

Health-related stigma: Rethinking concepts and interventions¹

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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 socio-economic 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 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 relates to 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 suggestions for health studies of stigma highlight needs for disease- and culture-specific research that serves the interests of international health.

Keywords: *Stigma, hidden burden, illness, cultural epidemiology, health social science, vulnerability*

Introduction

In recent years, the concept of stigma has been attracting increased attention among health professionals and the general population. Through the popular press, it has now entered the vocabulary of public culture to characterize a recognized 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 is becoming a priority interest of public health. It is also a matter of particular interest because stigma is such a prominent feature of many chronic diseases and health problems throughout the world. In addition to stigma associated with diseases and conditions, another aspect of health-related stigma concerns processes by which marginalized groups become more

vulnerable to health problems, because they are identified with other conditions and situations that are stigmatized, such as poverty, ethnicity, sexual preferences and other factors that may contribute to social disadvantage or discrimination (Parker & Aggleton, 2003).

Social science studies of stigma since the 1960s have been concerned with many diverse conditions, and the breadth of interests covered has provided insights and depth to understanding of the concept, but at the same time also introduced ambiguities in the meaning and priority of various aspects of health-related stigma. Hence, it is important to specify our interests at the outset, examining historical underpinnings and essential features of Goffman's (1963) seminal contribution on the topic of stigma for social research. Based on that, we suggest a formulation of health-related stigma to guide health social science research, policy and practice, focusing on pertinent diseases and their relevant socio-cultural contexts. Our interest may be distinguished from social science studies of stigma that set out to examine many diverse conditions for collective insights to explain stigma as a unitary principle of social theory independent of target and setting.

Concepts of stigma

Current formulation and public understanding

Over the past decade, the concept of stigma has become familiar to readers of 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 Goffman's 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

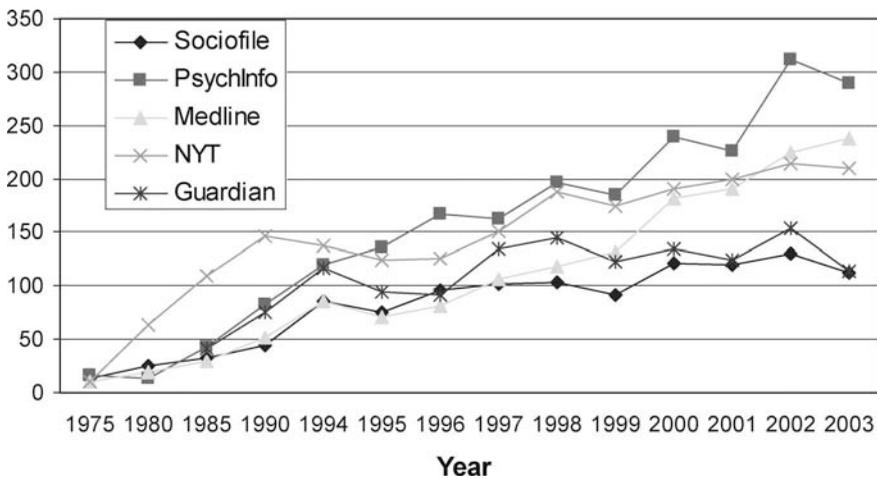


Figure 1. Stigma citations in the scientific literature and popular press. Note: *Medline* citations were identified by searching for “stigma” as a MeSH heading or textword in titles or abstracts, but excluding subject headings for plants and flowers to eliminate botanical, rather than social, research studies. *Psychoinfo* and *Sociofile* citations were identified with the same search syntax in OVID. Citations from *The New York Times* and *The Guardian* newspapers were identified from a full text search in the Lexis–Nexis Academic database.

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 Goffman's (1963) conceptualization of stigma, which glosses the term 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.

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: (a) "Abominations of the body," which referred to physical deformities (cf. individual stigmata); (b) "blemishes of individual character . . . weak will . . . passions, treacherous and rigid beliefs, and dishonesty." Mental disorders, addictions and unemployment were examples (cf. deviant individuals). (c) "Tribal identities" referred to stigmatized 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.

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, (a) the language and taxonomy of abominations, blemishes and tribal identities is antiquated. (b) 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. (c) Perhaps most important, the conceptual framework based on normalcy and deviance is both inadequate and inappropriate for cross-cultural research and policymaking, and implications of a dominant *normal* run 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, it focused on social interactions, particularly dyadic interactions, without sufficient attention to social structural features that modulate social interactions. Viewed from an anthropological perspective, the thesis that stigma is homogeneous, regardless of the heterogeneous conditions to which it may be associated, limits its practical utility. Adaptations recognizing diverse contexts of stigma and conditions that are stigmatized are required to serve the practical interests of health research, disease control and community action.

Stigma and health research

Several reasons make stigma an important consideration for social and health policy and for clinical practice. The emotional impact of social disqualification contributes to the physical, psychological and social burden of any illness in various ways; for example, 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 of leprosy is likely to be far more troubling than these symptoms.

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, perception 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 behaviour from appropriate precautions for some health problems may require a delicate balance of public health risks and restrictive or exclusionary management based on current medical and epidemiological evidence. Though exclusionary, such behaviour 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 (TB) may be appropriate, even though the same behaviours would be stigmatizing after treatment has begun and risk of infection eliminated. Similarly, health personnel avoiding contact with patients treated for leprosy who are no longer infectious is indeed stigmatizing, inasmuch as such behaviour 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, though it may be construed as discriminatory for a person because they have

been diagnosed with HIV infection. 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 & Arnold, 1986), less has been written about cultural differences in the manifestations of stigma, that is, how adverse social judgments are made and experienced. Studies of its magnitude and nature need to account both for the disease- and culture-specific aspects of stigma. A single scale or instrument is likely to be inadequate to fulfil the needs for disease- and culture-specific studies of stigma.

Infectious disease-related stigma

Several infectious diseases—for example, TB, HIV/AIDS and leprosy—illustrate common and distinctive features of stigma. Stigma has a substantial impact on the experience of illness, help-seeking and treatment adherence for TB in various ways. In areas with high prevalence of TB and HIV, stigma of TB may be enhanced by association with AIDS, which in turn has been shown to contribute to treatment delay for TB in an HIV high-prevalence area of Thailand (Ngamvithayapong, Winkvist, & Diwan, 2000). TB-related stigma, however, is a matter of much broader significance than just its association with AIDS. From research in Thailand, Johansson, Long, Diwan and Winkvist (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 programmes become more significant. Why do substantial numbers reject the DOT approach to treatment? In a recent study in Kerala, India, Balasubramanian, Oommen and Samuel (2000) reported that stigma and concerns about not being identified as a patient with TB were responsible for 28% of patients not being observed in a DOTS programme, and this was a substantially greater problem for women (50%) than for men (21%).

Another study of social stigma in Maharashtra, India, 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 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.

Approaches to study of health-related stigma

Research questions and agendas for study of stigma should be shaped by consideration of needs to formulate disease- and culture-specific interventions that consider psychological processes of individuals, social dynamics of institutions, and various social and economic processes that influence policy. Health-related stigma may be experienced and explained

differently by people who have a stigmatized condition and others who do not, and self-perceived stigma may differ from enacted stigma (Scambler, 1998). Effective policy benefits from consideration of various perspectives. Study of people with a stigmatized health problem provides an account of self-perceived stigma; study of people without that problem in the community clarifies social contexts of stigmatization. Changes in the social meaning of a stigmatized condition that occur when someone acquires it are influenced both by a need to live with the condition and by a range of social experience and ideas about the implications of that condition from prior life experience.

Clarifying the stigmatizing attitudes and behaviours of health care providers, as well as manifestations of stigma in the organization of health services and health policies, explains how stigma may be embedded 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 problems in that regard. 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 a stigmatized health problem are another specialized group of particular interest for studying stigma. Like the affected individual, others in the family, because of their association with that person, 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, as Wahl (1999) showed from study of people recovering from schizophrenia. Inasmuch as stigma is multilayered and situational, even affected people might stigmatize those with more severe conditions, or which appear more socially disqualifying for other reasons.

Cultural epidemiology of stigma

Cultural contexts influence both the selection of conditions that are stigmatized, and local manifestations of stigma, suggesting questions appropriate for study with methods of cultural epidemiology (Weiss, 2001). 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 (Raguram, Weiss, Channabasavann, & Devins, 1996; Weiss, Jadhav, Raguram, Vounatsou, & Littlewood, 2001). Raguram, Raghu, Vounatsou and Weiss (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 analyse 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 (Johansson, Long, Diwan, & Winkvist, 2000).

To study the stigma of a target health problem from the vantage point of people who do not have the condition (rather than patients or others with the condition), EMIC interviews query illness-related experience, meaning and behaviour with reference to vignettes depicting typical presentations. Such interviews may be administered to respondents sampled in the general population or special groups, such as health care providers. 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). Such findings indicate how people with stigmatized conditions may cope with it.

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, TB 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 (Moneyham et al., 1996; Yoshioka and Schustack, 2001).

To avoid contributing to stigma, important questions of social policy should be guided by scientific evidence. 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 needed 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).

Approach to health-related stigma interventions

Practical implications and the kinds 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 I.

Interventions may focus on support for affected persons, changing behaviour among people who stigmatize in the general population (or particular subgroups), and eliminating or controlling the stigmatized condition. For many conditions, various combinations of these approaches may be appropriate. Counselling helps people with various stigmatized conditions, such as TB, 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 for the general public try to correct misinformation and unfounded fears about the risks and dangers of people with stigmatized 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 stigmatized condition.

Efforts to alleviate the stigma of epilepsy and HIV/AIDS have focussed 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

Table I. Focus and approach to interventions for mitigating stigma.

| Focus | Approach | Example ^a |
|------------------|---|---|
| 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 |

^aExamples are illustrative but incomplete. Stigma-mitigating strategies are not limited to a single focus or approach (see also Miller and Major, 2000). Reprinted from *The Lancet*, vol. 367, Weiss, M. G., & Ramakrishna, J. (2006). Stigma interventions and research for international health, *The Lancet*, 367, 536–538. Copyright 2006 with permission from Elsevier.

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.

Research objectives

Research on health-related stigma is mainly concerned with clarifying the nature of its burden, and with developing and testing strategies for mitigating problematic stigma. A research agenda should address the following six aims:

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- and culture-specific features. The epidemiology of stigma is concerned with distinctly different questions than the epidemiology of the target condition. Problem- and setting-specific instruments based on cultural epidemiological approaches should acknowledge local features of stigma and include both quantitative and qualitative assessments. Such assessments should examine the following dimensions of stigma, as they apply to particular research questions:

- 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- and setting-specific indicators of the denial of full social acceptance.

2. *Compare stigma for different health problems and in different settings*
Variation in the motivations and manifestations of stigma for different target health problems in different cultural and clinical settings suggests the need for comparative study of stigma. It may be useful to determine whether and how stigma for the same disorders varies across treatment sites (e.g., government and private clinical services and various complementary and specialist health services). Regional and cultural comparisons provide opportunities to exchange information from experience at different sites confronting similar problems.
3. *Identify determinants of stigma and their practical implications for help-seeking 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 and dangerousness, moral judgments about persons with a stigmatized health problem, magico-religious ideas about the cause, anticipation of burdensome demands for assistance or other factors. Possible 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*
As health policy and programme 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. 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. Both quantitative and qualitative assessments contribute to the assessment of such changes over time.
5. *Improve knowledge about functional impairment and misperceived risk of spreading stigmatized health problems, so that laws and health policy do not promote 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 non-infective persons.
6. *Examine ambiguities arising from efforts to formulate simple, stigma-mitigating messages for complicated health problems*
Inasmuch as health information and programmes 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 TB 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 people with “organic” conditions are 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. Goffman’s conceptualization of stigma 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 his gloss of stigma as disqualification from full social acceptance as its definitive feature. It applies this concept to social aspects of international health problems that are targets of stigma.

Our review highlights the importance of accounting for particular features of stigmatized health problems and their socio-cultural contexts, and the value of identifying determinants and effects of practical significance for health policy. With reference to prior work in the field, we have outlined an agenda for research that indicates how a focus on problem- and setting-specific features of stigma may contribute to international health.

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Note

1. Abridged version of background paper presented by Mitchell G. Weiss.

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