LEPROSY (HANSEN'S DISEASE) AND STIGMA

AN ANNOTATED BIBLIOGRAPHY

Compiled by Lesley Jo Weaver
Emory University, Atlanta, USA
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IDEA & The Innovia Foundation

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http://www.morhan.org.br/
Official website of the Movement to Reinsert People Afflicted with Hansen's Disease (MORHAN). Founded in 1981 by Francisco Augusto Vieira Nunes and colleagues (see this website for his brief biography: http://www.casadebacurau.com.br/en/nav.html), the organization has dedicated its work to fighting stigma. The website is in Portuguese.

http://www.smhf.or.jp/e/outline02.html
A portion of the Sasakawa Memorial Health Foundation's website, this link directs you to the first of three pages that comprise an overview of the socio-economic aspects of Hansen's disease and SMHF's activities surrounding stigma alleviation and reintegration.

http://www.nippon-foundation.or.jp/eng/leprosy/index.html
This is the official website of the Nippon Foundation, a Japanese organization that has been working on leprosy elimination since 1974. Through the Sasakawa Memorial Health Foundation, the Nippon Foundation partnered with WHO in the 1980s to develop and disseminate multi-drug therapy (MDT) for Hansen's disease. The chairman, Yohei Sasakawa, has served as WHO's Goodwill Ambassador for Leprosy Elimination since 2001. The foundation currently focuses on social education programs aimed at eliminating discrimination. The site also contains its own mini-database of articles organized into five categories: Action by the Chairman, The Global Appeal, Events in the World of Leprosy, The Work of the Nippon Foundation, and Articles that have Appeared in Outside Media.

http://www.idealeprosydignity.org/
This is the website of the International Association for Integration, Dignity, and Economic Advancement. The organization's leadership team is comprised primarily of individuals who have themselves faced the challenges of leprosy. Information on IDEA's Global Campaign to Eliminate the Stigma (begun in 2003) can be found here, along with IDEA newsletters and information from The Oral History Project which presents the voices of people who have had leprosy, past and present, as an important means of challenging stigma.

http://www.leprosyhistory.org/
This is the website of the International Leprosy Association's Global Project on the History of Leprosy, an archival project that contains comprehensive searchable databases of the following resource types: archives around the world with materials on leprosy, leprosaria around the world, research institutions that address leprosy, individuals who have worked with or experienced leprosy themselves, a searchable-by-year timeline of developments in the treatment of leprosy, and finally a general timeline of events related to leprosy around the world.

http://www.hansensdisease.org/
This is the website of the group Support for People with Hansen's Disease/Leprosy, established in 2001 as a therapeutic effort by a woman with leprosy with the assistance of IDEA. It has grown into a support network for people with Hansen's disease, their families, and their friends. It also has links to personal stories of people with HD, facts about HD, and a place for medical referrals.

http://www.hrsa.gov/hansens/museum/default.htm
Website of the National Hansen's Disease Museum in Carville, Louisiana. According to the website, "The museum's mission is to collect, preserve and interpret the medical and cultural artefacts of the Carville Historic District and to promote the understanding, identification and treatment of Hansen's Disease (leprosy) by creating and maintaining museum displays, travelling exhibits, publications and a Web site in order to educate and inform the public." The site has information about the museum's exhibits and collections, as well as visitor information and volunteer opportunities.

http://www.kit.nl/smartsite.shtml?ch=FAB&id=7641
This is the official website of the International Consortium for Research and Action Against health-related Stigma (ICRAAS), an organization within the Netherlands' Royal Tropical institute (KIT). Established in 2004, the consortium grew out of a conference held in the Netherlands. At the bottom of the page is a research link, which houses some 1,765 documents and announcements about stigma-related articles from the news, websites, research progress reports, project descriptions, products and services, etc. There are also links to KIT's newsletter, library, and publications.

www.kalaupapaohana.org
The website of Ka 'Ohana O Kalaupapa, a Hawaiian social action organization dedicated to safeguarding the residence and promoting the dignity of every individual exiled to Kalaupapa peninsula since 1866. The organization's main mission is to ensure that state and federal laws protect patients so that they can live out their lives in Kalaupapa with access to the support and services they need, and the group is also working on construction of a monument and a genealogy. The site includes personal stories of Kalaupapa residents and historical photographs.

www.thestar.info/index.htm
This is the website of *The Star*, a journal published by current and ex-residents of Carville. The publication has been in existence for 60 years and is still being produced. This site contains the history of the publication, PDF copies of early editions, information about leprosy, links to related sites, and short biographies of the "colorful characters of Carville," many of whom have written autobiographies listed in this database. See http://www.thestar.info/star_PDF.htm
for PDFs of some of the earliest issues.

Moloka'I Kalaupapa: the people, the place, the legacy [motion picture, 60 minutes]. Mariposa, CA: Panorama International Productions. Pearl Harbor: Arizona Memorial Museum Association.
Here in the beauty of a tropical Eden is a place once dark with pain, anger and fear; a community where strangers were constant companions and civilization was a millennium away. This is the story of the people of Moloka'I, of their ongoing courage and hope, their history, and their experiences that have made Kalaupapa the special place that it is. It also explores the legacies of Father Damien, Brother Dutton, and Mother Marianne, who promoted a philosophy that was later adopted as the foundation of the global hospice movement. Available from Amazon.com.

Keywords: film, documentary, leprosy, Hawaii, Molokai, Kalaupapa, history, hospice

Anonymous. 2004. Report of the research workshop on health-related stigma and discrimination. Amsterdam: Royal Tropical Institute.
This is the official report of the conference that led to the development of the International Consortium for Research and Action Against health-related Stigma (ICRAAS). It contains sections on development of a model of health-related stigma, measurement of stigma, and interventions for stigma reduction.

Keywords: report, conference, ICRAAS, stigma, measurement, model, intervention

Anderson J and Harrison L (directors). 1999. Secret people: the naked face of leprosy in America [58-minute motion picture]. Boston: Fanlight Productions.
During the height of fears over AIDS, some "extremists" argued that people with such diseases should be forcibly isolated from the rest of the population. Most of us said, "That could never happen here." But once, and not all that long ago, it did. From the 1920's to the late 1950's United States citizens with leprosy were forcibly transported to Carville, America's last leprosarium. Abandoned by family and friends, stripped of their constitutional rights to vote, to get married and bear children, even to use the telephone, many of Carville's "residents" nonetheless accomplished the remarkable act of transforming their prison into a home. *Secret People* tells a story of outrageous discrimination and stigma in our public health system, interwoven with a haunting and bittersweet chronicle of human courage and perseverance. Copies of the film are available from: http://www.fanlight.com/catalog/films/276_sp.php.

Keywords: leprosy, film, documentary, America, USA, Carville, history, stigma, discrimination

Arboleda-Florez J. 2002. What causes stigma? World Psychiatry 1(1):25-26.
This article provides a brief theoretical overview of the concepts of stigma, prejudice, and discrimination. It identifies two key elements of stigma: the ‘mark’ of difference, and the subsequent devaluation of the person. It also discusses the difference between public stigma and self-stigmatization. The article primarily deals with the stigma of mental illness; however, its insights are applicable to any type of stigma experience.

Keywords: Stigma, prejudice, mark, self-stigmatization, mental illness, mental health

Awofeso N. 1992. Appraisal of the knowledge and attitude of Nigerian nurses toward leprosy. Leprosy Review 63(2): 169-172.
The attitudes of nurses toward leprosy are studied in this paper. The findings show that their knowledge of leprosy is lacking and that they also fear leprosy. This study recommends that leprosy should be included in the basic nursing curriculum in order to increase awareness and to decrease the stigma of leprosy.

Keywords: leprosy, stigma, Nigeria, nurses, knowledge, fear, education

Bainson KA, Van den Borne B. 1998. Dimensions and process of stigmatization in leprosy. Leprosy Review 69(4): 341-350.
Leprosy has struck fear into human beings for thousands of years. This is partly because it causes considerable deformities and disabilities. In 1991, the 44th World Health Assembly adopted a resolution to eliminate the disease as a public health problem by the year 2000. However, one of the major obstacles to achieving this objective is the stigma associated with the disease. Stigma against leprosy patients affects all aspects of leprosy control. This paper describes a model of the

stigmatization process in leprosy. The process of stigmatization can be divided into two stages. The first stage describes how certain cognitive dimensions of leprosy lead to a variety of affective responses towards the disease. The second stage involves how these affective responses contribute to social devaluation of the leprosy patient and, consequently, the adoption of negative behaviours towards them.

Keywords: leprosy, stigma, social model

Barkataki P, Kumar S, Rao PSS. Knowledge of and attitudes to leprosy among patients and community members: A comparative study in Uttar Pradesh. Leprosy Review 77(1):62-68.
The roles of literacy and gender in enhancing help seeking behaviour in leprosy need further research in order to maximize the effectiveness of health education programmes. A study on leprosy knowledge and attitudes was carried out in Uttar Pradesh on a random sample of 130 leprosy patients, 120 non-leprosy patients, and 150 community members. Almost everyone in the three groups knew of leprosy, but only a larger proportion of leprosy patients (60%) mentioned anaesthetic patch, as compared to about 20% or less in the other groups. A vast majority in all groups mentioned bad blood, or divine curse as the cause. Even among leprosy patients, less than 10% of illiterates and only about 40% of literates cited infection as the cause of leprosy. However, almost all stated that leprosy was curable, though they couldn't mention MDT specifically. They felt that not all patients need have deformity. Nearly 70% felt that leprosy affected social participation, over 90% attributing this to adverse social stigma. Multivariate analyses, adjusted for sex, confirmed the significant association of literacy with both knowledge and attitudes. In the light of massive health education and IEC campaigns, the findings from this study are disappointing. Adult literacy programmes combined with more innovative focused approaches to suit various target audiences can impact knowledge and attitudes better.

Keywords: India, knowledge, attitudes, leprosy, help-seeking

Barrett R. 2005. Self-mortification and the stigma of leprosy in northern India. *Medical Anthropology Quarterly,* 19(2): 216-230.
This article examines the bio-cultural dynamics of social discrimination and physical disfigurement among people with leprosy, or Hansen's disease (HD), in Banaras, northern India. Based on the narratives and observations of people living in colony and street settings, I trace three destructive processes by which the social stigmata of leprosy become physically expressed. First, strategies of concealment further the progression and spread of HD through late detection and under-treatment. Second, the internalization of stigma can lead to bodily dissociation and injury through self-neglect. Finally, some people intentionally seek injuries under conditions of desperate poverty. As a result of such mortification processes, these people came to embody, quite literally, the prejudices that exacerbated their condition in the first place.

Keywords: leprosy, stigma, disability, India

BBC (British Broadcasting Corporation) MPM Ltd. 1998. A Report on the baseline survey of the leprosy elimination campaign. Bush House Strand London WC 2B 4PH, London, UK.
This is a report based on quantitative survey conducted by New Era, Kathmandu, Nepal and submitted to the BBC. The data capture different dimensions of public perceptions about leprosy, including general awareness about the disease; its nature, etiological factors, perceptions about treatment; and attitude of the community towards leprosy patients. Based on the quantitative

findings, report also includes some suggestions for the treatment and destigmatization of the leprosy patients.

Keywords: Nepal, leprosy, elimination, perception, public, stigma, destigmatization

Bekri W, Gebre S, Mengiste A, Saunderson RP, Zewge S. 1998. Delay in presentation and start of treatment in leprosy patients: A case-control study of disabled and non-disabled patients in three different settings in Ethiopia. International Journal of Leprosy and Other Mycobacterial Diseases 66(1): 1-9.

The delay incurred by leprosy patients between the onset of symptoms and the start of treatment has not been well characterized. Because reducing this delay is likely to be the most productive of all activities aimed at preventing disability, we compared the various components of delay in disabled and nondisabled new leprosy cases in a case-control study. Disabled patients had a median overall delay of 26 months, while nondisabled patients incurred a delay of only 12 months. The total delay was divided into three components: a) the delay between the onset of symptoms and the first act of health-seeking behaviour, which was significantly longer for disabled patients; b) the delay between the first action and the first visit to a recognized clinic, which was also significantly longer for disabled patients; and c) the delay between the first clinic visit and the start of treatment, which was significant in some cases. The study compared two rural areas of Ethiopia, one with high and one with low rates of disability in new cases. High rates of disability were thus associated with high levels of stigma, being from the Christian rather than the Muslim community, and the use of traditional medicine. There was, surprisingly, no association with knowledge about the transmission, symptoms and curability of leprosy. Implications for health promotion activities are discussed.

Keywords: leprosy, treatment delay, treatment seeking, Ethiopia, disability, stigma, religion, traditional medicine

Blackburn J. 2000. The leper's companions: a novel. New York: Vintage.

This is a magico-historical novel about a grieving woman who travels back in time to a village in the year 1410. The novel tells the stories of disastrous events that occur in this year of the village's life, all of which begin when a mermaid washes up on a nearby beach. Subsequently, a child is born with a fish's head, a cow dies, and a mysterious blindness spreads through the village. A woman is beset by devils; a blind shoemaker goes mad when his sight is restored; a person with leprosy is miraculously cured; a young widow eats a map and is filled with longing for faraway lands. All, including the narrator, eventually embark on a long and arduous pilgrimage to Jerusalem, from which only two will return. [Synopsis compiled from reviewer Alix Wilber's text on Amazon.com]

Keywords: leprosy, novel, cure, fiction

Brandsma JW, Schwarz RJ, Anderson AM, Herm FB. Transformation of a leprosy hospital in Nepal into a rehabilitation centre: The Green Pastures Hospital experience. Leprosy Review 76(4):267-276.

Green Pastures Hospital for leprosy patients in Pokhara Nepal, was established in 1957 by the International Nepal Fellowship (INF) in a decade which saw the establishment of many similar hospitals in other leprosy endemic countries. This paper describes the process of 'transformation' of an established and well known leprosy hospital in Western Nepal from 1997 onwards into a general rehabilitation hospital. Careful preparation, with full involvement of existing staff and co-operation with other agencies in the hospital catchment area were key factors in what has now become a successful venture. Surgical procedures and orthopaedic appliance services for non-leprosy affected persons have increased in recent years and the introduction of a dermatology service has resulted in out-patient attendance rising from about 1000 in 1999 to 4500 in 2003. Many of the changes described have been made in order to reduce financial dependence on donor sources of support, but the underlying reason for transformation is still based on the vision of the INF mission to work for and improve the condition of the marginalized in society.

Keywords: International Nepal Fellowship, hospital, leprosy, Nepal, facilities, experience

Breitha OR. 1991. Olivia: my life of exile in Kalaupapa. Hawaii: Arizona Memorial Museum Association.
In 1934, at the age of eighteen, the life of Olivia Robello Breitha was radically changed when she was diagnosed with what would later be called Hansen's Disease. In this, her life story, Olivia has tried to put in writing her thoughts and the events of her life.

Keywords: leprosy, Hawaii, Kalaupapa, autobiography

Briden A. 2003. An assessment of knowledge and attitudes towards leprosy/Hansen's disease amongst healthcare workers in Guyana. Leprosy Review 74(2):154-162.
This study, set in Guyana, aims to assess attitudes, ideas and knowledge of the disease amongst healthcare workers. A self-completing questionnaire was designed and distributed amongst healthcare workers in both Georgetown Central Hospital and Suddi Hospital over a 4-week period in September 2000. They showed that knowledge of the disease was relatively good, but that certain facts were not widely known. For example, half the respondents did not know that leprosy is now curable; many thought it could be transmitted through touch. Although most respondents did not display prejudice in their own responses, many implied that prejudice, was still present in the wider community. A significant minority believed that patients should be kept apart from other people. It is evident from the study that some prejudices and misconceptions still exist. In order to reduce this, an emphasis needs, to be placed on education regarding transmission and the low rate of infectivity of leprosy; that it is not spread by touch and is now curable, also that, if treated in the early stages, it has a very good prognosis. It is these areas which health education should focus upon.

Keywords: leprosy, Guyana, stigma, attitudes, health workers, prejudice, misconception

Brown W. 2006. Can social marketing approaches change community attitudes towards leprosy? Leprosy Review 77(2):89-98.
This essay explores how the concept of social marketing can be employed to change attitudes towards leprosy. Firstly, the concept of social marketing is discussed, then the attitudes that people have about leprosy, the stigma that people with leprosy and their families may face, and the detrimental effects that this can have on their lives. The effect of knowledge and education on attitudes towards leprosy is discussed, as this can be a key component of social marketing campaigns. Various methods of social marketing used to change attitudes and reduce stigma are examined, such as mass media campaigns, school based education, methods which involve community leaders, and the integration and improvement of leprosy services. The success of the social marketing campaign in Sri Lanka is described, which aimed to remove the fear of leprosy,

and to encourage patients to seek and comply with treatment. Finally, it is argued that social marketing, used correctly, can be highly effective at changing community attitudes towards leprosy, reducing stigma and improving the lives of patients, who become able to seek treatment sooner as they lose their fear of stigmatization.

Keywords: Northwestern Botswana, knowledge, India, Nepal implementation, transmission, integration, Bangladesh, campaigns, smoking

Buckingham, J. 2002. Leprosy in colonial South India: Medicine and confinement. London: Palgrave Macmillan.
This book is not only a history of a disease, it is also a history of colonial power in 19th-century British India as seen through the lens of British medical and legal encounters with leprosy and its sufferers. The book offers a detailed examination of the contribution of leprosy treatment and legislative measures to negotiated relationships between indigenous and British medicine and the colonial impact on indigenous class formation, while asserting the agency of disadvantaged classes of people with leprosy in their own history.

Keywords: leprosy, history, British, legislation, politics, colonialism, class

Butlin, C. R. 2003. Nepal Network of Leprosy NGOs. Leprosy Rev 74: 163-166.
In Nepal, several Non Governmental Organizations have been assisting the government in implementation of the National Leprosy Elimination Program (NLEP), but working independently in different geographical areas with very little interaction. This article describes how they developed a forum for discussion and mutual support, which led to more effective cooperation with the government authorities.

Keywords: NGO, leprosy, Nepal, networks, policy, elimination

Castillo S, Marra D (directors). 1992. Simple courage: an historical portrait for the age of AIDS [60 min television program]. Santa Monica: Blue Rider Films.
This Emmy Award-winning documentary, originally produced for Hawaiian Public Television, chronicles the treatment of leprosy victims in Hawaii in the 19th and early 20th century, when more than 8,000 sufferers were banished to an isolated peninsula on the island of Molokai. One man, however, took it upon himself to bring comfort to these hopeless people. He was Father Damien, a Catholic missionary from Belgium, who spent 16 years caring for the "untouchables" until he himself succumbed to the disease. He transformed their prison into a place of decency and respect. Using archival footage and moving interviews with survivors from the '30s and '40s, *Simple Courage* shows the emotional pain of banishment from their ancestral homes added to the ravages of the disease. Details Hawaii's tragic handling of its leprosy epidemic and the modern-day application of this history for this age of AIDS.

Keywords: documentary, leprosy, Hawaii, Emmy, film, Father Damien, history, banishment, exile, AIDS

Chaturvedi SK, Singh G, Gupta N. 2005. Stigma experience in skin disorders: An Indian perspective. Dermatologic Clinics 23(4):635.
Dermatologic disorders generally have a major impact on patients' daily activities, psychologic and emotional state, and social relationships. The intensity of impact of skin disease on an individual person is extremely variable, however, and depends on natural history of the disorder; the patient's demographic characteristics, personality, character, and value; the patient's life situation; and the attitudes of society. Social stigma toward dermatologic disorders in the Indian society is quite widespread, especially toward leprosy. Dermatologists are expected to consider quality of life issues along with social aspects, nature of disorder, efficacy, and tolerability of various therapeutic options to optimize relief and comfort to their patients.

Keywords: leprosy, psychiatric morbidity, gender differentials, vitiligo, psoriasis, attitude, life

Chen SM, Chu TS, Want QH. 2005. Qualitative assessment of social, economic and medical needs for ex-leprosy patients living in leprosy villages in Shandong Province, The People's Republic of China. Leprosy Review 76(4):335-347.
After successful control of the endemic of leprosy in Shandong Province, China, how to deal with ex-leprosy patients living in the leprosy villages/leprosaria has become a hot topic among programme managers, medical staff and governmental officials at different levels. One of the possible solutions in dealing with the problem was proposed to combine small leprosy villages into a few larger, already existing, leprosaria/leprosy villages with better facilities, in order to provide better care for ex-leprosy patients and make better use of existing resources. With this assumption, social, economic and medical needs felt by ex-leprosy patients in three leprosy villages of Shandong province were assessed qualitatively, and the possibilities and obstacles regarding combination were explored. The results showed that the basic needs for living, such as food and clothes, were provided by state governments, although living standards remained at a low level. Medical care was not satisfactory, as many health problems related and unrelated to leprosy were increasing, and self-care needed to be addressed, as the dependents grew older and the disability status became worse. Although the majority of ex-leprosy patients, medical staff and government officials interviewed agreed with the idea of the adjustment of leprosy villages/leprosaria, some obstacles, including stigma, existed. Government commitment, ideally at top level, was needed in order to facilitate the process of combination.

Keywords: collaborative project, prevention, services, Nepal

Cross H, Choudhary R. 2005. STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal. Leprosy Review 76(4):316-324.
This paper focuses primarily on the extent to which a Stigma Elimination Programme (STEP) affected the social participation of people affected by leprosy in southern Nepal. The Participation Scale (popularly known as The P Scale) was applied to compare leprosy affected people who participated in STEP groups with a control group comprising leprosy affected people who lived in villages where STEP had not been implemented. It was found that STEP participants had significantly higher levels of participation compared with controls and that their levels of social participation were higher than would be expected even for the general population. It was also found that leprosy affected people without visible deformity or ulceration (whether in the STEP group or not) do not appear to suffer participation restriction in southern Nepal.

Keywords: leprosy, Nepal, intervention, stigma reduction

Deacon HJ. 2003. Patterns of exclusion on Robben Island, 1654-1992. In: C. Strange and A. Bashford (eds.) Isolation: Places and practices of exclusion. New York: Routledge, pp.153-172.

Robben Island, a small island about 10 km off the coast of Cape Town, South Africa, has since the 16th century been a place of exile for political dissidents (perhaps most famously Nelson Mandela, who was imprisoned there between 1964 and 1982), criminals, people and animals under quarantine, sex workers, 'lunatics', 'lepers', and black and female military trainees. After South Africa's 1994 democratic transition, the island was recast as a site of nation-building and a symbol of national reconciliation. This book chapter examines Robben Island as both a geographically isolated entity and a symbolic container for broader political discourses of exclusion in South Africa.

Keywords: Robben Island, leprosy, South Africa, politics, race, exclusion

Deacon HJ. 1994. Leprosy and racism at Robben Island. In: van Heyningen E, ed. Studies in the history of Cape Town 7: 45-83.

In the 19th century, the global social impact of leprosy was considerable, and the South African response to leprosy control lay on the extreme end of the spectrum, with compulsory legal segregation for all lepers. This paper, which has a limited focus on the major leper asylum on Robben Island between 1846 and 1931, sketches the social history of leprosy in the Cape during the latter half of the 19th century. It discusses the way in which racism and the perception and treatment of those suffering from leprosy were linked during the 19th century. The particularly severe segregatory response to leprosy at the Cape was based on a recognition of the special colonial 'problem' in having a large number of black lepers who were seen both as particularly susceptible and particularly irresponsible. Racism affected the colonial reaction to leprosy, as it also increasingly affected the position of black and white lepers on Robben Island. The use of segregation or quarantine for medical reasons (with racist undertones) was closely linked to the rising social segregation in Cape Town (on a racial basis).

Keywords: Roben Island, leprosy, asylum, social history, race

Deacon HJ. 1994. The politics of race, madness, and disease: a history of the medical institutions on Roben Island, Cape Colony, 1846-1910 [unpublished thesis]. Oxford: The Queen's College.

This book investigates the relationship between medicine and society in a colonial context, providing a case study in the social history of medicine. It analyses the changes brought about in British medical theories and practices when they were brought within the ambit of social power relations in the Cape Colony. Using the records of the Robben Island General Infirmary, the thesis focuses on medical ideas and practices surrounding the treatment of the poor, the insane and the leprous in the Cape between 1846 and 1910. Criticisms of the 'lunatic' asylum prompted the introduction of 'moral management' reforms in the 1860s. All white 'lunatics' were removed by 1913. The staff on Robben Island remained exclusively white however, with a substantial proportion of males, in contrast to developments in 'leper' hospitals and 'lunatic' asylums on the mainland. The resultant expense of running the institutions, and the decline in local cases of leprosy, encouraged the closure of the 'lunatic' asylum in 1921 and the 'leper' hospital in 1931. See especially Chapter 6, "Leprosy, racism, and segregation".

Kewords: leprosy, Robben Island, thesis, social history of medicine, politics, race, mental health, mental illness

El Hassan LA, Khalil EAG, El-Hassan AM. 2002. Socio-cultural aspects of leprosy among the Masalit and Hawsa tribes in the Sudan. Leprosy Review 73(1): 20-28.
Social and cultural factors influencing knowledge, attitudes and practices (KAP) towards leprosy in two communities in eastern Sudan were studied to determine their effects on treatment seeking and compliance. The study was qualitative using focus small group discussions, personal interviews and direct observation. Knowledge about the pathological cause of leprosy was lacking but the clinical manifestations were well recognized, particularly among the Masalit, in whom the disease is more common than the Hawsa. Between both tribes, the stigma of leprosy was not strong and the degree of rejection was more towards those with severe disease, particularly patients with ulcerated lesions and severe deformities. Patients were cared for by the family and lived in a separate hut within the families' housing compounds. In this remote area where medical services are scarce or nonexistent, those interviewed did not realize that leprosy was treatable by modem medicine. This influenced the treatment-seeking behaviour of patients, who were often treated by spiritual healers and other traditional medicine practices.

Keywords: leprosy, stigma, social and cultural factors, Sudan, Masalit, Hawsa, traditional medical practices

Elissen, MCCA. 1991. Beliefs of leprosy patients about their illness: A study in the province of South Sulawesi, Indonesia. Tropical and Geographical Medicine 43(4): 379-382.
In Bone district, Province of South Sulawesi, Indonesia, a total of 50 randomly selected leprosy patients were interviewed about their beliefs about their illness with the help of a questionnaire. It became evident that their knowledge about leprosy was generally satisfactory, but only few patients adopted the bacterial theory as cause of their disease. Besides it was found that leprosy patients tend to self-discriminate. Traditional beliefs and religious ideas played an important role. To overcome the stigma, more health education based on a multidisciplinary approach is required. Beside the modern medical theory, cultural beliefs and religious views have to be taken into consideration.

Keywords: leprosy, stigma, self-discrimination, Indonesia, traditional beliefs

Farrow J. 1999 [1937]. Damien the leper: a life of magnificent courage, devotion, and spirit. New York: Doubleday.
Written by Hollywood director John Farrow, this well-known biography chronicles the life of Belgian priest Joseph de Veuster (1840-1889). At the age of 33, de Veuster left his comfortable life to devote himself to service. He became Father Damien and spent the next 16 years of his life serving as the resident priest at the Molokai colony, where he contracted leprosy himself and died at the age of 49.

Keywords: Father Damien, biography, Hawaii, Molokai, leprosy

Floyd-Richard M, Gurung S. 2000. Stigma reduction through group counselling of persons affected by leprosy - a pilot study. Leprosy Review 71(4): 499-504.
Stigmatization of persons with leprosy causes the emotional harm of social, economic and spiritual deprivation. Individual counselling has benefits in addressing these psychosocial problems but is

a slow process and effects few people at any one time. Our experience of group counselling of stigmatized persons achieved the following: addressing common issues to more than one person at a time, encouraging the unity of sufferers, developing compassion for others, understanding the common effects of stigmatization, and beginning to overcome its harmful effects.

Keywords: leprosy, stigma, group counselling, England

Gaudet M. 2004. Carville: remembering leprosy in America. Jackson, MS: University Press of Mississippi Press.
Drawn from interviews with living patients and extensive research in the leprosarium's archives, this book tells the stories of former patients at Carville. Patients reveal how they were able to cope with the devastating blow the diagnosis of leprosy dealt them. They also describe the outside world and of the culture they forged within the treatment center, which included married and individual living quarters, a bar, and even a jail. Through their memories and stories, we see their very human quest for identity and endurance with dignity, humor, and grace.

Keywords: Carville, life histories, archives, leprosy

Gershon W, Srinivasan GR. 1992. Community-based rehabilitation: An evaluation study. Leprosy Review 63(1): 51-59.
Leprosy gives rise to two types of stigmatization, one from the disease and its neuropathic manifestations, with their resultant disability and handicaps, and the other due to social ostracism. The process of rehabilitation should begin from the moment the disease is diagnosed, and the earlier its detection the better the prognosis for patients. The family unit to which the patient belongs plays a vital role in his social life, ensuring and enhancing his self-respect and dignity in society, and this fact must be recognized when evolving a strategy for rehabilitation. In no circumstances should a patient be removed from his natural home environment. It is important that the community is made leprosy conscious and gets more involved in hastening the social assimilation of patients. One of the major functions is the removal of the social stigma in the family and in the community and this involves communication skills to ensure interaction between the staff and patients' families and the education of the community.

Keywords: leprosy, stigma, stigmatization, rehabilitation, home environment, community, social assimilation

Gill AL, Bell DR, Gill GV, Wyatt GB, Beeching NJ. 2005. Leprosy in Britain: 50 years of experience in Liverpool. QJM 98(7):505-511.
Leprosy is a chronic infection that presents with varying dermal and neurological symptoms, and which can lead to extensive disability and morbidity, often with accompanying social stigma. This study reviewed the patients presenting to the Liverpool School of Tropical Medicine (LSTM) between 1946 and 2003, looking specifically at country of birth and of infection, details of clinical presentation, diagnosis, management and reactions. Most patients (64%) were born in the Indian subcontinent, and most were thought to have contracted the disease there (62%). Features at presentation included anaesthetic skin lesions in 19 (36%), hypopigmentation in 15 (30%), and peripheral nerve enlargement in 25 (50%). Diagnoses were made by a combination of clinical data and biopsy (60%), and slit skin smears were positive for acid-fast bacilli in 61% of multibacillary patients. Initial presentation was with a leprosy reaction in five cases (10%), and reactions were documented in 42% of all patients. Treatments were varied, progressing from traditional Eastern

medicine to the WHO-approved multidrug therapy in use today, with prophylaxis for children and close contacts. Leprosy remains an important diagnosis to consider in patients with a history of work or travel in the tropics, and is a diagnosis with far-reaching medical, social and emotional consequences.

Keywords: leprosy, history, England, India, retrospective study, case histories, chemotherapy

Gill AL, Gill GV, Beeching NJ. 2008. Familial transmission of leprosy in post-war Britain: Discrimination and dissent. QJM 101(5):407-413.
A Polish immigrant, who was resident in the United Kingdom (UK), presented with lepromatous leprosy and was detained in two hospitals against his wishes in the late 1940s. The public reaction to his diagnosis was remarkable, with street riots and questions in the Houses of Parliament about this 'leper'. His wife was persecuted and had to change her name. The patient died of tuberculosis during enforced isolation in hospital, and several years later his daughter (who had never left the UK) presented with a left median nerve palsy and probable lepromatous dactylitis of the left third finger, eventually requiring amputation and prolonged dapsone treatment. Her disease resolved slowly but completely. We believe these two familial cases represent the first documented episode of autochthonous leprosy transmission in the UK since the early 1920s. They also demonstrate the ability of this disease to engender fear, dissent and discrimination amongst the public. Parallels are drawn with reactions to the cholera epidemics in nineteenth century Britain, and to HIV/AIDS, SARS and multi-drug resistant tuberculosis in more recent times.

Keywords: Mycobacterium leprae, United States, risk factors, epidemic, contacts, history stigma AIDS, quarantine

Gould T. 2005. Don't fence me in: From curse to cure: Leprosy in modern times. London: Bloomsbury Publishing Plc.
Written by former BBC radio producer and literary editor of New Society magazine Tony Gould, this book is based on research he carried out in the Wellcome Library, London, one of the world's major resources for medical history. The book chronicles the recent history of leprosy through accounts of the family life and suffering of people who have been affected by the illness. Its chapters move geographically through Norway, Hawaii, the Philippines, Japan, South Africa, Nigeria, Nepal, and Louisiana; Gould also traces the contributions of major figures such as Father Damien.

Keywords: medical history, leprosy, Norway, Hawaii, Philippines, Japan, South Africa, Nigeria, Nepal, Louisiana, Father Damien

Gould T. 2005. A disease apart: leprosy in the modern world. London: Bloomsbury Publishing Plc.
In this book, Gould traces leprosy's recent history by examining the lives of people who have made a difference, ranging from household names like Father Damien to such lesser-known heroes as Stanley Stein, who waged a victorious battle against the U.S. Public Health Service. Gould argues it is the combination of leprosy's mysterious causes and its physical manifestations that inspire the cruel treatment that patients have faced for millennia. Despite what appear to be great strides--the author cites leprosarium closures from declining incidence of the disease in industrialized nations--Gould claims that the battle is far from over.

Keywords: leprosy, history, Father Damien, Stanley Stein, key figures, leprosy eradication

Grange JM, Lethaby JI. 2004. Leprosy of the past and today. Seminars in Respiratory and Critical Care Medicine 25(3):271-281.

Despite enhanced disease control efforts, leprosy remains an important cause of disability in several countries. Being based on case detection, the exact prevalence of the disease is not easily estimated. Currently around 600,000 new cases are treated annually. Advances in immunology and molecular biology have led to a greater understanding of the disease and to hopes for improved diagnostic tests and vaccination strategies. The major advance, though, is the development of highly effective combination drug regimens which, provided all doses are taken, rarely fails to cure. The challenge to leprosy control services is to overcome the stigma associated with the disease so that patients present with minimal lesions and before disabilities have developed. Although it is hoped that leprosy as a serious public health problem will be eliminated within a few years, continuing care for those suffering from deformity and rejection by society will be required for several decades.

Keywords: leprosy, Mycobacterium leprae, hypersensitivity reactions, multi-drug therapy, vaccination, stigma

Gussow Z. 1989. Leprosy, racism, and public health: social policy in chronic disease control. Boulder, CO: Westview Press.

From a 1990 book review by Corinne Wood published in the American Journal of Physical Anthropology 82(3):398-399: “This book is a challenging exploration of the causes and ramifications of the stigma associated with leprosy. Rather than examining the disease in a traditional medical context, Gussow focuses on the United States to ferret out the far-reaching roots and branches of this stigma. In so doing, he draws on his more than two decades of experience at the US Public Health Hospital in Carville, Louisiana. …Gussow argues that modern-day leprosy is not the disease referred to in the Bible. He also goes further, however, to assert that this ‘mistaken identity’ served the needs of the Western missionaries who were zealously involved in saving and serving newly colonized peoples. …In a powerful portrayal of viciously racist campaigns directed against Chinese immigrants into the US and Hawaii, Gussow traces this racism as a major element in the far-reaching stigmatization of leprosy in the New World.” The book is out of print but occasionally available through Amazon.com.

Keywords: leprosy, United States, Carville, social policy, racism, public health

Hannah B. 1995. Old terror, new hearts. The Oxford American, October/November: 40-49.

Harmon JP. 2000. King of the microbes: the autobiography of Johnny P. Harmon. Baton Rouge: self-published.

This is the autobiography of Johnny P. Harmon, a former resident of Carville. While at Carville, Harmon participated in a series of experimental treatments for leprosy, including “fever therapy.” He also met his future wife, Anne, at the hospital, where they had two children who were subsequently raised by foster parents until Johnny and Anne’s release in 1957.

Keywords: autobiography, Carville

Heijnders ML. 2004. The dynamics of stigma in leprosy. International Journal of Leprosy and Other Mcobacterial Diseases 72(4):437-447.

Leprosy in Nepal is a stigmatizing disease. This paper explores the different coping strategies employed by people affected by leprosy to manage stigma. It is based on a qualitative study conducted in the eastern part of Nepal. It will show that a difference exists between experienced stigma and the anticipation of stigma. Both types of stigma result in different coping strategies. In managing stigma people go through different phases. This paper will show that stigma is a dynamic process, and will elaborate on the concealment cycle, as developed by Hyland, to produce a more detailed understanding of the stigmatization process in Nepal. Doing so, it highlights the importance of a mutual concealment phase and the importance of triggers to exposure and discrimination. Changing from one phase to a subsequent phase in the stigmatization process is always triggered. It highlights further, that even within the same culture and even the same village, social differentiation makes a significant difference on the impact of stigma and the coping strategies employed in managing stigma. Stigma enforces already existing inequalities in social class, gender, and age.

Keywords: stigma, leprosy, Nepal, coping, management, qualitative

IDEA (International Association for Integration, Dignity, and Economic Advancement) [eds]. 1997. Quest for dignity: personal victories over leprosy/Hansen's disease. Oak Hill, WV: IDEA.

This 112-page book with 100 museum-quality black and white photographs was published in association with the launch of the Quest for Dignity exhibit at the United Nations in 1997. Through quotations, short life stories and powerful images, Quest for Dignity illustrates how people affected by leprosy around the world are challenging the stigma and defying old stereotypes as they transform the traditionally negative image of leprosy into a positive message of hope and triumph.

Keywords: leprosy, photography, stigma, social change

IDEA (International Association for Integration, Dignity, and Economic Advancement) [eds]. 2000. The texture of our souls. Oak Hill, WV: IDEA.

This 48-page booklet contains inspiring quotations, poetry and powerful images, largely chronicling the challenges faced by the older generation of individuals who were diagnosed with leprosy prior to the advent of a cure.

Keywords: leprosy, inspiration, photography, life histories

IDEA (International Association for Integration, Dignity, and Economic Advancement) [eds]. 2002. Freeing ourselves of prejudice. Seneca Falls, NY: IDEA Center for the Voices of Humanity.

This 32-page booklet contains empowering quotations and dignified images from IDEA members around the world, illustrating a strong determination to end prejudice and misunderstanding.

IDEA (International Association for Integration, Dignity, and Economic Advancement) [eds]. 2004. Peace: The fruit of justice. Seneca Falls, NY: IDEA Center for the Voices of Humanity.

Jacob JT, Franco-Paredes C. 2008. The stigmatization of leprosy in India and its impact on future approaches to eliminate and control. PLOS Neglected Tropical Diseases 2(1):e113.

Written by two physicians with field experience, this brief article takes a historical perspective on the growth of leprosy stigma in India. It concludes by calling for holistic interventions that incorporate stigma reduction and non-allopathic medical practitioners in disease control programs.

Keywords: leprosy, stigma, health, impact, history, implications

Jacobson RR, Krahenbuhl JL. 1999. Leprosy. Lancet 353(9153): 655-660.
Leprosy is an ancient disease that is still poorly understood and often feared by the general public and even by some healthcare professionals. Fortunately, improvements in the management of leprosy over the past three decades have diminished the stigma and greatly altered the outlook for patients. Public understanding of the disease has benefited from WHO's goal of eliminating leprosy as a public health problem by the year 2000. Unfortunately that goal has also led many to believe that leprosy has been or will soon be eradicated. The incidence of the disease has in fact changed very little, and eradication of a bacterial infectious disease such as this is unlikely with chemotherapy alone. Nevertheless, as a result of the WHO's efforts, patients nearly everywhere should have access to care, and the incidence may begin to diminish if adequate control efforts are maintained beyond the year 2000. Given the mobility of patients today a physician anywhere may occasionally see a case or be asked about the disease, so a basic understanding of leprosy and its management should prove useful.

Keywords: leprosy, globalization, WHO, eradication, public perception, chemotherapy

Johansen PM, Ramirez JP. 2008. Leprosy: Praise and concern [letter to the editor]. Public Health Reports 123: 551.
While acknowledging the great work of WHO, the Nippon Foundation, and Novartis toward the eradication of leprosy, this letter to the editor cautions against premature assumptions that the illness need no longer be part of the global health agenda. They cite reasons why reported numbers of people with leprosy may have declined in recent years, mostly having to do with altered methods of report and diagnosis, which may be leading to an unrealistically low report of leprosy prevalence. They note that disease incidence has “remained essentially unchanged for decades.” Finally, they call for redoubled efforts to identify and treat new cases, develop a vaccine, destigmatize the illness, and provide ongoing financial support.

Keywords: leprosy, stigma, eradication, politics, global health, WHO

Jopling WH. 1991. Leprosy stigma. Leprosy Review 62(1): 1-12.

Joseph GA, Sundar Rao PSS. 1999. Impact of leprosy on the quality of life. Bulletin of the World Health Organization 77(6):515-517.
Leprosy is considered by many as not merely a medical condition, but as a condition encompassing psychological, socioeconomic and spiritual dimensions that debilitate an individual progressively, unless properly cared for. This study documents the nature and extent of decreases in the quality of life (QOL) of an affected person. It explores the following six domains: physical; psychological; level of independence; social relationships; spiritual; and environmental. The study revealed that quality of life decreased progressively in leprosy-affected persons. Women had a better QOL score than men in almost every domain. Given the secondary role of women in Indian rural society, this may simply imply an acceptance of their situation. The findings are discussed in comparison with other diseases and in the context of a poor socioeconomic environment. With modern amenities,

better education and higher expectations, the perception of an individual regarding his or her own quality of life is bound to change. The need for frequent assessments and further studies along these lines is emphasized.

Keywords: leprosy, quality of life, debilitation, independence, physical, psychological, social, spiritual, environmental, gender, India

Kaur H, Van Brakel W. 2002. Dehabilitation of leprosy-affected people - a study on leprosy-affected beggars. Leprosy Review 73(4): 346-355.
Leprosy is one of the most socially stigmatized diseases known today. The affected people not only face physical impairments but also suffer psychosocial repercussions due to the community's attitude. With lack of social support and self-confidence, some dehabilitated leprosy-affected persons end up as beggars. The present study focuses on the long-term consequences of leprosy in leprosy-affected beggars in Delhi. The process of dehabilitation in each case has been studied. It has been found that dehabilitation is a continuous process. The combination of leprosy, physical impairments and social stigma causing further participation restriction, lead to dehabilitation of people affected by leprosy, and ending in a state of beggary for some. There is a need to develop a holistic approach including both prevention of dehabilitation and rehabilitation to overcome both the disease and its consequences. Measures to prevent such dehabilitation in future along with the rehabilitation of leprosy-affected beggars have been suggested.

Keywords: leprosy, stigma, India, beggars, dehabilitation, rehabilitation, repercussions

Kellersberger ER. 1951. The social stigma of leprosy. Annals of the New York Academy of Sciences 54(1): 126-133.

LeBeaux, DJ. 1985. Love me, somebody. New York: Vantage Press.
This is the autobiography of DJ LeBeaux, who was only a child when diagnosed with leprosy and sent to Carville. It is available used from Amazon.com.

Keywords: autobiography, Carville

Leprosy Control Program, Department of Health Service, Ministry of Health and Population, Government of Nepal. 2006/07. Annual Report 2006/07.
From a total of 100,000 documented cases of leprosy in Nepal in 1966, the reported prevalence had dropped to 3,787 in July 2006. Nevertheless, Nepal is still one of the three leprosy endemic countries (in 2008) with the leprosy prevalence rate of more than 1/10,000 people. Despite the steady decline in prevalence and improving new case detection rate, this report identifies some constraints and weaknesses of the leprosy elimination campaign. [**Note**: Recent news releases from the concerned government officials indicate that they are working toward the goal of declaring leprosy eliminated in Nepal by 2009.]

Keywords: Nepal, leprosy, elimination, government, policy

Leekassa R, Bizuneh E, Alem A. 2004. Prevalence of mental distress in the outpatient clinic of a specialized leprosy hospital Addis Ababa, Ethiopia. Leprosy Review 75(4):367-375.
Leprosy is a chronic disease that leads to physical disability as a result of nerve damage. Stigma and associated psychosocial problems are common and may increase the risk of mental disorders. This study was conducted to estimate the prevalence of mental distress amongst people attending

a Specialized Leprosy and Dermatology Hospital, ALERT, Addis Ababa, Alternate patients from the daily register of outpatients were interviewed for symptoms of mental distress using the Self Reporting Questionnaire (SRQ). The study population consisted of 786 people. Of these. 60% had leprosy and the remainder had other skin diseases. Among people with leprosy the prevalence was 52-4% compared with 7-9% in those with other skin conditions. Physical disability was also strongly associated with mental distress. This study showed that the 1-month prevalence of mental distress was significantly higher in patients with leprosy compared to patients with other dermatological conditions. Our study has indicated a need for the integration of psychosocial care into our current medical treatment of patients with leprosy.

Keywords: psychiatric morbidity, Western Ethiopia, population, illness, leprosy, stigma

Lockwood DNJ, Suneetha S. 2005. Leprosy: Too complex a disease for a simple elimination paradigm. Bulletin of the World Health Organization 83(3):230-235.
Can leprosy be eliminated? This paper considers the question against the background of the WHO program to eliminate leprosy. In 1991 the World Health Assembly set a target of eliminating leprosy as a public health problem by 2000. Elimination was defined as reaching a prevalence of < 1 case per 10 000 people. The elimination program has been successful in delivering highly effective antibiotic therapy worldwide. However, despite this advance, new-case detection rates remain stable in countries with the highest rates of endemic leprosy, such as Brazil and India. This suggests that infection has not been adequately controlled by antibiotics alone. Leprosy is perhaps more appropriately classed as a chronic stable disease than as an acute infectious disease responsive to elimination strategies. In many countries activities to control and treat leprosy are being integrated into the general health-care system. This reduces the stigma associated with leprosy. Implications are discussed.

Keywords: leprosy, diagnosis, prevention, control, complications, chronic disease, therapy, health care delivery, drug therapy, combiation, biomedical research.

Martin, B. 1950. Miracle at Carville: the story of one girl's triumph. Garden City, NY: Doubleday.
This is the autobiography of Betty Martin, a woman who lived for over 20 years at Carville. Diagnosed at age 19, when she was a New Orleans debutante engaged to be married to a young man, Martin spent the bulk of her young life at Carville. This classic autobiography is out of print but available on www.redapplebooks.com, and also occasionally on Ebay or Amazon.com.

Keywords: autobiography, Carville

Martin B. 1959. No one must ever know. Garden City, NY: Doubleday.
This second instalment of Betty Martin's autobiography chronicles the struggles that she and husband Harry, whom she met at Carville, faced when attempting to resume a "normal" life after living there for twenty years, being treated with sulfones, and eventually released. Although out of print, it is available online from various rare book dealers, including www.alibris.com.

Keywords: autobiography, Carville

McCurry J. Japanese leprosy patients continue to fight social stigma. Lancet 363(9408):544.
This letter outlines a brief history of attitudes toward leprosy in the past hundred years in Japan, which includes incarceration, sterilization, and isolation. While stigma is still widespread, the

author suggests that "Japanese society is beginning to make amends for its collective wrongs" through government programs and acknowledgment by a hotel executive that banning people with leprosy from his establishment was wrong.

Keywords: leprosy, Japan, retribution, government

G. Mehari "Leprosy and Stigma in Ethiopia: a survey of the literature". Unpublished paper. Addis Ababa University, November 2008

The history of leprosy in Ethiopia seems to have followed unique routes. Initially, people with leprosy were not segregated and their movement was not restricted. Helping people with leprosy was highly valued, and the church and rulers of Ethiopia tolerated leprosy-affected people and provided them with charity. People with Hansen's disease accompanied some of the emperors when they marched to and from battlefields. At the beginning of the 20th century, with the emergence of leprosaria and the spread of euro-centric explanations of leprosy, this positive attitude towards people with Hansen's disease was challenged. The new leprosy discourse challenged the previous attitude of people as shaped by the Ethiopian Orthodox Church. Thereafter, Ethiopian rulers facilitated the emergence of leprosaria and the subsequent segregation of people with leprosy. This was exacerbated as the educated elite spread fear among the people by disseminating exaggerated information. However, current developments show that people affected by leprosy are not segregated from society. This is clearly observed at the one-time leprosarium at Gebre Kiristos, where leprosy sufferers and people who are not affected by the disease now live together. See also entry for T. Melese (2005) *Leprosy, Leprosaria and society in Ethiopia*.

Melese T. 2005. Leprosy, leprosaria and society in Ethiopia. Addis Ababa: AHRI (The Armauer Hansen Research Institute).

Originally written in English as an MA thesis in History, it was published in 2005 with the support of The Armauer Hansen Research Institute (AHRI), Addis Ababa. The book contains the following chapters: 1) Introduction which deals with the pathological and social aspects of leprosy, and the historical context of the disease in the World, Africa, and Ethiopia (1901-1965). 2) Fear and compassion: the rise and expansion of leprosaria in Ethiopia. 3) The Century Campaign to arrest Mycobacterium leprae. 4) Leprost and society: a tentative attempt at reconstructing a social history of leprosy in the 20th century. 5) Conclusion. The book has a preface written by Dr Howard Engers, and a forward written by Professor Richard Pankhurst, a famous professor of history at Addis Ababa University, Ethiopia. The book runs at 276 pages: 181 pages of text, end notes, references, and index.

Nalaielua HK, Bowman SK. 2006. No footprints in the sand: a memoir of Kalaupapa. Honolulu: Watermark Publishing.

When Henry Nalaielua was diagnosed with Hansen's disease in 1936 and taken from his home and family, he began a journey of exile that led him to Kalaupapa, a remote settlement on the Hawaiian island of Moloka'i. This is Henry's story--an unforgettable memoir of the boy who grew to build a full and joyous life at Kalaupapa, and still calls it home today. *No Footprints in the Sand* is one of the few memoirs ever shared with the public by a Kalaupapa patient. Its intimacy and candor make it, in the words of Pulitzer Prize-winning poet W.S. Merwin, "a rare and precious human document." Nalaielua's story is an inspiring one; despite exile, physical challenges and the severing of family ties, he has faced life -- as an artist, musician and historian -- with courage, honesty, hope and humor.

Keywords: Biography, Kalaupapa, Hawaii, Molokai, exile

Navon L. 1998. Beggars, metaphors, and stigma: A missing link in the social history of leprosy. Social History of Medicine 11(1): 89-105.
Students of leprosy stigma are at odds over its sources, intensity, and current persistence. On the basis of a study of leprosy in Thailand that combined an archival survey with anthropological fieldwork, the present article suggests that prior to the discovery of a cure for the disease, its sufferers encountered ambivalent rather than severely stigmatizing reactions. Yet the public's selective exposure--mainly to beggars with the disease--paved the way to the perception of leprosy as the epitome of stigmatization and to its transformation into a metaphor for degradation. Progress in the medical treatment of the disease significantly improved patients' social acceptance but also allowed them to keep their illness a secret. Their consequent disappearance from the public eye turned the figurative use of leprosy in the spoken language into the main source of shaping its image. This development contributed to the irrefutability and perpetuation of the negative image, and even to its intensification to the extent of utter divorce from concrete reality. After expounding this thesis, the paper discusses its potential contribution to resolving the disputes over the roots, severity, and persistence of leprosy stigma on the international level.

Keywords: leprosy, stigma, history, Thailand, fieldwork

Navon L. 1996. Beyond constructionism and pessimism: theoretical implications of leprosy destigmatization campaigns in Thailand. Sociology of Health and Illness 18(2):258-276.
Based on a study of leprosy destigmatization campaigns conducted in Thailand since the 1970s, this article examines the difficulties in their implementation, the extent of their success and the degree to which they are actually needed. The findings indicate that these campaigns are doomed to fail because of problems inherent in any attempt to transmit a normalizing message, and also because of stigmatization derived from the metaphorical use of leprosy in spoken language. The study also found that educating the public about leprosy only increased the risk of stigmatization. However, it appears that the stigma itself bears the potential for destigmatization, since the worse the image of the disease, the less likely its identification with the patients diagnosed today, thus sparing them actual negative reactions. These conclusions serve as a basis for examining assumptions about knowledge and power underlying the constructionist analysis of destigmatization processes.

Keywords: stigma, destigmatization campaigns, normalization, constructionism, leprosy, Thailand

Nicholis PG, Wiens C, Smith WCS. 2003. Delay in presentation in the context of local knowledge and attitude towards leprosy: The results of qualitative fieldwork in Paraguay. International Journal of Leprosy and Other Mycobacterial Diseases 71(3):198-209.
The primary objective of this research was to explore help-seeking behavior in the context of knowledge, attitude, and practice as factors contributing to delay in presentation in leprosy. The secondary objective was to demonstrate the value of basic qualitative research methods in this context. Fieldwork was based at the Hospital Mennonita Km 81, the referral center for leprosy services in Paraguay. The findings linked delay in presentation to traditional beliefs, lack of awareness of the early symptoms of leprosy, stigma, seeking help from natural healers, and to

interactions with the health services. Traditional beliefs diminish the importance of the early symptoms of leprosy. Stigma has an impact on decisions to seek help. Natural healers have maintained their traditional status in society; their preferred treatments for leprosy are ineffective. Only rarely do natural healers refer to the health services. Once presented to the health services, some individuals affected by leprosy experienced lengthy delays in diagnosis and start of treatment. To address the traditional values of a society and provide effective public health initiatives is a clearly a major challenge for program organizers and for health education. Increased awareness of leprosy and sensitivity to its social consequences among health service practitioners is a further priority.

Keywords: leprosy, treatment, barriers, access to care, qualitative, traditional beliefs

Nicholls PG, Bakirtzief Z, Van Brakel WH, Das-Pattanaya RK, Raju MS, et al. 2005. Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk. Leprosy Review 76(4):305-315.
The World Health Organisation International Classification of Functioning, Disability and Health defines participation as involvement in a life situation. Participation restrictions are problems experienced in any life situation, for example, in relationships or in employment. Our research explored risk factors for participation restrictions experienced by people affected by leprosy. Our objective was to develop a screening tool to identify individuals at risk. An initial round of qualitative fieldwork in eight centres in Nepal, India and Brazil identified 35 potential risk factors for participation restriction. These were then further assessed through quantitative fieldwork in six centres in India and Brazil. In all, 264 individuals receiving leprosy treatment or rehabilitation services made a retrospective assessment of their status at time of diagnosis. Their level of participation restriction was assessed using the Participation Scale. Regression analysis identified risk factors for participation restriction including fear of abandonment by family members (odds ratio 2.63, 95% CI 1.35-5.13) and hospitalization at diagnosis (3.98, 1.0-7.32). We recommend four consolidated items as the basis for a simple screening tool to identify individuals at risk. These are the physical impact of leprosy, an emotional response to the diagnosis, female gender and having little or no education. Such a tool may form the basis for a screening and referral procedure to identify newly diagnosed individuals at risk of participation restrictions and in need of actions that may prevent such restrictions.

Keywords: leprosy, risk factors, Nepal, participation, restrictions

Nisar N, Khan IA, Qadri MH, Shah PGN. 2007. Knowledge attitude and practices about leprosy in a fishing community in Karachi Pakistan. Pakistan Journal of Medical Sciences 23(6):936-940.
This study sought to determine the level of knowledge, attitude and practices regarding leprosy in a fishing community of Karachi. About 300 people who did not have leprosy were interviewed randomly using a structured pre tested questionnaire. The findings of this study showed lack of knowledge about the cause, sign symptom, treatment and prevention of disease. The attitude towards those with leprosy was positive, showing sympathy, but at the same time a significant level of stigma was found about the leprosy patient among the community. The majority of people did not receive any health education sessions or attend any seminar on leprosy and only 3% were aware of the leprosy center in the area. The study concludes that the community lacks knowledge about leprosy, but there is some contradictory evidence: a high positive attitude was found with significant level of stigma. More emphasis should be placed on health education in this setting.

Keywords: leprosy, knowledge, attitude, stigma

Obregón D. 1996. The social construction of leprosy in Colombia, 1884-1939. Science, Technology and Society 1 (1): 1-23.
This is an overview of the process of construction of leprosy as a disease extremely dangerous by the Colombian medical community.

Keywords: leprosy, lazarettos, medical history, Colombia, bacteriology, Nineteenth and Twentieth centuries.

Obregón D. 2002. Batallas contra la lepra: Estado, medicina y ciencia en Colombia. Medellín: Banco de la República/EAFIT, 436 p.
This books deals with the history of the medicalisation of leprosy in Colombia from approximately the 1870's up to the 1940's. It is based on governmental and medical sources, as well as a few patients' narratives. A disease-apart approach was institutionalised by establishing two distinct domains of public health: a special official agency was set up for leprosy, while all other diseases were handled through a different department. However, in spite of the efforts of physicians and the government, leprosy was not thoroughly medicalised. Patients actively opposed compulsory segregation with attempts at converting lazarettos into prison-asylums. Non-leprosy sufferers remained at the lazarettos, and scientific medicine competed with popular healers, herbalists, and charlatans within these institutions. The medicalisation of leprosy was only partially accomplished because of its demarcation as a disease-apart.

Keywords: leprosy, lazarettos, medical history, Colombia, bacteriology, Nineteenth and Twentieth centuries.

Obregón D. 2002. Building national medicine: leprosy and power in Colombia, 1870-1910. Social History of Medicine 15 (1): 89-108.
This article shows how the Colombian medical community was interested in constructing a national medicine to conform to "universal" medical expertise. One of the main strategies to medicalise leprosy was to provoke fears through exaggerating the number of leprosy sufferers to demonstrate that charity was incapable of dealing with the problem. People with leprosy, who had been hitherto object of compassion and charity, became a danger to be fought. The government approved laws of compulsory segregation of leprosy patients in the 1890's, while the 1897 international conference on leprosy held in Berlin gave international sanction to isolation. People with leprosy actively resisted segregation as a violation of their individual rights.

Keywords: leprosy, lazarettos, medical history, Colombia, bacteriology, Nineteenth century.

Obregón, D. 2003. The state, physicians, and leprosy in modern Colombia. In: Disease in the History of Modern Latin America, Diego Armus ed. Durham & London: Duke University Press, pp. 130-157.
This article analyses how leprosy became an obstacle for the civilising and modernising project of the Colombian elites in the early twentieth century. The government enacted extremely severe laws in order to control lazaretto with the purpose to block the social and economic links of the town-lazarettos with the external world, and also attempted to expel from the lazarettos a large population free of leprosy, mainly composed of relatives of leprosy sufferers, who were confined within leprosaria. The period in which the Colombian State began to control leprosaria coincided

with the formation/modernisation of the Colombian State. Refinement of the arts of government, definition of citizenry (for example, through the establishment of such obligations as denouncing victims of leprosy), and exclusion of a social group defined as "lepers" came together.

Keywords: leprosy, lazarettos, medical history, Colombia, bacteriology, Twentieth century.

Obregón D. 2004. "Lèpre". In: Dictionnaire de la pensée médicale, D Lecourt (ed.) Paris: Presses Universitaires de France, pp. 673-677.
The topic of this entry is the alleged legacy of leprosy since Biblical times and how when it became an infectious disease in the late twentieth century, the disease became "tropical"; that is, a disease of inferior and poor people. The "Dark Ages," with all their horrors, seemed to be present in the colonies, and Europeans and North Americans feared that the appalling illness would propagate to the "civilized" world. At the end of the nineteenth century, traditions that depicted leprosy as a heinous disease began to revive.

Keywords: leprosy, history, Middle Ages, Nineteenth century.

Ohtani F. 1998. The walls crumble: the emancipation of persons affected by Hansen's disease in Japan. Tokyo: Tofu Kyokai Association.

Opala J, Boillot F. 1996. Leprosy among the Limba: Illness and healing in the context of world view. Social Science & Medicine 42(1): 3-19.
This study analyzes the traditional beliefs and practices concerning leprosy in the Limba people of Sierra Leone. It shows that this dialectally diverse ethnic group has two views of leprosy and its cause, and two varieties of stigma associated with the disease. The Limba have abandoned their traditional treatments for leprosy in response to an effective leprosy control programme, but retained their traditional world view, including its definition of illness, which holds a person seriously ill only when he has severe pain or disability. Thus, they seek treatment from the programme, but often at a relatively advanced stage of the disease. The study points the way to improved communication between leprosy workers and Limba patients by focusing on the points at which their views differ, and by identifying concepts within Limba world view that can be adapted by leprosy workers to help convey their message. The study emphasizes the importance of world view as a key to understanding patient attitudes and behaviour, and to making valid cross-cultural comparisons, but notes that it can take years for an investigator to understand the world view of a particular culture.

Keywords: leprosy, world view, Limba, Sierra Leone, stigma, disease model, qualitative,

Peters ES, Eshiet AL. 2002. Male-female (sex) differences in leprosy patients in South Eastern Nigeria: Females present late for diagnosis and treatment and have higher rates of deformity. Leprosy Review 73(3): 262-267.
A study was undertaken to investigate the possibility that female leprosy patients in South Eastern Nigeria may be at a disadvantage with regard to early presentation for diagnosis and the prevention of disability. A hospital-based retrospective examination of case notes for the period 1988-1997 was undertaken, totalling 2309 adult patients of whom 1527 were male and 782 were female (confirming the usual 2:1 male-female ratio for this disease). The results indicate that in this part of Nigeria, female leprosy patients have a much longer period between first symptoms or signs and presentation for diagnosis, compared with males; on average, the period before diagnosis in

women was almost twice as long as that in men. Furthermore, they suffered a higher proportion of disabilities. There was no evidence to support discrimination against females with leprosy by the health staff or community and female health workers were available in both hospital and primary health care centres to receive and examine female patients. The main factors that account for late presentation of females with leprosy in this area have still to be defined.

Keywords: leprosy, Nigeria, gender, treatment seeking, deformity

Premkumar R, Kumar KS, Dave SL. 1994. Understanding the attitude of multidisciplinary teams working in leprosy. Leprosy review 65(1): 66-77.
This study investigated the attitude of health personnel who were working for the National Leprosy Eradication Programme (NLEP) in India. The sample population was the NLEP employees of 2 state governments, consisting of 8 health professional groups. A questionnaire was developed for each of these groups to elicit information on 5 aspects of the relationships with their patients. The main outcome of the study was that two-thirds of the personnel tested possessed the 'minimum desirable' interaction with their patients. A further analysis showed that although they possessed a caring attitude towards patients from low socioeconomic classes, a domineering attitude towards these same patients was also prevalent. Analysis according to speciality revealed that laboratory technicians had the highest 'desirable attitude' (74-67%) and health educators had the lowest (57-5%), while the rest of the team members fell in between. The stigma shown towards leprosy was higher among doctors when compared to the rest of the team members.

Keywords: leprosy, health personnel, attitudes, medical care, NLEP, India

Quinlan M. 1914. Damien of Molokai. London: R&T Washbourne, Ltd.
This early biography of Father Damien begins with his youth in Belgium and follows him until his death after contracting leprosy at Molokai, where he had served as priest. The chapters alternate between background information and particularities of Damien’s experiences. The first chapter provides background on the history of leprosy and its stigma, with particular attention to Biblical references and the relationship between the Church and leprosy. Subsequent chapters weave Damien’s experience as a missionary (drawn from his letters to family) with a missionary history of the Hawaiian Islands, and, afterward, his experience at Molokai with vivid descriptions of the area and its inhabitants. Because of its particularly religious focus, this biography will be of special interest to those studying the relationship between religion and leprosy. One edition is published with RL Stevenson’s open letter. The book is available for free download in PDF format from: http://www.archive.org/details/damienofmolokai00quinuoft.

Keywords: Father Damien, biography, religious history

Rafferty J. 2005. Curing the stigma of leprosy. Leprosy Review 76(2):119-126.
The stigma of leprosy is a real phenomenon in many people's lives that affects their physical, psychological, social and economical well-being. There are many causes for this damaging image of leprosy. There is no one easy answer to dispelling this image; it is something that has to be done in partnership with communities and patients. Many papers document the effects of stigma, but few discuss or trial solutions. Education and media campaigns counteract false beliefs about leprosy and raise awareness of new advances in the field. Leprosy care is increasingly provided in an integrated setting showing patients and their communities that leprosy is not a disease apart. Physical and socio-economic rehabilitation is worthwhile in restoring self worth and status in the

community and helps patients to find employment. Group counselling can allow those with leprosy to talk about their feelings and experiences to empower one another. Gradually attitudes towards leprosy are changing, but there is still much to be done if the underlying menace of stigma is to be dealt with. We as health professionals must be prepared to make the first move and give that first touch. Certainly more research is needed. In the highly endemic countries the road to elimination may yet be long. Perhaps with effort we will one day be able not only to treat the disease, but also to cure the stigma of leprosy, and make that road an easier one.

Keywords: leprosy, stigma, needs, rehabilitation, care, empowerment

Ramirez Jr. JP. 2009. Squint: My Journey with Leprosy. Jackson: University Press of Mississippi.
Squint: My Journey with Leprosy is the autobiography of José P. Ramirez, Jr. (b. 1948), with a foreword by James Carville. For Ramirez, receiving a diagnosis of Hansen's Disease in 1968 meant exile and hospitalization in the only leprosarium in the continental United States: Carville, Louisiana, 750 miles from his home in Laredo, Texas. He was separated from family and loved ones, and had to face loneliness, prejudice, and the stigma associated with the term 'leper'. The goals he had had for his life were suddenly and drastically derailed. However, Ramirez confronted the hardships he was dealt with, and in his lifetime overcame barriers both real and imagined to eventually become an international advocate on behalf of persons with disabilities.

Schwarz RJ, Macdonald M. 2004. A rational approach to nasal reconstruction in leprosy. Plastic and Reconstructive Surgery 114(4):876-882.
Destruction of the nasal septum and nasal bones by Mycobacterium leprae and subsequent infection is still seen regularly in leprosy endemic areas. The social stigma associated with this deformity is significant. Many different procedures have been developed to reconstruct the nose. Patients operated on at Anandaban Hospital and the Green Pastures Hospital and Rehabilitation Center between 1986 and 2001 were reviewed. There were 48 patients with an average age of 47 years. Five deformities were mild, 22 were moderate, 13 were severe, and eight were not graded. Bone grafting with nasolabial skin flaps was performed in 14 cases, bone grafting alone was performed in 10 cases, flaps alone were performed in seven cases, and cartilage grafting was performed in 10 cases. In three patients, a prosthesis was inserted, and in three patients a gull-wing forehead flap was performed. Overall, excellent or good cosmetic results were obtained in 83 percent of cases. Grafting with conchal cartilage was associated with the best cosmetic results and had minimal complications. Bone grafting with or without nasolabial flaps was associated with a 50 percent complication rate of infection or graft resorption. In mild to moderate deformities, cartilage grafting is recommended; for more severe deformities, bone grafting with bony fixation and skin flaps is recommended. Perioperative antibiotics must be used, and these procedures should be performed by an experienced surgeon. In very severe cases with skin deficiency, reconstruction with a forehead flap gives good results.

Keywords: leprosy, nasal reconstruction, plastic surgery, case review

Seng LK. 2008. 'Our lives are bad but our luck is good': A social history of leprosy in Singapore. Social History of Medicine 21(2):291-309.
This paper examines the social history of individuals with leprosy living in Singapore under the law of compulsory segregation. Using official sources and oral history interviews, the paper explores both the colonial and postcolonial states' motivations behind the policy and its effects on

leprosy sufferers and the public at large in a cosmopolitan, progressive country. First, by tracing the continuity of the colonial policy into the postcolonial period, segregation, it is argued, stemmed not only from British anxieties towards the Asian 'races', which appeared to be the case in the earlier era, but from a deeper 'high modernist' resolve, shared by both the British and the postcolonial People's Action Party governments, to mould individuals into model subjects and citizens using the principles and techniques of modern science and administration. This paper also presents patient experiences of and responses to segregation and the social stigma against leprosy. It contends that official social control over the leprosarium was never completely hegemonic but was continually contested, individually and collectively, and overtly and covertly, by the residents, giving form in the long run to semi-autonomous ways of everyday life in the institution.

Keywords: leprosy, Singapore, Malaya, colonial medicine, compulsory segregation, high modernism, asylum

Shale MJH. 2000. Women with leprosy - A woman with leprosy is in double jeopardy. Leprosy Review 71(1): 5-17.
Leprosy is a major public health problem in much of the developing world, and is the subject of intense effort to reduce this threat. In common with other tropical diseases, men and women may be affected in different ways, be they biologically or socioculturally. It is suggested that women, already socially inferior to men in many societies, suffer greater problems than men in such matters as receiving health education, access to treatment and mobility. Hardship resulting from the disease is probably also felt more by women than men, with greater social and marital rejection and loss of self esteem. The following is a discussion of the biological (sex) and sociocultural (gender) aspects of the disease in women, and tries to assess whether the female leprosy patient really is in greater jeopardy than her male counterpart.

Keywords: leprosy, stigma, gender, barriers to treatment

Shieh C, Wang HH, Lin CF. 2006. From contagious to chronic: A life course experience with leprosy in Taiwanese women. Leprosy Review 77(2): 99-113.
This study used the narrative analysis method to explore stories told by Taiwanese women who had suffered from leprosy. Twenty-one women from a leprosarium, a long-term care centre, and the community participated in either focus group discussions or individual interviews. Their stories were analysed in two phases: structural and holistic content analyses. Structural analysis identified four life stages: before being diagnosed, after being diagnosed, living with leprosy, and the future. Holistic content analysis uncovered common themes in each life stage. Findings indicated that stigma was experienced throughout the life course of these women. At this stage of life, these women were facing not only physical impairments and disabilities from the leprosy, but also the usual chronic health problems of the elderly. This study suggests that prevention and treatment of leprosy-related physical impairments and chronic diseases are important.

Keywords: dermatology, infectious diseases, pathology, tropical medicine

Silla, E. 1998. People are not the same: Leprosy and identity in Twentieth Century Mali. Portsmouth, NH: Heinemann.
This book draws on an extensive collection of life histories to elaborate the perspectives of patients. It weaves the transformation of “leper” identities with changes in medical and social responses to the disease. By situating seemingly local experiences of patients within the larger context of

national and global change, the book contributes to a historical understanding of a wide range of issues including stigma, marginality, begging, and migration. Silla discusses the obstacles that leprosy presents for marriage, farming, and participation in other facets of "normal" life in Mali. He also explores the communities that arise at treatment centers in Bamako and elsewhere (where people with leprosy often migrated after being alienated from their villages), and how these communities socially and politically empower their members.

Keywords: leprosy, Mali, life histories, identity, obstacles, migration

Simeons ATW. 1959. The mask of a lion. New York: Alfred A. Knopf.
This out-of-print novel, written by a physician who spent 20 years in India, tells the story of Govind, a Hindu tailor who becomes a social outcast and joins a travelling band of beggars when he discovers that he has leprosy. It also describes the conditions of India's leprosaria, illuminating reasons why many people with leprosy have historically chosen a life of begging over life in a hospital. The book is occasionally availably via Amazon.com or Barnes & Noble's used and out-of-print books finder. See the Nov 24, 1952 Time Magazine article "Untouchables" for a synopsis: http://www.time.com/time/magazine/article/0,9171,817417,00.html?promoid=googlep

Keywords: leprosy, novel, India, fiction, leprosarium

Squires S, Wilhelm J (directors). 2008. Triumph at Carville: a tale of leprosy in America [28-minute video program]. The Wilhelm Group.
This PBS documentary premiered on March 28, 2008. The program outlines the history of the 100-year-old national leprosarium in Louisiana known as "Carville." Crafted from contemporary interviews, old radio shows, movie news accounts and other archival materials—including exclusive photographs taken by a longtime patient—the film takes viewers inside Carville and introduces them to patients, nuns, doctors and staff who lived and worked there. It challenges many popular misunderstandings about leprosy and provides fresh insight into the ancient affliction that is today called Hansen's disease. Available from PBS at: www.shoppbs.org/product/index.jsp?productid=3031637.

Keywords: Carville, documentary, PBS, history, film

Stewart R. 2000. Leper priest of Moloka'i: the Father Damien story. Honolulu: University of Hawaii Press.
This biography presents and analyzes much new information about Father Damien and his years in Hawai'i. The correspondence between Damien, his colleagues in the Catholic Church, his Protestant supporters, and agents of the Hawaiian Board of Health gives a fuller understanding of the extent of Damien's work at the settlement and the tensions underlying his relations with Church bureaucrats, who were both impressed by his energy and zeal and irritated by his wilfulness and independence. But even his detractors could not deny that he was almost singlehandedly responsible for tremendous improvements to Kalaupapa in the face of overwhelming odds.

Keywords: Father Damien, Molokai, leprosy, Kalaupapa, Hawaii, biography

Stein S. 1963. Alone no longer. New York: Funk & Wagnalls.
This is the inspiring autobiography of Sidney Levyson, who took the name Stanley Stein upon entering the U.S. Public Health Service Hospital in Carville, Louisiana in 1931. Available from the IDEA website bookstore at: http://www.idealeprosydignity.org/book/book.htm

Keywords: autobiography, Carville

Stevenson RL. 1890. Father Damien: an open letter to the Reverend Doctor Hyde of Honolulu. London: Chatto and Windus.
This is an open letter from Scottish novelist and travel writer Robert Louis Stevenson, who visited Molokai for eight days shortly after the death of Father Damien. The letter is addressed to Presbyterian minister Rev. Dr. Hyde of Honolulu, who had heavily criticized the late Father Damien in a previous letter to a fellow clergyman. Stevenson's response staunchly defends Damien's character and made waves in the press at the time it was written. He originally sent the letter to the Sydney Morning Herald (he was, at the time of its authorship, travelling in Australia), which refused to publish it on legal grounds. However, the letter was soon picked up by British and American newspapers, where it helped to publicize the great works of Father Damien.

Keywords: Molokai, Father Damien, open letter, Hawaii

Stigter DH, de Geus, L, Heynders ML. 2000. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. Leprosy Review 71:492-498.
This study describes community behaviour towards persons affected by leprosy in the eastern Terai districts of Nepal. The results show that 95% of the persons affected by leprosy recognized by the community have visible signs such as wounds, swellings and deformed feet or hands. Motives for negative community behaviour are mostly found in the fact that people fear infection by germs, but fear of a curse from God is also mentioned. Leprosy control programmes should focus on prevention of impairments and disabilities, because it seems that a visible sign is an important trigger for negative community behaviour.

Keywords: leprosy, Nepal, community response, beliefs

Stoddard CW. 1885. The lepers of Moloka'i. Notre Dame, IN: Ave Maria Press.
American author Charles Warren Stoddard visited Molokai several times in the late 1800s, where he befriended Father Damien and recorded his impressions in this brief book. Along with the open letter from Robert Louis Stevenson, Stoddard's book contributed greatly to Father Damien's favorable public impression and continuing legacy. The book is available for free download in PDF form from Google books; also available in hard copy from various online rare booksellers.

Keywords: Molokai, Father Damien, open letter, biography

Suite M, Gittens C. Attitudes towards leprosy in the outpatient population of dermatology clinics in Trinidad. Leprosy Review 63(2): 151-156.

Tayman J. 2006. The colony: the harrowing true story of the exiles of Molokai. London: Scribner.
Former *Outside* editor Tayman crafts a tale of fear, endurance and hope in telling the story of these unfortunate victims of ignorance (leprosy is caused by a simple bacterium and isn't nearly as contagious as was long believed). Drawing on letters, journals, newspaper articles, medical documents, interviews, and eyewitness accounts of the surviving members of the colony, Tayman has created a fitting monument to the strength and character of the inhabitants of the colony. As

Tayman's narrative approaches the second half of the century, the accounts become more personal, culled from interviews with elderly patients who were originally sent to Molokai as children.

Keywords: Molokai, exile, Hawaii, leprosy, history

Tsutsumi A, Izutsu T, Islam Am, Maksuda AN, Kato H, Wakai S. 2007. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. Social Science and Medicine 64(12):2443-2453.
The present study aims to determine the quality of life (QOL) and general mental health of leprosy patients compared with the general population, and evaluate contributing factors such as socio-economic characteristics and perceived stigma. A total of 189 patients (160 outpatients, 29 inpatients) and 200 controls without leprosy or other chronic diseases were selected from Dhaka district, Bangladesh, using stratified random sampling. A Bangladeshi version of a structured questionnaire including socio-demographic characteristics-the Bangla version of the World Health Organization Quality of Life Assessment BREF (WHOQOL-BREF)-was used to assess QOL; a Self-Reporting Questionnaire (SRQ) was used to evaluate general mental health; the Barthel Index to control activities of daily living (ADL); and the authors' Perceived Stigma Questionnaire was used to assess perceived stigma of patients with leprosy. Medical records were examined to evaluate disability grades and impairment. QOL and general mental health scores of leprosy patients were worse than those of the general population. Multiple regression analysis revealed that factors potentially contributing to the deteriorated QOL of leprosy patients were the presence of perceived stigma, fewer years of education, the presence of deformities, and a lower annual income. Perceived stigma showed the greatest association with adverse QOL. We conclude that there is an urgent need for interventions sensitive to the effects of perceived stigma, gender, and medical conditions to improve the QOL and mental health of Bangladeshi leprosy patients.

Keywords: leprosy, quality of life, mental health, perceived stigma, Bangladesh

Ulrich M, Zulueta AM, Caceresdittmar G, Sampson C, Pinardi ME, Rada EM, Aranzazu N. 1993. Leprosy in women: Characteristics and repercussions. Social Science & Medicine 37(4): 445-456.
Physiological, socioeconomic and cultural factors play important roles in the response of women to *Mycobacterium leprae* and in the impact of leprosy on their lives. They appear to develop stronger immunological responses to *M. leprae* than men, as suggested by lower incidence and less severe clinical forms of disease in most areas of the world, as well as stronger reactions of cell-mediated immunity after prophylactic vaccination. Genetic factors and physiological status including pregnancy, intercurrent infection and malnutrition might be among the factors that modulate this response. Women in leprosy-endemic areas of the world, with few exceptions, suffer from marked economic and social dependency and inferiority that can only be heightened by the social stigma associated with leprosy. Nevertheless, they bear an enormous responsibility for the health of their families, often as head of the household, and they often possess a unique capacity to influence community opinion. The incorporation of women at all levels into active roles in health care programs may constitute one of the decisive factors in the success or failure of leprosy control.

Keywords: leprosy, gender, women, leprosy control

Van Brakel W, ed. 2002. Workshop on social science and leprosy research: full report.

This is the official report of a conference held in New Delhi in 2002. There were 42 participants from 12 countries. The conference addressed four major areas having to do with social science and leprosy: advocacy, media, IEC, and training; counselling, treatment adherence, and self-care; rehabilitation, community-based research, and community participation; and stigma, gender, and delayed presentation. The report is organized around summaries of discussions in these four realms and recommendations for research.

Keywords: conference, report, social science, leprosy, New Delhi, India

Van Brakel W. 2003. Measuring leprosy stigma: A preliminary review of the leprosy literature. International Journal of Leprosy and Other Mycobacterial Diseases 71(3):190-197.

A literature review was conducted to review work done to date on measuring stigma related to leprosy. References were obtained through a PubMed (Medline) search and through examining relevant bibliographies. The studies reviewed indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. The consequences of stigma affect individuals as well as the effectiveness of leprosy control activities. Despite enormous cultural diversity, the areas of life affected are remarkably similar. They include mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions. This suggests that development of a standard stigma scale for leprosy may be possible. Data obtained with such an instrument would useful in situational analysis, advocacy work, monitoring and evaluation of interventions against stigma, and research to better understand stigma and its determinants.

Keywords: leprosy, literature review, measurement, analysis

Van Brakel W, Anderson AM, Mutatkar RK, Bakirtzief Z, Nicholis PG, et al. 2006. The participation scale: Measuring a key concept in public health. Disability and Rehabilitation 28(4):193-203.

The purpose of this study was to develop a scale to measure (social) participation for use in rehabilitation, stigma reduction and social integration programs. A scale development study was carried out in Nepal, India and Brazil using standard methods. The instrument was to be based on the Participation domains of the International Classification of Functioning, Disability and Health (ICF), be cross-cultural in nature, and assess client-perceived participation. An 18-item instrument was developed in seven languages. The Participation Scale was found to be reliable and valid to measure client-perceived participation in people affected by leprosy or disability. It is expected to be valid in other conditions also. The scale allows collection of participation data and impact assessment of interventions to improve social participation. Such data may be compared between clients, interventions and programmes. The scale is suitable for use in institutions, but also at the peripheral level.

Keywords: London handicap scale, spinal cord injury, international classification, social participation, disabilities, leprosy, stigma, rehabilitation, questionnaire

Van Brakel W. 2007. Disability and leprosy: The way forward. Annals of the Academy of Medicine Singapore 36(1):86-87.

This letter provides an overview of recent findings and developments in research and policy about leprosy-related stigma. It also identifies current research priorities related to disability, including community-based rehabilitation, stigma and discrimination, prevention of disability, and reactions and nerve damage.

Keywords: nerve function impairment, risk factors, stigma, Bangladesh, neuropathy, prediction, India

Various authors. 2005. International Journal of Leprosy and Other Mycobacterial Diseases 73(4).
This edition of IJL opens with an interesting image of child patients and staff at Robben Island Leprosy Hospital, South Africa, circa 1920 as part of its "Images from the History of Leprosy" series. The issue also contains the following articles: "Visible deformity in childhood leprosy—a ten-year study" (Kar and Job); "Close contacts with leprosy in newly diagnosed leprosy patients in a high and low endemic area: comparison between Bangladesh and Trinidad" (Richardus, Meima, Marrewijk, Croft, and Smith); "Factors contributing to the decline of leprosy in Spain in the second half of the Twentieth Century" (Alfonso, Vich, Vilata, and de las Aguas); "Study of apoptosis in skin lesions of leprosy in relation to treatment and lepra reactions" (Ajith, Gupta, Radotra, Arora Kumar, Dogra, and Kaur). All issues of IJL may be of interest in studies of stigma and leprosy; this particular one is cited here because of the Robben Island image.

Keywords: photography, Robben Island, leprosy, history, deformity, Bangladesh, Trinidad, Spain, lepra reaction

Weiss MG, Ramakrishna J. 2006. Stigma interventions and research for international health. Lancet 367: 536-538.
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 characterized 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.

Keywords: stigma, public health, intervention, definition

White C. 1996. Physical and metaphorical confinement: the experience of Hansen's disease (leprosy) in the United States. Human Mosaic 30(1-2): 12-28.
Drawing on the author's work at Carville Hospital, where she collected oral histories of patients and staff, as well as autobiographies, memoirs, and media images of the leprosy patient in the 20th century, this article examines the ways in which stigma confines the lives of people affected by leprosy, in both a physical and a metaphorical sense. Whether self-inflicted or imposed upon the individuals at Carville, confinement is a salient theme that runs through their narratives, often long after they have left the physical hospital itself. With many quotes from interviewees, the author gives voice to the experiences of these stigmatized individuals.

Keywords: leprosy, confinement, institution, Carville, USA, media

White C. 2002. Sociocultural considerations in the treatment of leprosy in Rio de Janeiro, Brazil. Leprosy Review 73:356-365.
Based on 11 months of field research, this article identifies some of the challenges that leprosy patients face in Brazil today and seeks to determine how this information can be utilized not only to improve the quality of life of patients, but also to reduce incidence and prevalence rates of the disease in Brazil. The author argues for early detection through increased educational campaigns, better training of physicians in leprosy detection, and greater access for patients to medical services, such as improved treatment of adverse reactions to leprosy medication, physical therapy, and psychological and social support.

Keywords: skin disease, America, South America, infection, bacteriosis, mycobacterial infection, human, treatment, review, cultural aspect, Brazil, social aspect, scientific research, leprosy

White C. 2003. Carville and Curupaiti: experiences of confinement and community. Historia, Ciencias, Saude—Manguinhos 10: (suppl. 1):123-141.
This article presents a brief history of isolation policies and the development of community structures at two leprosaria, Carville and Curupaiti, in the United States and Brazil, respectively. The modern dilemmas faced by the administration, staff, and residents of these institutions is also discussed.

Keywords: medical anthropology, leprosy, Hansen’s disease, United States, Brazil, stigma

White C. 2005. Explaining a complex disease process: talking to patients about Hansen’s disease (leprosy) in Brazil. Medical Anthropology Quarterly 19(3):310-330.
This article explores the ways in which people who are affected by Hansen’s disease in Rio de Janeiro learn about different aspects of their illness and its treatment from health care professionals. Typically, patients’ explanatory models of HD tend to be syntheses of folk models of illness and health, biomedical models to which they are exposed at different stages in the treatment process, and individual experiences of illness. The sensitive presentation of biomedical information about HD to patients has the potential to increase adherence to treatment programs and increase patient confidence in the biomedical system.

Keywords: Brazil, leprosy, Hansen’s disease, explanatory models, medical discourse, medical anthropology

White C. 2008. Iatrogenic stigma in outpatient treatment for Hansen’s disease (leprosy) in Brazil. Health Education Research: 23(1):25-39.
This paper explores how iatrogenic stigma, or stigma that is produced through a patient's encounter with physicians or with biomedicine in general, might emerge in outpatient treatment for Hansen's disease, or leprosy. Based on in-depth interviews with people affected by Hansen's disease and observations conducted at several public health clinics in Rio de Janeiro, Brazil, this research identified several aspects of the biomedical encounter that generated or contributed to stigma, either felt or enacted. Also noted in the research were positive examples of techniques used by physicians and health care workers for minimizing or circumventing stigma. The paper touches upon several topics, such as culturally mediated responses to medication side effects and communication between health care workers and patients, that might be salient or useful for health educators and others who are attempting to reduce health-related stigma.

Keywords: iatrogenic, stigma, physician, doctor-patient relationship, Brazil, biomedicine, leprosy

White C. 2009. An uncertain cure: living with leprosy in Brazil. New York: Routledge.
In this book, White explores the shantytowns of Rio de Janeiro to describe contemporary leprosy experiences among poor and working class Brazilians. In this ethnographic account, the author exposes the web of historical, socioeconomic, religious, and political forces that complicate the path to wellness and perpetuate high rates of infection. Drawing on nearly ten years of research, White shows how anthropological research can contribute to more effective treatment of chronic infectious diseases around the world.

Keywords: Brazil, leprosy, ethnography, illness experience, poverty, anthropology

White N. 2009. In the sanctuary of outcasts. A memoir. New York: William Morrow
In 1993 the author, a successful journalist and publisher, was sentenced to 18 months in prison. He was sent to Carville, Louisiana. In the preface White explains that for more than a century Carville served as the United States' national leprosarium. Individuals who contracted the disease were forcibly quarantined at its remote location. By the 1990s, the number of patients at Carville had dwindled to 130, the very last people in the continental United States confined because of the disease. The hundreds of empty beds were thereafter used for the confinement of Federal prisoners. Based on his experiences there, and long talks with many of the patients, some of whom became good friends, White tells of the injustices and the tragedies that had marked their lives.

Keywords: United States, leprosy, Hansen's disease, illness experience, life stories.

Withington SG, Joha S, Baird D, Brink M, Brink J. 2003. Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: A one-year cohort of new leprosy cases in north Bangladesh. Leprosy Review 74(2):120-132.
The current leprosy elimination strategy focuses almost exclusively on delivery of leprosy diagnostic services and multi-drug treatment (MDT). However, the specific problems of people newly diagnosed with leprosy or cured with MDT primarily relate to impairment of nerve function and social and economic consequences of the diagnosis of leprosy. This study was carried out to investigate the relation between socio-economic factors and the development of nerve impairments and stigma. In addition the relation between socio-economic factors and selection for socio-economic assistance was studied. The study population was a cohort of 2364 newly diagnosed people with leprosy in rural Bangladesh in 1996, including 42.5% women, with an overall mean age of 31.4 years. Three hundred and sixty people (15-2%) had WHO grade 1 or 2 disability identified at diagnosis, and 50 (2.1%) had stigma identified on interview at home visit conducted within one month of diagnosis. One hundred and eighty-eight people (8%) were selected for specific assistance for rehabilitation, primarily interest-free loans for income generating activities or vocational training. Factors independently associated with WHO grade 1 or 2 disability at diagnosis were multibacillary (MB) classification, adult status, and manual occupations. Smear positivity, female sex, and the presence of dependents were associated with an increase in the experience of stigma. The presence of nerve impairments and stigma, as well as several indices of poverty were clearly associated with selection for inclusion in an integrated program for socio-economic assistance. An increased focus by leprosy services on the socio-economic factors associated with poorer physical and social outcomes is recommended. Where adequate finances

and trained staff are available, efforts could be made to identify those at higher risk of poor outcomes, and to provide or to mobilize appropriately targeted socio-economic interventions.

Keywords: leprosy, Bangladesh, cohort study, poverty, stigma, health services

Yancey P, Brand P. 1997. The gift of pain. Grand Rapids, MI: Zondervan.
From reviewer David Graham: “In this combination memoir/medical ruminations, originally published under the title *Pain: The Gift Nobody Wants*, Dr. Paul Brand and Philip Yancey share Dr. Brand's work as a physician, with reflections from a lifetime of thinking about pain. It is natural for Dr. Brand to explore the subject of pain, for in a career as a surgeon working among leprosy patients, he has seen the devastating effects that come upon people who lack pain - damaged feet, fingers, noses, or eyes, often leading to infection and death. Part one of this book traces Dr. Brand's path into medicine. Part two explores his career in pain, and part three shares how Dr. Brand has learned to befriend pain, seeing it as a gift, an essential requirement for health. As a Britain who has spent roughly one third of his long life in England, one third in India, and one third in the United States, Dr. Brand's life on three different continents has given him first-hand glimpses of how people view pain.”

Keywords: leprosy, memoir, physician, doctor, pain, surgery, biography