHO/TDR SEB Report Series, Number 4. Accepted for publication.

World Health Organization. The 'undefined and hidden' burden of mental health problems. Fact sheet Number 218. Revised November 2001.

<http://www.who.int/mediacentre/factsheets/fs218/en/>. Accessed 24 November 2004.

World Health Organization. "Out of the Shadows." A global campaign against epilepsy. WHO Press Release, 4 May 2000.

<http://www.who.int/inf-pr-2000/en/pr2000-30.html>, accessed 24 November 2004.

Wright, Beatrice. *Physical disability: a psychosocial approach*. Second edition. New York: Harper and Row, 1983.

Yoshioka, M.R.; Schustack, A. Disclosure of HIV status: cultural issues of Asian patients. *AIDS Patient Care & STDS* 15(2):77-82, 2001.