

for delivery of social services, and tracking of public expenditures must all involve marginalised people. Mechanisms must be established that enable them to hold governments, donors, and others accountable for the decisions made on behalf of poor and marginalised populations.

Third, underlying policies that create and perpetuate stigmatising conditions and poverty must be challenged. Policies that increase the vulnerability of the poor must be redressed, including user-fees that exclude the poorest members of society from accessing health services, and structural adjustment policies that have forced staggering

retrenchment of personnel in public services. Fistula will continue to exist as long as countries like Tanzania are strapped by severely limited resources for basic social services, including prevention, treatment, and care for those with neglected conditions.

**Conflict of interest statement**

I declare that I have no conflict of interest.

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## Stigma interventions and research for international health

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The stigma of many diseases and disorders prevalent in the world today is cause for increasing public health concern, raising the question of whether new research is necessary before enlightened health policies can be implemented. Because stigma is a very broad topic, it is important to acknowledge distinctive features of health-related stigma and the social burden of illness. We have formulated a definition of health-related stigma: a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem. The judgment is medically unwarranted with respect to the health problem itself, just as stigma targeting other aspects of group identity (such as race or sexual orientation) is also unwarranted, and may adversely affect public health policy and individual health status.

### A research agenda

With this definition in mind, we propose the following research objectives.

**(1) Document the burden of stigma for serious health problems**

Studies of the magnitude and nature of stigma need to address both its disease-specific and culture-specific aspects. The epidemiology of stigma is concerned with distinctly different questions than the epidemiology of the target condition. In place of a single instrument typical of epidemiological surveys, setting-specific cultural epidemiological approaches, which acknowledge local features of stigma and include both quantitative and qualitative assessments, are more appropriate.<sup>1</sup>

**(2) Compare stigma for different health problems and in different settings**

What motivates stigma and how it becomes manifest varies for different conditions. This variation also

reflects social and cultural values and differences in health programmes and behaviours of health-care personnel at different treatment sites in a community, in different parts of a country, and in different countries.

**(3) Identify determinants of stigma and its effect on health policy and on illness experience and behaviour**

Stigma may be motivated by inappropriate fears of contagion or danger, moral judgments about people with the condition, magico-religious ideas about the cause, or other factors. Various proposed effects of stigma that merit study include the magnitude and nature of its contribution to suffering, delay in appropriate help-seeking, and treatment dropout and effectiveness. Quantitative study of stigma that specifies its magnitude and determinants is enhanced by qualitative data that clarify the nature of observed relations, which in turn facilitates translation of findings into policy and practice.

**(4) Evaluate changes in stigma over time, and in response to interventions and social change**

It is assumed, for example, that the development of efficacious treatment helps to reduce the stigma of an incurable or difficult-to-treat condition, but that assumption needs to be verified. Further research is needed to evaluate the effects of social change in general, and stigma interventions in particular, on people with a stigmatised condition and in the general population.

**(5) Improve knowledge about the nature and risk of target health problems, so that laws and health policy minimise stigma**

Fears and fantasies provide fertile ground for stigma to flourish. Community understanding and social policy need to be informed by science, so that laws and health policy are not influenced by stereotypes, prejudices, and unfounded speculations. 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 overestimations of the risk of contracting diseases.

#### **(6) Develop clear, simple, and unambiguous messages about complicated health problems and stigma**

With regard to HIV/AIDS, for example, communications to the public need to convey the importance of practising safe sex without also suggesting that people with HIV are blameworthy for their condition.<sup>2</sup>

#### **Approaches to the study of stigma**

Stigma research entails studying several groups in society, including stigmatised individuals themselves, community residents without the disease, health-care personnel whose practices affect stigma within the health system (and who may themselves be stigmatised by working with affected people), and community leaders whose attitudes and actions can promote or mitigate stigma. The families of stigmatised individuals are also of interest as potential secondary targets of stigma, as are friends, loved ones, and others who work with the targeted individuals. Caregivers, however, are not necessarily supportive; a study of schizophrenia by Wahl<sup>3</sup> showed that more than a third of respondents with the condition identified relatives as perpetrators of stigma.

#### **Cultural epidemiology**

Just as several groups need to be studied within a culture, it is also important to study stigma across cultures. Accordingly, researchers have been developing a cultural epidemiological approach assessing illness-related experience, meaning, and behaviour.<sup>4,5</sup> In interviews, individuals with the target health problem may be asked about any reluctance to disclose the problem, exclusion or rejection from school or work, diminished self-esteem, blame and devaluation, family effects, ability to marry, and effects on marriage. Responses are coded on a four-point scale in a database that also includes narrative accounts of these issues. In interviews with individuals who do not have the target condition, the questions are reframed in the form of a vignette about a person with the health problem.

#### **Ethnography and social context**

Other useful approaches have used ethnographic methods. An early study by Lang<sup>6</sup> examined AIDS-related stigma, and Kleinman<sup>7</sup> has studied epilepsy-related stigma in China. His review shifted the focus from stigma to the broader context of social experience, considering how epilepsy (and illness more generally) is affected by, and how it affects local worlds.

The survey instrument developed by Wahl<sup>3</sup> was innovative insofar as it studied stigma from the point of view of people with schizophrenia, and it integrated

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quantitative and qualitative methods. Unexpectedly, it showed that patients considered it stigmatising and upsetting when caregivers advised them to lower their expectations in life because of their problems. Caregivers explained that they wanted to protect their patients from the frustration and stress of unachievable expectations, unaware that their advice was perceived as stigmatising. Such findings provide useful insights for clinicians, highlighting the value of studying both patients and providers.

#### **Policy studies and interventions**

Development of social and health policies for minimising stigma must take into consideration such key issues as access to care, health financing, and research support, as well as basic human rights. Studies of tuberculosis and HIV/AIDS policies are particularly important for subgroups of the population already socially stigmatised, and underscore the relation between human rights and disease-related stigma.<sup>8</sup> Lerner's account and related questions—such as driving privileges for people with controlled epilepsy, forced isolation of people with active tuberculosis, and involuntary notification of sexual partners of people with HIV/AIDS—indicate practical needs for policy to examine not just stigma and health, but also how stigma, culture, liability, and ethics interact.

The kind of interventions to mitigate stigma vary with the condition. When ivermectin became available to control onchocerciasis, and thus prevent the unbearable

	Approach	Example*
Health problem	Public health to control the disease	Onchocercal skin disease
	Early recognition and treatment for cure or disability prevention	Leprosy
Stigmatisers	Information, education, and communication (IEC) and social marketing to enhance compassion and reduce blame	Epilepsy
	Correct misapprehensions of risk and danger	Various infectious diseases
Emotional impact	Counselling	Most conditions
	Peer support groups and therapeutic communities	Mental health problems
Social policy	Advocacy, lobbying, and legislation	HIV/AIDS
	Research support	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.<sup>10</sup>

**Table: Focus and approach to stigma-mitigating interventions**

itching and socially unacceptable scratching that stigmatises people with onchocercal skin disease, questions arose whether the disease was serious enough to justify the resources needed to control it in 16 affected African counties. Documenting the role of stigma helped motivate establishment of WHO’s African Programme for Onchocerciasis Control.<sup>9</sup> In this case, control of the disease, rather than counselling or support groups to deal with the impact of stigma, reflected the priority of a population-based strategy. Similarly, leprosy control programmes made effective use of a simple message—that leprosy can be cured—once the introduction of multi-drug therapy made that a credible claim. By contrast, efforts to alleviate the stigma of epilepsy and HIV/AIDS have focused on helping individuals acknowledge and adjust to life with incurable but treatable diseases. The table presents a framework indicating the focus and approach for interventions to reduce stigma. By considering a relevant formulation of

stigma and ways of proceeding with clinic, community, and policy studies, we have indicated directions for needed research to mitigate burdensome, health-related stigma.

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## Stigma and global health: looking forward

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Following the landmark international conference “Stigma and Global Health: Developing a Research Agenda”, the Fogarty International Center and its partners at the US National Institutes of Health (NIH), other US government agencies, and the Canadian Institutes of Health Research issued a request for applications for research proposals that would address challenges raised at the conference. The major goal of the request was to stimulate interdisciplinary, investigator-initiated research on (1) the role of stigma in health and disease, (2) the mechanisms by which it affects the health and well-being of individuals, groups, and societies worldwide, and (3) opportunities to intervene to prevent or mitigate stigma and its adverse consequences. Specifically, the Fogarty International Center and its partners sought to bring together researchers who

traditionally take a more qualitative approach (eg, anthropologists) with those whose approach is more quantitative (eg, epidemiologists) around the broad problem of stigma and global health. Ultimately, this programme will provide new insights that will benefit the health of the US population and the global community.

Applications were accepted from anywhere in the world. Although studies on US-based challenges fit within the scope of the request for applications, research with a global perspective was specifically encouraged, with higher levels of funding offered for multinational projects involving developing countries.

Over 100 applications were submitted, about half of which involved international research partnerships between researchers in developed and developing countries. Awards were made primarily to international