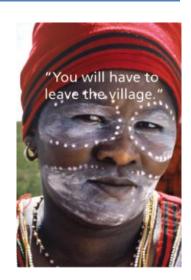# Dossier "Health-related stigma"

This dossier is an information product of the Department of Information & Library Services (ILS) of the Royal Tropical Institute (KIT). It is a copy of an archived version of the former web document that was last updated in 2012. Some web links may no longer be valid. An overview of all ILS dossiers on health, gender, local governance, culture, and sustainable economic development can be accessed at http://www.kit.nl/4733 or in search4dev.nl.

Last update: Friday 21 December 2012

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Scope

'The stigma is something that kills human beings - sometimes far more than the disease.' (Nelson Mandela)

The main aim of this dossier is to provide information on health-related stigma and its harmful consequences, including discrimination and social exclusion and to provide links to other resources on this topic.

The dossier is a spin-off of the activities of the International Consortium for Research and Action Against health-related Stigma (ICRAAS).

We hope that this Stigma Dossier will contribute to the advance of the fight against stigma by providing knowledge, access to instruments, and, most importantly, to people and organizations with experience in the various aspects of stigma and stigma reduction.If you would like to make any comments on this dossier or suggest additional resources, please contact the editor Ilse Egers.

External links

- [Leprosy statistics - latest data](#)
- [Tuberculosis: Data and country profiles](#)

In-Depth

Text by [Wim van Brakel](#)
Health - Leprosy Unit, Royal Tropical Institute

Stigma related to chronic health conditions such as HIV/AIDS, leprosy, tuberculosis, mental illness and epilepsy is a global phenomenon with a severe impact on individuals and their families, and on the effectiveness of public health programmes. The effects on the affected individual include psychosociological stress and depression, fear, various participation restrictions and increased (risk of) disability and advanced disease. Many negative effects on public health programmes and interventions have been reported, including delay in diagnosis and treatment, resulting in continuing risk of disease transmission in case of infectious diseases and in more severe morbidity and poorer treatment prognosis in most conditions. Concealment may result in continued risk behaviour and failure to embrace preventive behaviour in conditions such as HIV/AIDS and TB, and in poor treatment adherence or default from treatment, as has been reported in leprosy, TB, HIV/AIDS, mental illness and epilepsy. In TB and HIV/AIDS, poor treatment adherence increases the risk of the development of drug resistance.

Despite extensive knowledge regarding the consequences of stigma and discrimination, comparatively little progress has been made in systematically addressing these in public health programmes. Many stigma reduction interventions have been carried out, but their effectiveness is often not known. This is partly because tools to measure the impact have not been available, particularly not in developing country settings. Quite a number of scales and indicator sets have been developed, but usually these have been validated in one health field only. Instruments that could be applied across a range of public health areas would allow assessment of stigma reduction strategies and interventions and comparison between different approaches. In addition, good instruments are essential for stigma research. Fortunately, progress is being made and potentially useful measurement tools have been developed, particularly in the field of HIV/AIDS, mental health, epilepsy and leprosy. These should be field-tested more widely, cross-validated between conditions and applied to measure the effectiveness of the many stigma reduction interventions that are implemented across the world.

In addition to causing untold human suffering and significant barriers to public health programmes, stigma and discrimination violate based human rights. The recent adoption of a UN Convention on the Rights of Persons with Disabilities will be an important tool in the fight against stigma. This is just one example of one 'tool' that can be used for the benefit of people who are affected by many different stigmatized conditions across the world.

We believe there is much to be gained from collaboration and sharing of knowledge, research findings and tools between experts, researchers and programme implementers working with different stigmatized conditions. Despite apparent differences between conditions and cultures in the determinants of stigma, many cross-cutting issues and synergies can be identified. We believe we can learn a lot from each other!This section contains full-text resources on health-related stigma and discrimination. These resources are in the public domain and may be used free of charge, provided the

author and source are acknowledged. Often, they are final draft versions of papers that have been published elsewhere. KIT welcomes further contributions to this section from ICRAAS members or others. These may be submitted to Ilse Egers and should contain a description of the resource and the status with regard to copyright.

KIT's Involvement

Text by Wim van Brakel
Health - Leprosy Unit, Royal Tropical Institute

The Health Department of the Royal Tropical Institute coordinates the activities of the ICRAAS, the International Consortium for Research and Action Against health-related Stigma .

The Consortium was established in November 2004, as an initiative of the participants of the international Research Workshop on Health-Related Stigma and Discrimination, held in The Netherlands. The aim of the ICRAAS is to reduce health-related stigma and its harmful consequences, including discrimination and social exclusion. ICRAAS builds on the existing body of research and implementation experiences of its consortium partners. It aims to deepen understanding of stigma processes and develop measurement tools and stigma reduction strategies through sharing, combining and exchanging knowledge and expertise and through collaborative future research and actions on health-related stigma and discrimination.

ICRAAS Objectives

- Facilitate the exchange of knowledge and expertise on health-related stigma and its consequences between researchers working in different public health fields.
- Stimulate action against health-related stigma and action to promote social inclusion.
- Exchange instruments and toolkits between public health fields.
- Support scientists from the South in studying health-related stigma and its consequences and stigma reduction activities.
- Provide a platform for scientific discussion of issues related to health-related stigma and discrimination.
- Create a multi-discipline forum of scientific excellence in the field of health-related stigma research to guide and monitor research projects carried out under its umbrella.
- Increase the scientific credibility of funding applications to major donor agencies made under the umbrella of the consortium.

SARI Project (Stigma Assessment and Reduction of Impact) - *July 2007*

Research proposal
Many people are severely affected by leprosy-related stigma and social exclusion. This stigma can prove very persistent and disabling and may be experienced as worse than the condition itself. The people effected by leprosy and often also their family members are denied full social acceptance. In many cases, stigma has also a direct impact on their economic situation. Apart from these direct effects on individuals and groups of people, stigma and discrimination often form a major barrier for the effective implementation of leprosy programmes.

Awareness of the importance of health-related stigma is increasing and many projects have gained some experience with stigma reduction activities. However, much of this experience remains local, and the effectiveness and impact of these interventions is not know or measured. The SARI project will examine experiences with stigma reduction strategies such as empowerment, contact, socio economic rehabilitation or other interventions not yet specifically described, used in Community Based Rehabilitation (CBR) programmes.

The impact of these stigma reduction strategies and activities will be evaluated by comparing stigma levels in communities where CBR programmes are operating, with comparable communities that have not benefited from these interventions.

- To document in detail the stigma reduction interventions used.
- To study the effectiveness of strategies and activities in terms of impact on social participation and inclusion.
- To validate a toolkit of existing stigma assessment instruments that can be used for baseline assessments and monitoring and evaluation of stigma reduction interventions in the field of leprosy.

Specific objectives
The study will be carried out with partners in India as a pilot project. The study will involve people affected by leprosy in all aspects of the project. The study will take 24 months and will include four CBR programmes and four control areas without CBR activities. During an expert meeting in September 2007 a selection will be made of instruments to measure the different aspects of stigma (enacted stigma (discrimination), perceived stigma and self or internalized stigma) and its impact on social participation. Both quantitative and qualitative methods will be considered.

Resources

This Quick link is a predefined search and offers access to all KIT Library resources in the field of stigma and health.

Full text documents

2013

- A global HIV stigma reduction framework adapted and implemented in five settings in India
  To support India's National AIDS Control Programme (NACP), ICRW with the United Nations Development Programme (UNDP) has adapted an existing global HIV stigma reduction framework for the Indian context and pilot tested the frameowrk in five settings in India. This report synthesizes the lessons learned from the process, including the feasibility and relevance of the framework for use by the NACP and other global stakeholders in informing stigma reduction interventions and measurement.
  ICRW, STRIVE, UNDP | 2013
- Reducing stigma to improve engagement in HIV care among men who have sex with men
  Men who have sex with men (MSM) are particularly vulnerable to HIV as well as to other physical and psychological health concerns. MSM experience multi-layered stigma and discrimination as a result of their perceived or real HIV status and their same-sex behavior.

Because of social and cultural non-acceptance of their sexuality and fear of being ridiculed, MSM experience internalized stigma, which manifests as guilt, depression, lack of confidence and unwillingness to discuss their sexual lives. This not only influences their mental health but also, combined with enacted or perceived stigma by health care providers, can impede the utilization of health services by MSM. Through a process of research and joint discussion of findings, this project created a foundation for combating stigma at both the individual and institutional levels. It was part of a larger effort to adapt and pilot test a global stigma reduction framework to the Indian context.

The Humsafar Trust

ICRW | 2013

- [Reducing HIV-related stigma among female sex workers](#)
HIV-positive sex workers are a highly marginalized group in India because of their HIV status and because their work is considered immoral and illegal. As a result they experience intersecting stigmas that impede their health and livelihood options. Using a community-based participatory approach, this project aimed to improve the quality of life of HIV-positive female sex workers (FSWs) by addressing the stigma and discrimination they face. The initiative was conducted in Bagalkot and Belgaum districts in north Karnataka and was part of a larger effort to adapt and pilot test a global stigma reduction framework to the Indian context.

Karnataka Health Promotion Trust (KHPT)

ICRW | 2013

- [Longitudinal study of rural health workforce in five counties in China: research design and baseline description](#)
Xu H., Zhang W., Zhang X. et al.
The village doctors have served rural residents for many decades in China, and their role in rural health system has been highly praised in the world; unfortunately, less attention has been paid to the health workforce during the ambitious healthcare reform in recent years. Therefore, we conducted a longitudinal study to explore the current situation and track the future evolution of the rural healthcare workforce. Village doctors in rural China are facing critical challenges, including aging, gender imbalance, low education, and a lack of social protection. This study may be beneficial for making better policies for the development of the health workforce and China's healthcare reform.

Human Resources for Health | May 2013

- [The role of HIV-related stigma in utilization of skilled childbirth services in rural Kenya: a prospective mixed-methods study](#)
Turan J., Hatcher A., Medema-Wijnveen J. et al.
The Maternity in Migori and AIDS Stigma Study (MAMAS Study) is a prospective mixed-methods investigation conducted in a high HIV prevalence area in rural Kenya, in which they examined the role of women's perceptions of HIV-related stigma during pregnancy in their subsequent utilization of maternity services. Findings of this study point to the urgent need for interventions to reduce HIV-related stigma, not only for improving quality of life among persons living with HIV, but also for better health outcomes among all childbearing women and their families.

PLOS Medicine | 2013

- [Perceived discrimination, social support, and perceived stress among people living with HIV/AIDS in China](#)
Su X., Lau J., Mak W. et al.
This study surveyed PLWH recruited from multiple sources in two cities in China. The results highlight the importance to reduce discrimination toward PLWH and the difficulty to alleviate its negative consequences. It is warranted to improve mental health among PLWH in China and it is

still important to foster social support among PLWH as it has direct effects on perceived stress.
AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV | 2013

- [HIV/AIDS-related stigma felt by people living with HIV from Buea, Cameroon](#)
  Jacobi C., Atanga P., Bin L. et al.
  This study measured the HIV/AIDS-related stigma felt by PLWHIV in Cameroon using "The people living with HIV stigma index" questionnaire. In this setting the major problems faced by the PLWHIV with regard to stigmatization and discrimination were gossiping and verbal insults, which was felt by about half of the interviewees. Equally important was internal stigma, half of the PLWHIV felt ashamed and guilty to be HIV infected. This is the first report of this kind in Cameroon.
  AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV | 2013

- [Perception of epilepsy among public workers: Perspectives from a developing country](#)
  Ekenze O., Ndukuba A.
  Health-care workers have better perceptions of epilepsy, but stigma against PWE is still prevalent. Perception of epilepsy and attitudes towards PWE may improve with public enlightenment programs.
  Epilepsy & Behaviour | 2013

2012

- [Quality of life, health-related stigma, and the social context: longitudinal analyses of PLWHA in Uganda and a literature review](#)
  Takada S.
  The dissertation examines the experience of living with stigmatized health conditions in the social context. The first paper examines the dynamic, bi-directional relationship between social support and HIV-related stigma. The second paper examines the trajectory and determinants of health-related quality of life of PLWHA initiating antiretroviral therapy. The third paper is an interdisciplinary review of health-related stigma.

  Harvard University's DASH repository | 2012

- [Mass social contact interventions and their effect on mental health related stigma and intended discrimination](#)
  Evans-Lacko S., London J., Japhet S. et al.
  Stigma and discrimination associated with mental health problems is an important public health issue, and interventions aimed at reducing exposure to stigma and discrimination can improve the lives of people with mental health problems. Social contact has long been considered to be one of the most effective strategies for improving inter-group relations. This study assessed the impact of a population level social contact intervention among people with and without mental health problems. Findings emphasise the importance of facilitating conditions to promote positive social contact between individuals and also suggest that social contact interventions can work on a mass level. Future research should investigate this type of large scale intervention among broader and more representative populations.
  BMC Public Health | 2012

- [How perceptions of HIV-related stigma affect decision-making regarding childbirth in rural Kenya](#)
  Medema-Wijnveen J., Onono M., Bukusi E. et al.
  In this sample of pregnant women in rural Kenya, those who anticipated HIV-related stigma were less likely to have positive attitudes towards facility-based childbirth. Furthermore,

negative attitudes about facility-based childbirth were associated with the intention to deliver outside a health facility. HIV-related stigma reduction efforts might result in more positive attitudes towards facility-based childbirth, and thereby lead to an increased level of skilled birth attendance, and reductions in maternal and infant mortality
PLOS One | 2012

- [Measuring HIV stigma and discrimination](#)
  Stangl A.; Brady, L.; Fritz K.
  This brief is designed to guide researchers in the study of HIV-related stigma and discrimination, either as the main focus of research or as an element within related studies.
  International Center for Research on Women | 2012

- [Population-based study of epilepsy in Cambodia associated factors, measures of impact, stigma, quality of life, knowledge-attitude-practice, and treatment gap](#)
  Bhalla D., Chea K., Hun C. et al.
  Factors in pre- and perinatal period were found to be most crucial for epilepsy risk in Cambodia which inturn provides major prevention opportunities. Mean stigma was mainly related to treatment efficacy. A global action plan for treatment, stigma reduction and improvement of QOL should be set-up in this country.
  PLOS One | 2012

- [The role of HIV-related stigma in utilization of skilled childbirth services in rural Kenya: a prospective mixed-methods study](#)
  Turan J., Hatcher A., Medema-Wijnveen J. et al.
  The Maternity in Migori and AIDS Stigma Study is a prospective mixed-methods investigation conducted in a high HIV prevalence area in rural Kenya. The role of women's perceptions of HIV-related stigma during pregnancy in their subsequent utilization of maternity services is examined.
  Findings point to the urgent need for interventions to reduce HIV-related stigma, not only for improving quality of life among persons living with HIV, but also for better health outcomes among all childbearing women and their families.
  PLoS Medicine | 2012

- [Caring for caregivers of people living with HIV in the family: a response to the HIV pandemic from two urban slum communities in Pune, India](#)
  Kohli R., Purohit V., Karve .L. et al.
  The study explored the perceptions and norms regarding care being provided by family caregivers of PLHIVs in India. Gender related stigma and discrimination existed irrespective of women being the primary family caregivers. The support from marital families indicates a need to explore care and support issues at natal and marital homes of the women living with HIV respectively. Home based care training and respite care for the caregivers is recommended. Gender sensitive interventions addressing gender inequity and HIV related stigma should be modeled while designing interventions for PLHIVs and their family caregivers.
  PLoSOne | 2012

- [Shadow on my heart: a culturally grounded concept of HIV stigma among Chinese injection drug users](#)
  Li X., Wang H., He G. et al.
  Although stigma is a significant barrier to HIV prevention and treatment globally, the culture specific psychosocial processes through which HIV-infected Chinese experience stigma have not been described. This study used grounded theory to explore the social and psychological processes of HIV-related stigma experienced by Chinese injection drug users and proposed a culture-specific concept of stigma.
  J Assoc Nurses AIDS Care | 2012

- [The development of a lay health worker delivered collaborative community based intervention for people with schizophrenia in India](#)
  Balaji M., Chatterjee S., Koschorke M. et al.
  This study aimed to develop a lay health worker delivered community based intervention in three sites in India. The intervention comprised five components (psycho-education; adherence management; rehabilitation; referral to community agencies; and health promotion) to be delivered by trained lay health workers supervised by specialists. The intervention underwent a number of changes as a result of formative and pilot work. While all the components were acceptable and most were feasible, experiences of stigma and discrimination were inadequately addressed.
  BMC Health Services | 2012
- [Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya](#)
  Mbuba C., Abubakar A., Odermatt P. et al.
  The aim of this study was to develop and validate a tool to measure perceived stigma among people with epilepsy in Kilifi, Kenya. The authors reviewed existing scales that measured stigma, particularly of epilepsy. They conducted a qualitative study to determine salient concerns related to stigma in Kilifi. The conclusion of the article is that the Kilifi Stigma Scale for Epilepsy is a culturally appropriate measure of stigma with strong psychometric properties.
  Epilepsy & Behaviour | 2012
- [Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya](#)
  Cuca Y., Onono M., Bukusi E. et al.
  Pregnant women who fear or experience HIV-related stigma may not get care for their own health or medications to reduce perinatal transmission of HIV. This study examined factors associated with anticipating and experiencing HIV-related stigma among pregnant women attending antenatal care clinics in rural Kenya. Over half of the HIV-positive women interviewed postpartum reported having experienced stigma, much of which was self-stigma. Women experiencing minor depression, and those whose family knew of their HIV status had significantly greater adjusted odds of experiencing stigma. Lack of women's empowerment, as well as depression, may be important risk factors for HIV-related stigma and discrimination.
  AIDS CARE | 2012 | pp. 1173-1180
- [Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia](#)
  Feyiss G., Abebe L., Girma E. et al.
  This study was conducted to explore stigma and discrimination against PLHIV amongst healthcare providers in Jimma zone, Southwest Ethiopia.
  BMC Public Health | 2012
- [Coping with HIV related stigma and well-being](#)
  Sanjua´n P., Molero F., Fuster M. et al.
  The goal of this study was to analyze the relationships to be found among stigma perception, active and avoidant coping strategies, and subjective and psychological well-being in a sample of 133 people with HIV. The results showed that stigma perception and avoidant coping strategies (venting, self-blame, denial, behavioural disengagement and substance use) were positively associated, whereas, both stigma perception and avoidant coping were negatively associated with different measures of well-being (affect balance, self-acceptance and environmental mastery).
  Journal of Happiness Studies | 2012 | pp. 1-14
- [Impact of stigma, culture and law on healthcare providers after occupational exposure to HIV and hepatitis C](#)

Zaidi M., Griffiths R., Newson-Smith M. et al.
This qualitative study examined the lived experience of occupational exposure to HIV or hepatitis C reported by four HCPs working in a tertiary care hospital in United Arab Emirates. Findings were based on interviews conducted as part of a larger two-year study investigating an intervention to improve the reporting and management of blood and body fluid exposures in the hospital.
Culture, Health & Sexuality: An International Journal for Research, Intervention and Care | 2012 | pp. 379-391

- HIV and tuberculosis: The construction and management of double stigma
  Daftary A.
  This paper examines the lived experience of TB disease and HIV from the perspective of affected individuals to analyze how they may think about their dual illness; how they understand their illness with TB in relation to HIV, and vice versa; and how they characterize their (stigmatized) experiences in the context of their perceptions and identities.
  Social Science & Medicine | 2012 | pp. 1-8

- The ambivalence of stigma and the double-edged sword of HIV/AIDS intervention in Burkina Faso
  Gausseta Q., Overgaard Mogensena H., Yameogob W. et al.
  This article analyses the causes of HIV stigmatisation in Burkina Faso as perceived by people living with HIV/AIDS and people working in AIDS-related Community Based Organisations. The findings of the study show that moral or social stigmatisation does not in any simple way derive from fear, ignorance or inaccurate beliefs but that it is also established and continually reinforced by official campaigns addressing HIV/AIDS.
  Social Science and Medicine | 2012 | pp. 1037–1044

- Health related quality of life among patients with Tuberculosis and HIV in Thailand
  Kittikraisak W., Kingkaew P., Teerawattananon Y. et al.
  Health utilities of tuberculosis (TB) patients may be diminished by side effects from medication, prolonged treatment duration, physical effects of the disease itself, and social stigma attached to the disease.
  PLoSOne | 2012 | pp. 8

- The burden of knowing: balancing benefits and barriers in HIV testing decisions. a qualitative study from Zambia
  Jürgensen M., Tuba M., Fylkesenes K. et al.
  This study draws on social stigma theory to enhance the understanding of the continuity of HIV related stigma in the presence of ART, and argues that the burden of knowing an HIV status and the related reluctance to get HIV tested can be understood both as a form of label-avoidance and as strong expressions of the still powerful embodied memories of suffering and death among non-curable AIDS patients over the last decades. Hope lies in the emerging signs of a reduction in HIV related stigma experienced by those who had been tested for HIV. Further research into innovative HIV testing service designs that do not add to the burden of knowing is needed.
  BMC Health Services Research | 2012 | pp. 11

2011

- Interventions for stigma reduction – Part 2: Practical Applications
  Cross H., Heijnders M., Dalal A. et al.
  This paper reports the endeavors of the Working Group assigned to develop guidelines for interventions to reduce stigma. One conclusion of the group's deliberations was that a "Stigma

Intervention Matrix" could be a useful guide for cross-checking the development of situation-specific stigma interventions. The Stigma Intervention Matrix is presented in this paper.
Disability, CBR & Inclusive Development | 2011 | pp. 62-70

- People Living with HIV Stigma Index: Asia Pacific Regional Analysis 2011
  This report provides findings from the rollout of the People Living with HIV Stigma Index (PLHIV Stigma Index) in nine countries in Asia and the Pacific (Bangladesh, Cambodia, China, Fiji, Myanmar, Pakistan, Philippines, Sri Lanka, Thailand). It provides the first large-scale regional comparison of standardized HIV-related stigma indicators.
  UNAIDS | 2011

- The stigma of Tuberculosis
  Christodoulou M.
  In the mid-19th century, colloquial names for tuberculosis, such as the white plague, with reference to the pallor common in patients with tuberculosis, and consumption, reflecting the atrophy of an infected body, engendered fear of the disease and those with it. This fear often led to stigmatisation; although the disease is now much better understood, fear and stigma remain and create barriers to effective management. The importance of stigma in relation to tuberculosis control has been emphasised in recent months, with non-governmental organisations, such as Via Libre in Peru, raising awareness of this issue in public health campaigns.
  The Lancet Infectious Diseases | 2011

- Comparing HIV-related symbolic stigma in six African countries: social representations in young people's narratives
  Hubert K., Hubert E., Obyerodhyambo O.
  HIV-related symbolic stigma arises from moralistic value judgements attached to people living with HIV and has negative consequences from both public health and human rights perspectives. Relatively little is known about cross-national variation in symbolic stigma. With the purpose of informing stigma reduction efforts within and across settings, the authors compared social representations of HIV in six African countries with estimated adult HIV prevalence rates ranging from 1 to 33%.
  Social Science & Medicine | 2011

- Dealing with HIV-Related stigma: A qualitative study of women outpatients from the Chris Hani Baragwanath Hospital
  Lekganyane R., Plessis du G.
  The purpose of this study was to explore HIV-infected women outpatients' experiences of stigma and the coping strategies that they devised to deal with it. The elements of stigma and the coping strategies employed as uncovered in this study suggest a basis from which interventions aimed at assisting HIV-infected people to deal with stigma can be planned.
  Journal of the Association of Nurses in AIDS Care | 2011

- Piecing it together for women and girls: the gender dimensions of HIV-related stigma
  Using evidence from the People Living with HIV Stigma Index this publication outlines the gender dimensions of HIV-related stigma in Bangladesh, Dominican Republic and Ethiopia.
  International Planned Parenthood Foundation | 2011

- Labeling of mental disorders and stigma in young people
  Wright A., Jorma A., Mackinnona A.
  Mental disorders are common in young people, yet many do not seek help. The use of psychiatric labels to describe mental disorders is associated with effective help-seeking choices, and is promoted in community awareness initiatives designed to improve help-seeking. However these labels may also be coupled with stigmatizing beliefs and therefore inhibit help-seeking: lay mental health or non-specific labels may be less harmful. The authors examined the

association between labeling of mental disorders and stigma in youth.
Social Science & Medicine | 2011

- Socio-economic status and HIV/AIDS stigma in Tanzania
  Amuri M., Mitchell S., Cockcroft A. et al.
  The level of HIV and AIDS stigma in Tanzania is high with independent associations with several disadvantages: poverty, less education and living in rural areas. Other vulnerable groups, such as survivors of intimate partner violence, are also more likely to have a stigmatising attitude. HIV prevention programmes should take account of stigma, especially among the disadvantaged, and take care not to increase it.
  AIDS Care | 2011

- Stigma and HIV risk among Metis in Nepal
  Wilson E., Pant S., Comfort M., et al.
  This study was conducted to explore the social context of stigma among Metis in Nepal to better understand their risk for HIV. Fourteen in-depth interviews were conducted with Metis in Kathmandu, Nepal. We found that stigma from families leading to rural-urban migration exposed Metis to discrimination from law enforcement, employers and sexual partners, which influenced their risk for HIV.
  Culture Health and Sexuality | 2011

- Social stigma as an epidemiological determinant for leprosy elimination in Cameroon
  Nsagha D., Bissek A., Nsagha S. et al.
  The present study was performed to investigate the role of social stigma as a determinant for leprosy elimination in a leprosy endemic region of Cameroon. The high proportion of positive attitudes among the participants and in different divisions is a positive indicator that the elimination of leprosy social stigma is progressing in the right direction.
  Journal of public health in Africa | 2011

- Perceived stigma among patients receiving antiretroviral therapy: a prospective study in KwaZulu-Natal, South Africa.
  Peltzer K., Ramlagan S.
  The aim of this study is to examine whether internalized AIDS stigma among HIV patients one year after antiretroviral therapy initiation is associated with socio demographic characteristics, health status, social support, quality of life, and ARV adherence.
  AIDS Care | 2011

- Social–cultural aspects of epilepsy in Kilimanjaro Region, Tanzania: Knowledge and experience among patients and carers
  Mushi D., Hunter E., Mtuy C. et al.
  Poor knowledge and strong cultural and religious beliefs characterize the experience of people with epilepsy (PWE) in this population. Epilepsy-related stigma contributes to overall disease burden and PWE face exclusion across major life domains. There is a need to educate communities and inculcate perceptions and attitudes that promote early detection of epilepsy and early care-seeking behavior.
  Epilepsy & Behavior | 2011

2010

Mental illness - stigma and discrimination in Zambia
Kapungwe, A., Cooper, S., Mwanza J. et al.
The aim of this qualitative study was to explore the presence, causes and means of addressing individual and systemic stigma and discrimination against people with mental illness in Zambia. This is to facilitate the development of tailor-made anti stigma initiatives that are culturally sensitive for Zambia and other

low-income African countries. The results from this study underscore the need for greater commitment from governments and policy-makers in African countries to start prioritizing mental illness stigma as a major public health and development issue.
Afr J Psychiatry | 2010

- Roadmap toward an expanded response to HIV stigma and discrimination
  Carr D., Eckhaus T., Brady L. et al
  The paper draws primarily on a rapid scan of the field conducted from May to August 2009 consisting of in-depth interviews with 21 key informants representing networks of people living with HIV. Although there is growing evidence on effective stigma reduction approaches, there is little cost-effectiveness data to help policy-makers prioritize stigma reduction in national plans. While there are tested tools for community and health care settings, their existence is not widely communicated to the field. Moreover, programs lack tools for addressing stigma experienced by multimarginalized groups, such as sex workers and injecting drug users. Although there have been legal reform successes, such as in Nepal and South Africa, greater advocacy is needed to counter discriminatory laws.
  ICRW | 2010
- HIV principles and stigma reduction training curriculum: Addressing HIV and stigma in the healthcare setting in the Middle East and North Africa region
  The purpose of this curriculum is to support a truly sustainable HIV response in the Middle East and North Africa Region, centered on positive leadership, prevention, education, and mentorship, as well as gender equity and sensitivity.

  Measuring the degree of HIV-related stigma and discrimination in health facilities and providers
  This working report presents the findings from an internet-based survey designed to validate the items in the Health Facility and Provider Stigma Measurement Tool. The goal was to assess the validity of items designed to measure the key drivers of stigma. This report may be especially useful to stigma researchers, healthcare workers, healthcare administrators, and evaluators.
  USAID | 2010
- HIV prevention intervention to reduce HIV-related stigma: evidence from China
  Li L., Liang L., Lin C. et al.
  Results of this study: Compared with no change over time for the control group, the intervention successfully reduced the level of HIV-related stigmatizing attitudes among the target population at the 12-month follow-up, and the effect increased by two-fold (with respect to odds ratios) at the 24-month follow-up.
  Aids | 2010
- Mental health and development: targeting people with mental health conditions as a vulnerable group
  Funk M. et al.
  This report presents compelling evidence that people with mental health conditions meet major criteria for vulnerability. The report also describes how vulnerability can lead to poor mental health, and how mental health conditions are widespread yet largely unaddressed among groups identified as vulnerable. It argues that mental health should be included in sectoral and broader development strategies and plans, and that development stakeholders have important roles to play in ensuring that people with mental health conditions are recognized as a vulnerable group and are not excluded from development opportunities.
  World Health Organization | 2010

- [Let's lose the stigma around leprosy. For too long people with leprosy have been pushed to the margins of society because of ignorance about the disease](#)
  Sasakawa, Y.
  At its 15th session, which ended at the beginning of October, the UN human rights council adopted a resolution encouraging governments to eliminate discrimination against people affected by leprosy – and their family members. As the World Health Organisation's Goodwill Ambassador for Leprosy Elimination, I have long campaigned for this outcome.
  Guardian.co.uk | 2010
- [Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis](#)
  Livingston J.; Boyd J.
  The review draws attention to the lack of longitudinal research in this area of study which has inhibited the clinical relevance of findings related to internalized stigma. The study also highlights the need for greater attention on disentangling the true nature of the relationship between internalized stigma and psychosocial variables.
  Social Science & Medicine | 2010
- [We are all in the same boat! Using art and creativity approaches with young people to tackle hiv-related stigma](#)
  This toolkit is a set of ideas on how to use art and creative approaches to build a new understanding about HIV stigma and human rights, and on how young people can work together to challenge stigma and discrimination. The toolkit uses different art forms and creative activities.
  UNICEF | 2010
- [Mental health and development: targeting people with mental health conditions as a vulnerable group](#) (Summary)
  The new WHO report on mental health and development is a call to action to all development stakeholders - governments, civil society, multilateral agencies, bilateral agencies, global partnerships, private foundations, academic and research institutions - to focus their attention on mental health. The report presents compelling evidence that persons with mental and psychosocial disabilities are a vulnerable group but continue to be marginalized in terms of development aid and government attention.
  World Health Organization | 2010

  [Tackling HIV-related stigma and discrimination in South Asia](#)
  Stangl, A.; Carr, D.; Brady, L.
  The findings in this report are based on project monitoring and evaluation data and case studies. According to the researchers the most promising work uses multiple strategies and stakeholders to address stigma, and involving marginalized communities is essential for strengthening capacity, ensuring appropriate messaging, and maximizing results.
  The World Bank | 2010)
- [Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India](#)
  Rahangdale L., Banandur P., Sreenivas A.
  This qualitative study explored the role of HIV-associated stigma as a barrier to access PPTCT services in Karnataka, using in-depth interviews and focus group discussions with HIV-infected women who had participated in the PPTCT program.
  AIDS Care | 2010
- [Perceived discrimination and stigma toward children affected by HIV/AIDS and their HIV-positive caregivers in central Haiti](#)

Surkana P., Mukherjee J., Williams D. et al.
The aim of this study was to identify factors associated with stigma and/or discrimination among HIV-affected youth and their HIV-positive caregivers in central Haiti. Stigma carried out by health care workers, the community, family, and self was isolating; many women felt disclosure of HIV serostatus in order to obtain PPTCT services was not an option.
AIDS Care | 2010

- [Facilitator's guide for training on HIV and AIDS stigma and discrimination reduction](#)
This guide, published by the Christian Council of Ghana and World Association for Christian Communication, is designed to build the capacity of community members to enable them to lead a campaign on stigma reduction in their communities.
The Christian Council of Ghana | 2010

- [Tackling HIV stigma and discrimination in South Asia. Lessons Learned](#).
The findings in this report are based on project monitoring and evaluation data and six case studies conducted by the International Center for Research on Women. Cultural and media approaches were among other aspects found to be an effective means to broach sensitive topics and address drivers of stigma, such as cultural attitudes regarding sexuality.
The South Asia Regional Development Marketplace Partnership | 2008

- [Understanding and challenging HIV stigma toward entertainment workers](#)
Toolkit for action. Adapted version for use in Cambodia.
The toolkit was newly developed for the situation facing entertainment workers in Cambodia, but it is inspired by the ideas and experience of many organizations working to reduce stigma, and it draws on materials and ideas from other manuals on this subject.
USAID, ICRW, Pact | 2010

[Social discrimination against Men who have Sex with Men. Implications for HIV Policy and Programs](#)
This policy brief is an overview of social discrimination against gay men and other men who have sex with men (MSM) as it relates to HIV, and includes recommendations for concerted action and policy development. A review of literature that demonstrates the linkages between homophobia and vulnerability to HIV disease is presented with related examples.
MSMGF | 2010

- [Understanding and challenging stigma toward men who have sex with men. Tookit for action](#)
The toolkit was developed to address the situation facing MSM in Cambodia, but it is inspired by the ideas and experiences of many organizations working to reduce stigma.
USAID | 2010

- [Antiretroviral therapy and Reproductive Life Projects: Mitigating the stigma of AIDS in Nigeria](#)
Smith D.; Mbakwem B.
This article explores the reproductive life projects of HIV-positive men and women in southeastern Nigeria. For people who are HIV-positive, marrying and having children offer not only the opportunity to lead normal lives, but also a means to mitigate the stigma associated with the disease.
Social Science & Medicine | 2010

- [Perceived HIV stigma among children in a high HIV-prevalence area in central China: beyond the parental HIV-related illness and death](#)
Lin X., Zhao G. et al.
This article is about communitywide stigma reduction and the fact that psychological support should be part of the care efforts for children affected by AIDS. Stigma reduction efforts should not only target the stigma against PLWHA but also possible stigma against the entire community

(e.g., villages) with a high prevalence of HIV/AIDS.
AIDS Care | 2010

- [Modelling the impact of stigma on HIV and AIDS programmes: Preliminary projections for mother-to-child transmission](#)
Watts C., Zimmerman C., Eckhaus T. et al.
This analysis employs a mathematical model to project the impacts of stigma on service use and infant infections under different scenarios, including varying levels of stigma, HIV prevalence among women accessing antenatal care services, and health system capacity.
ICRW | 2010

[The relationship between HIV testing, stigma, and health service usage](#)
Young S., Bendavid E.
The authors explore whether HIV stigma is associated with seeking to conceal testing interest. According to the authors this is the first study to attempt to use observational data on health service usage for assessing stigma and people's attempts to deal with HIV testing stigma.
AIDS Care | 2010

- [Stigmatizing attitudes and behaviors toward PLHA in rural China](#)
Sullivan S., Xu J. et al.
The purpose of this study was to examine factors associated with HIV stigma in a rural Chinese community. A survey was conducted in north-west Anhui province to assess HIV-related knowledge, attitudes, and behaviors.
AIDS Care | 2010

- [AIDS stigma as an obstacle to uptake of HIV testing: evidence from a Zimbabwean national population-based survey](#)
Sambisa W., Curtis S. et al.
One of the conclusions of this article is that programmatic strategies aimed at increasing HIV testing uptake should consider reducing stigma toward people living with HIV/AIDS and also addressing the role of agency and structure in individual's decision to be tested for HIV.
AIDS Care | 2010

- **2009**
[Gender and community views of stigma and tuberculosis in rural Maharashtra, India](#)
Atrea S., Kudalea A., Morankar S. et al.
Stigma associated with tuberculosis is often regarded as a barrier to health seeking and a cause of social suffering. Stigma studies are typically patientcentred, and less is known about the views of communities where patients reside. This study examined community perceptions of TB-related stigma.
Global Public Health | 2009

- [Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review](#)
- [Perceived HIV stigma and life satisfaction among persons living with HIVinfection in five African countries: A longitudinal study](#)
- [Lepra News. Focus on: Fighting discrimination in Brazil](#)
- [HIV-related stigma and discrimination: A summary of recent literature](#)
- [Mediators of HIV-related stigma and risk behavior in HIV infected young women](#)
- [Stigma, social support, and depression among people living with HIV in Thailand](#)
- [Mental health and HIV/AIDS](#)
- [Gender, race/ethnicity, and social class in research reports on stigma in HIV-positive women](#)
- [Religion and HIV in Tanzania: influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes](#)
- [HIV stigma and missed medications in HIV-positive people in five African countries](#)

- Psycho-social impact and quality of life of people living with HIV/AIDS in South India
- Associations Between Social Capital and HIV Stigma in Chennai, India: Considerations for Prevention Intervention Design
- Psychotherapy as a treatment modality for psychiatric disorders: Perceptions of general public of Karachi, Pakistan
- Community-Based Rehabilitation (CBR) & Leprosy, International Workshop Report
- HIV and AIDS, stigma and AIDS support groups: Perspectives from women living with HIV and AIDS in central Thailand
- Care and secrecy: Being a mother of children living with HIV in Burkina Faso
- Development of a Yemeni AIDS Stigma Scale
- Assessment of changes in knowledge and stigmatization following tuberculosis training workshops in Taiwan
- HIV related stigma in the Netherlands
- A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings
- Video stories help health workers learn about the stigma of HIV/AIDS
- Understanding and challenging TB stigma. Toolkit for action
- A Human Rights-Based Approach to Neglegted Tropical Diseases
- HIV Stigma and Nurse Job Satisfaction in Five African Countries

2008

- Rethinking Theoretical Approaches to Stigma: A Framework Integrating Normative Influences on Stigma (FINIS)
- HIV/AIDS related stigma in Kumasi, Ghana
- Living on the outside: The impact of diabetes-related stigma
- Marring Leishmaniasis: The Stigmatization and the Impact of Cutaneous Leishmaniasis in Pakistan and Afghanistan
- Trauma, mental health, distrust, and stigma among HIV-positive persons: Implications for effective care
- The stigmatization of leprosy in India and its impact on future approaches to elimination and control
- Inclusion of persons affected by leprosy in community based rehabilitation
- Global trends in disability rehabilitation and their implications for leprosy programmes
- Epilepsy in Lao PDR: From research to treatment intervention
- Changes in stigma among a cohort of people on antiretroviral ttherapy: Findings from Mombasa, Kenya
- Tackling tuberculosis patients' internalized social stigma through patient centred care: An intervention study in rural Nicaragua
- Part-time hospitalization and stigma experiences: a study in contemporary psychiatric hospitals
- Fighting the stigma caused by mental disorders: past perspectives, present activities, and future directions
- Help-seeking behaviour for sexual-health concerns: A qualitative study of men in Zimbabwe

2007

- Resisting a stigmatized identity: Patients' strategies for the management of the HIV/AIDS stigma in a public hospital in Uruguay
- Stigma, gender, and their impact on patients with tuberculosis in rural Bangladesh

- [Social representations of tuberculosis: Stigma an prejudice](#)
- [Technical guide on community-based rehabilitation and leprosy](#)
- [Stigma: Formulating concepts and priorities for a public health agenda](#)
- [Barriers to accessing tuberculosis services in rural Gambia](#)
- [Culture and stigma: Adding moral experience to stigma theory](#)
- [Epidemic of Inequality. Women's rights and HIV/AIDS in Botswana & Swaziland](#)
- [Understanding and challenging HIV stigma. Toolkit for action](#)
- [Measuring the degree of stigma and discrimination in Kenya](#)
- [UN Position Paper Stigma and Discrimination](#)

KIT Library Queries
[Health-related Stigma](#)

Websites

- [International Centre for Research on Women (ICRW)](#)
- [Chicago Consortium for Stigma Research](#)
- [John Fogarty International Center for Advanced Study in the Health Sciences](#)
- [HIV/AIDS Anti-Stigma Initiative](#)
- [Siyam'kela: Measuring HIV/AIDS related Stigma](#)
- [ILEP - International Federation of Anti-Leprosy Associations](#)
- [The Open Society Mental Health Initiative](#)
- [Source International Information Support Centre](#)
- [Lepra Society Health in Action](#)
- [HIV and AIDS discrimination and stigma](#)
- [Global Project on the History of Leprosy](#)
- [People Living with HIV Stigma Index](#)
- [Casa de Bacurau](#)
- [TropIKA.net](#)
- [Global Initiative on Psychiatry](#)
- [The Leprosy Mission International](#)
- [Lepra Health in Action](#)
- [INFOLEP Leprosy Information Services - Library Catalogue](#)

Glossary

Discrimination
Unjustifiably different treatment given to different people or groups (Manse & Thompson (eds.) 1999, Combined Dictionary Thesaurus. Edinburgh, Chambers). Any measure entailing a distinction among persons depending on their confirmed or suspected health status (Carael et al., 2002).

Enacted stigma
Actual experiences of discrimination

Indicator
An indicator is the measure used to assess if an objective has been achieved or what progress has been made

Participation restriction
Problems an individual may experience in involvement in life situations
ICF, WHO | 2001

Perceived or felt stigma
The fear of being discriminated against
Siyam'kela | 2003

Self or internalized stigma
The devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself
Corrigan | 1998

Stereotype
The belief that all members of a group possess the same characteristics or traits exhibited by some members of that group

Stigma
1. A social process that exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them
Link and Phelan
2. A social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition
Weiss and Ramakrishna