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NEWS and NOTES

This department furnishes information concerning institutions, organizations, and individuals engaged in work on leprosy and other mycobacterial diseases, and makes note of scientific meetings and other matters of interest.

Stigma, Identity and Human Rights

The Experience of Leprosy in the Era of HIV/AIDS

Robben Island, South Africa

4–6 February 2005

Sponsored by IDEA and the ILA Global Project on the History of Leprosy

in Association with Robben Island Museum

From February 4–6, 2005, individuals from 16 countries whose lives have been impacted by stigma, either as a result of leprosy or HIV/AIDS joined in discussion with historians specializing in the fields of leprosy, HIV/AIDS and human rights. The powerful backdrop of Robben Island, an international symbol of (in the words of the Robben Island Museum) "the indestructibility of the spirit of resistance against colonialism, injustice and oppression", inspired discussions of how history can effect social change. At the same time, the legacy of Robben Island and all those who resisted its oppression empowered discussions on how stigma denies both identity and human rights with a view to developing concrete actions that can be used towards eliminating the power of stigma to destroy people's lives.

PROGRAM

Friday, February 4:

Banishment, Isolation, Resistance & Remembrance—Tour and Discussions: Interacting With the History of Robben Island

The Maximum Security Prison:

Welcome—Dr. Jo Robertson

Opening Remarks—Deirdre Prins-Solani and Richard Whiteing

Remarks by Mr. Yohei Sasakawa, President, The Nippon Foundation

Introduction to the History of Robben Island — Dr. Harriet Deacon

The Graveyard

Remembrance: IDEA Banner of Honor

Rev. Albrecht Hahne, Dr. P.K. Gopal, Zilda Borges, Alhaji Shehu Sarkin Fada, William Malo

Banishment: The Welfare of Society versus The Rights of Individual Freedom

Chairs: Dr. Harriet Deacon & Anwei Law

Sigurd Sandmo Norwegian segregation policies

Jose Ramirez, Jr. Banishment versus imprisonment

Ryohei & Suiko Shibata Japan's absolute segregation policy

Church of the Good Shepherd

Isolation: The Experience of Isolation

Chairs: Dr. Jo Robertson & William Malo

William Malo, Former resident, Kalaupapa, Hawaii, USA

Crescencio T. Rosello, Culion, Republic of the Philippines

Keteng Feng, Guangdong Province, Peoples Republic of China

Miyoji & Mieko Morimoto, Japan

Dr. Michael Chen, Guangdong, Peoples Republic of China

Dr. Arturo Cunanan, Culion, Republic of the Philippines

Clint Añabieza, Cebu, Republic of the Philippines

Saturday, February 5: Stigma & Identity

The Guesthouse

Resistance: Retaining Identity in the Face of Oppression

Chairs: Simonne Horwitz

Panel: Arega Kassa Zelelew, Artur C.M. De Sousa (Zackie Achmat—Treatment Action Campaign, South Africa, and Yasuji Hirasawa, Japan, were unable to participate at the last minute)

Stigma & Identity

Culture, Identity & Stigma: The African Experience

Chairs: Arega Kassa Zelelew and Dr. John Manton

Panel: Dr. Jean-Paul Bado, Linda Beer Kumwenda, Jan Mahlangu, Bhekani Memela

The Effect of Stigma on Individuals & Families

Chairs: Jose Ramirez, Jr. and Kofi Nyarko

Panel: S.K. Jung, Jae Heung Kim, Magdalena Ramirez, Dr. Harriet Deacon, Ms. Inez Stephney, Amar Timilsina, Adi Yosep, Jaimie Tomas Cabeto, Rev. Albrecht Hahne,

Breaking the Silence: Women & Stigma

Chairs: Zilda Borges and Mimi Badamuti

Panel: Natalia Isabel da Graca Marcal, Zoica Bakirtzief, Tiruwork Mengistu, Birke Nigatu, Saruto Labbo

Illuminating Ourselves: Redefining Traditional Images

Open discussion—The role of images and language in the formation of attitudes.

Achievements of people affected by leprosy or living with HIV/AIDS, past and present, as a means of challenging stereotypes and the stigma that is perpetuated by them.

From Ingeborg Grytten (Author, Norway, 17th century) to Akashi Kaijin (Poet, Japan, early 1900's)

Sunday, February 6—Human Rights (Multi-Purpose Learning Center)

Human Rights

Professor Bernardino Fantini

Ensuring the Rights of Humanity

Chairs: Professor Bernardino Fantini & Dr. P.K. Gopal

Panel: Alhaji Shehu Sarkin Fada, Chamada Abibo

In Conclusion: History as an Agent for Social Change

Prof. Megan Vaughan, Zilda Borges and Anwei Law

Excerpts from the meeting follow. Dr. Jo Robertson has provided summaries of the academic papers presented, and Anwei Law has provided transcripts of the other presentations and discussion. These have been combined and edited for brevity, attempting to preserve the sense and spirit of the discussions. Ed.

Friday, February 4:

Banishment, Isolation, Resistance & Remembrance—Tour and Discussions: Interacting With the History of Robben Island

The Maximum Security Prison

Deirdre Prins-Solani, Manager, Education Department, Robben Island Museum:

"Robben Island represents the triumph of the human spirit against adversity. What does it mean for the spirit to triumph? One of the ways in which we have interpreted it is that we triumph through resistance; that an act of resistance against oppression, an act of resistance against stigma, an act of resistance against segregation, is a triumph of the spirit.

"When you came into prison, your name was written down into a book and you were given a number. You were told any communication that happened between you and the authorities would be done through your number. You lost your name, you lost your identity, your sense of belonging. So there was an attempt to erase an identity. . .

So when we fight against oppression and segregation and we fight against erasure, the voices of people who have experiences of a particular condition should be the people who speak. And that's why when we learned who the participants in this workshop were, we were very excited. We said yes, this is in keeping with the mission of this institution."

Eugene Mokgoasi, Former Political Prisoner, Robben Island: "Coming to Robben Island . . . . you met people who had a common understanding, a common journey, and destiny like you. Robben Island was a learning institution. The first morning here, it was kind of cold, and a guy said to me, 'You're home now. You're not going to live tomorrow, you're not going to live yesterday, you're going to live today and today only. Now look around. You've got broth-

The IDEA Banner of Honor is displayed at the cemetery where people who had leprosy were buried on Robben Island. The Banner of Honor recognizes individuals who have had leprosy who have made significant contributions to their own countries. Photo by Pamela Parlapiano

ers, you've got fathers, you've got uncles, you've got everything you need. Whatever you need, approach any one of us.' And I felt safe, for the first time."

Richard Whiteing, Robben Island Museum: "We can see the prison, but when we go back to the hospital period and . . . we find an erasure that Deirdre mentioned. One of the unique aspects of the people living with leprosy and the buildings they lived in is that there's been an attempt to obliterate the built fabric. We have but one building that remains that was used by people with leprosy, and that is a church. The rest of the buildings were burned because of the fear of infection. But they can't obliterate the cultural landscape, so we still have trees that were planted at that time. We have a fishpond that was built for the children in the children's section. We have the graveyard. . . So often there has been a silencing, but what we will try and do is to help you imagine . . ."

The Graveyard: Remembrance: The IDEA Banner of Honor

Banishment: The Welfare of Society versus The Rights of Individual Freedom

Sigurd Sandmo, Curator, The Leprosy Museum, Bergen. Norwegian segregation policies. The Norwegian contributions to the struggle against leprosy worldwide are famous, partly because of Hansen's discovery of the leprosy bacillus in 1873, partly because the Norwegian leprosy policies of the 19th century served as models for other countries, especially in terms of legislation. The idea that the Norwegian policies were rather humane and rational, like Hansen saw them, seems however still widespread, but I think we lose an important opportunity to understand the dynamics of banishment if we attribute the building of modern leprosaria to a theory of contagion, disconnected from public stigma. In the golden age of Norwegian leprosy work, the physicians contributed willingly to the social banishment of leprosy sufferers outside the institutions, to make them easier to collect, and to make it more difficult for them to escape the modern leprosaria. In order to demonstrate both the connections and lack of connectedness between the theory of contagion and the Norwegian model of segregation, four examples of how the medical

Norway fraternity tried out different strategies in order to direct sufferers towards hospitalization from the 1840s to the 1880s, in the golden age of Norwegian leprology, are discussed. In 1877 the Norwegian parliament passed an act making provision for those suffering from leprosy, which practically forced this group into hospital. And in 1885, the parliament passed a much stricter act *On Segregation*. Outside the inner circles of leprologists, many considered this act as being a terrible mistake and perhaps even against the constitution. The segregationists and the contagionists won the dispute and the last obstinate cases of leprosy could finally be collected.

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Ryohei Shibata, IDEA Japan: "The main idea of the absolute segregation policy in Japan was to abolish and eliminate the patients; it was not to cure them. I was diagnosed with leprosy in 1947. I was shunned by society and segregated in a sanatorium on an isolated island. There, I was forced to wait for my life to end.

"A poet living in the sanatorium on the island where I was sent once said: 'Like those luminescent fish dwelling in the sunless depths of the sea, I will find no light until I light myself up from within. . . . After 21 long years, I finally returned to society.

"In Johannesburg I went to an Apartheid Museum. There I saw the history of the men who were put in jail for no reason other than being black. That particular image overlapped with my own experience. In this sense, apartheid, the Japanese segregation laws and segregation policy, were similar. One was for racial discrimination and the other was discrimination against those people who have leprosy."

Dr. Jo Robertson, Coordinator, ILA Global Project on the History of Leprosy, UK: "I don't think any of us have any idea how many places there were in the world where leprosy work was done. Not all of these places dealt with people who were affected by leprosy in the same way. Some were much more absolute in terms of the isolation than others. Some of the places in Africa were more treatment places than anything else. Going through this list alphabetically, it may seem as though the list is endless . . . . What surprised me when I looked at the register from Culion were the ages of the people . . . . you'd be surprised how young they were and I think this is true of many places, 15 yr olds, 11, yr olds, very, very young people."

Church of the Good Shepherd: The Experience of Isolation

Dr. Harriet Deacon, Consultant, Human Sciences Research Council, Cape Town, South Africa: "This building is very symbolic for this meeting; to be speaking in this building about the history of leprosy and its relationship to other forms of stigmatization. I think it's really essential, when we talk about Robben Island as a leprosarium, to understand the difference between the isolation of patients in the pre-1891 period, before the Leprosy Repression Act was passed, and the situation after1891, where people were forcibly institutionalized once they'd been identified as people with leprosy. In 1891, you had a huge influx of patients coming, largely involuntarily, to the island and often they felt that they were tricked into coming to the island. This church dates from 1895, from the period in which the leprosy patients were moved out of the village, and further isolated even from the staff on the island."

Jose Ramirez, Jr., M.S.W., IDEA USA: "People oftentimes think of 'banishment' as the same as 'imprisonment'. But for many of us, we think of 'banishment' in terms of leprosy, because there has been banishment . . . . With imprisonment you find that persons end up with a particular term to describe them — political prisoners, jailbirds, etc. But when there's banishment of a person with Hansen's Disease, there's the brand of the word 'leper' that we all dislike, so it's never a multitude of words to describe those with leprosy, it's only one word.

"When you talk about the laws related to leprosy, what you're really talking about are the laws of silence. People were not speak-

William Malo, who was isolated at Kalaupapa, Hawaii as a young man but has lived in the community for the last 40 years, presents his experiences in the panel discussion "The Experience of Isolation". To his left are Dr. Jo Robertson and Dr. Harriet Deacon. To his right are Mr. Feng Keteng and Dr. Michael Chen. Photo by Henry Law.

ing out about the injustices of banishment for those persons affected by leprosy in the last 3000 years. It has only been very, very recently that this has occurred. Persons with leprosy did not have an opportunity to be defended as do most who are imprisoned. So, what has happened is that banishment continues until death."

Cresenciano T. Rosello, Culion, IDEA Philippines: ". . . the very close family ties of the Filipinos made them regard segregation as an unmerited punishment that lasted for life. This condition triggered anti-segregation feelings and the families hid the afflicted family members in the forest and in caves . . . . The people who were banished to Culion for the last 98 years — their bones are crying for justice, justice that they did not have during their lifetime."

William Malo, IDEA, Hawai'i: "The people of Hawai'i knew that if you were taken and sent to Moloka'i, you would never be seen again. So, they were not afraid to hide you and to keep you at home as long as possible. They would continue to have your love at home. That's why when I was asked why the mothers were doing that, I said 'Love was greater than fear'. The love for their children or husband or wife who had the disease was greater than any fear and so they hid their family members in order to keep them at home."

Mieko Morimoto, IDEA Japan: "When you got leprosy in Japan you just basically had to throw away every single thing you had. Because of leprosy, I had to give up my education, job opportunities, and to see my family. I regret that I could not have children. I have always, always wanted to have children. I was young then and I just couldn't cope with the fact that I couldn't have children and it was almost like a sickness I had in my heart. However, I have to say that since I got leprosy I have learned a lot. I have also stood up throughout the country to regain our humanity."

Keteng Feng, Handa/IDEA China: "If you go to our village you cannot see any children because even now we are still not allowed to get married and have children. I was sent to this leprosy village in 1963. Many decades have passed. We have suffered many difficulties and in 1968 some people around our village came to attack us. Some people also committed suicide because their family wouldn't accept them. I was sent to the village in 1963 and I have only gone back home two times. I had to walk because we are not allowed to ride on the public bus. I had to spend more than 10 hours to walk back home. When I got there, my family didn't allow me to go into the house because they were afraid that I would bring them trouble."

Miyoji Morimoto, IDEA Japan: "Frankly speaking, and to be honest with you, I really do not want to look back . . . . But, I was specifically asked to talk about banishment and also about stigma and discrimination. From the age 14, my life was as leprosy patient Myoji Morimoto and I was never able to live as Myoji Morimoto alone. This is something that I still hold in my heart. Japanese law had it that you couldn't go to college; you couldn't even go out of the Sanatorium. Against all advice and recommendations from the doctors and nurses and everyone in Sanatorium, I left the Sanatorium and went to college for four years. Now, there are 13 national sanatoria in Japan and about 3,500 people live in them. The average age is 78 years old. We were discarded from our hometowns and families and also by the government."

Clint Añabieza, IDEA Philippines: "When I graduated in 1994, I was also diagnosed as a person with Hansen's Disease. Through the discrimination in society, the stigma comes. I decided to isolate myself because my family would face difficulties because of my situation. At that time the doctor did not confine me at the hospital and said it was okay to take your medicine outside. But I faced discrimination—sometimes the taxi driver would not allow me to ride in the car when they saw I had some patches on my face and hands. That's one reason that I isolated myself in a small house beside in the sea. Some of my brothers and sisters brought me food to eat, but later I managed to cook on my own.

"At that time, many people told me that I'm a person with leprosy, hopeless in this world. Some people told me that even though you are graduated from college, you will not be employed. I took my medicine almost two years but the stigma cannot be erased in 10 years or 20 years—it goes from generation to generation."

Dr. Michael Chen, Handa/IDEA China: "In China we still have more than 600 leprosy villages around the whole country and probably more than 60,000 people are isolated in these leprosy villages. Many of these places are in very, very remote areas, in mountainous areas that are not accessible by a vehicle. Some are even on an island like Robben Island and you have to go by boat. This is only the physical part of isolation and there are many, many difficulties from the psychological part. For example, if a chair is sat in by a person who has the disease, other people won't touch it again. This still happens in some of the general hospitals. If the hospital has treated people who had leprosy, then they have to destroy all the instruments and equipment after that. I'm glad to say that in China we're getting more and more members of the younger generation as volunteers. They go to leprosy villages and try to break the world of isolation and develop more contact between people affected by the disease and the community. I think we can have a better future and reach our goals of a world without discrimination and stigma in the future."

Dr. Arturo Cunanan, Jr, Culion, IDEA Philippines: "I was born and grew up in Culion. I am a third generation descendent of Culion . . . . If you review most of the history of isolation, it's never been towards the patients themselves, but towards the protection of the healthy individuals. Isolation was not for the purpose of curing the sick. In the past, there was no cure, but only care. Unfortunately, our policy makers and decision makers approached the issue of leprosy on medical aspects, whether unknowingly or knowingly, and the social aspects of leprosy were left to the religious side or non-governmental organizations . . . . I am very, very happy that during the last few congresses we are now hearing and learning that leprosy control should not simply be based on a medical approach."

Saturday, February 5: Stigma & Identity

The Guesthouse: Resistance: Retaining Identity in the Face of Oppression

Dr. Harriet Deacon: "There were various kinds of resistance that both political pris-

Participants in the Robben Island Conference (left to right): Simonne Horwitz, Wellcome Unit for the History of Medicine, Oxford; Mimi Badamuti, The Sinikithemba HIV+ Choir, South Africa; Ms. Inez Stephney, Human Sciences Research Council, South Africa; and Saruto Labbo, IDEA Nigeria. Photo by Pamela Parlapiano

oners in the post-1960 period and leprosy patients engaged in. For example, some people just buckled down and concentrated on education programs and developing a community among the patients. They collected lobster and crayfish on the beaches, smuggled contraband and alcohol, and smuggled newspapers in . . . . With the 1892 rebellion led by Franz Jacobs, there was active resistance against institutionalization on the island. The way in which Franz Jacobs' rebellion was silenced is interesting. There is almost nothing in the colonial archive here in Cape Town about the rebellion. The only place I've found any record of it was in London at the Public Records office. It has been wiped off the face of the colonial archive and there's only one printed reference to it that talks about a smoking gun . . . . The way in which the patients resisted was that they actually demanded the things that they felt should go with a humanitarian segregation of themselves and they resisted being treated like slaves or prisoners."

Simonne Horwitz, Wellcome Unit for the History of Medicine, Oxford University, U.K.:

"It's very fitting that we are here in site that's linked to rebellion and resistance. In my own work on Westfort . . . . (a leprosy hospital that's just outside of Pretoria) from about 1890–1948, one of the themes that I constantly find is that the authorities tried to segregate and oppress people by gender, by race and by their disease. They were constantly trying to segregate them, to take away their identity. Yet, it was very clear that people fought against that . . . . Yesterday there was talk about the political prisoners signing their names and it's the same with Mr. Pipe who was at Westfort . . . . a man who wrote to the newspapers . . . . not as a person affected by leprosy, but as a *person* — telling about how he was feeling, how he was treated in those early years. Because he spoke out about his oppression, he was forced to leave Westfort because they thought he was creating too much of an uproar. But he had created a sense of optimism amongst people who were fighting for their identity. There are a number of occasions where the women patients, for example, had a sit down strike and refused to work until they were called by their names, until they were recognized, until they were given some of the same things that Harriet was talking about on Robben Island. These were people who were very actively engaged in maintaining their identity and whether that was writing a newsletter about their lives or whether that was through strikes, [they] . . . actively tried to shape an identity that was not around their disease . . . . Zackie Achmat from the Treatment Action Campaign [in South Africa] is a person who's led a regeneration of civil society around issues of HIV and AIDS and he's taken an identity that has been stigmatized, an identity that was hidden around HIV/AIDS, and made it very public."

Arega Kassa Zelelew, IDEA Ethiopia: "When I remember 39 years back, my life was turned upside down. After facing repeated discrimination, I started to drink; I was a chain smoker. One day I thought, 'What am I doing?' So I started to think beyond disability, beyond stigma, beyond the disease. My life started to change. I started to resist.

"I helped found ENAELP, the Ethiopian National Association for Persons Affected by Leprosy, and also the Ethiopian Federation for Persons with Disabilities. If you fight, if you struggle, we can win, we will win. Now we have got the international organization IDEA and we have to resist social stigma, discrimination, isolation . . . . Our colleagues, our companions on Robben Island from 1846–1931, they were fighting alone here on this island. Now we are united and this gives us strength."

Anwei Law: International Coordinator, IDEA: "We all know that resistance takes a lot of different forms. There are lawsuits but there is also the creative expression of resistance through music and art and poetry. Certainly in Japan there is this wealth of poetry and creative expression that I think represented strong resistance during those very hard times. Within the oral history project and within IDEA, we are very much looking for the creative resistance and we encourage you to help us identify examples of this creative resistance."

Dr. Wim Van Brakel, Royal Tropical Institute (KIT) Leprosy Unit, The Netherlands: "I want to mention another side of the legal aspect. One is the repealing of any laws that might still be there that actively repress people affected by leprosy. On the other side, there may be some countries where there isn't a law like there was in Japan, but still you find that people with leprosy and people perhaps with other disabilities have been marginalized very seriously, either by civil society, or just by the community. And, you would also find that those countries have also signed disability acts as part of an international effort to try and raise the status of people with disabilities. So . . . . [we can] see if there is pro-disability legislation which would provide, for example, quotas for jobs or education. If that is there, it is important to fight to get that enforced . . . . for example, in India, part of the struggle is to actually get people to recognize that people with leprosy related disability come under that act and should have the right to have the same facilities that people with other disabilities would be accorded."

Stigma & Identity

The Effect of Stigma on Individuals & Families

Jose Ramirez, Jr.: "I can trace my family history all the way back to a small fishing village in Spain. That is very important to me and to my family . . . . When a person is diagnosed with Hansen's Disease, oftentimes that person's history is taken away . . . . whether it's through laws or through practices of different countries . . . . If you look at all of this collectively, the stigma throughout the world becomes a very powerful force . . . . I'm hoping that you will go ahead and focus, not so much on what we have lost, but on what we have gained and continue to gain."

Bhekani Memela, Sinikithemba HIV+ Choir, South Africa: "I am HIV positive. I am part of the choir which is called the Sinikithemba HIV+ choir. Our mission is to educate and help people to be in a position to disclose their status and to check their status, especially in the rural areas. In South Africa we are still facing the serious problem of stigma. . . .[which] is very high in our country. There are many, many, many dangers which you face when you disclose your status. We have people who have been killed because they disclosed their status . . . . staying quiet and not discussing or sharing your problems that you are facing with your disease doesn't help; instead it perpetuates the stigma.

"Ignorance becomes a barrier for people to help other people. We are trying right now to educate people, to make them aware, to share our stories. We are HIV+. HIV is here. It's real and it kills. There is help. It's only that people . . . . don't want to come forward to go to the counsellors, to go to the clinics, to say I'm having this problem with my life. If I myself and the other 14 members of the choir can go public and tell people that we are HIV positive but we are still living a fruitful and a healthy life, then we think . . . . that we will be in a position to reduce the level of death, to reduce the level of ignorance and to reduce the level of stigma."

Dr. Harriet Deacon and Inez Stephney and Sandra Prosalendis: Understanding HIV/AIDS stigma: a theoretical and methodological analysis.

This theoretical and methodological analysis is the first phase of a project initiated by the HSRC's Social Cohesion and Integration programme in Cape Town, in collaboration with the HSRC's Social Aspects of HIV/AIDS programme (SAHA). The larger project will develop ideas and test methodologies that can shed light on research on stigma in other contexts. We will also make recommendations about interventions to reduce the impact of HIV/AIDS-related stigma. This can support and inform the work of government and NGOs in managing the effects of the HIV/AIDS epidemic.

Most of the research on HIV/AIDS stigma has been done in the US, a country with large research resources, an early epidemic and pronounced stigmatisation of gay men, African-Americans and Haitian immigrants as carriers of HIV/AIDS. Considerable research attention is now being focused on HIV/AIDS research in general in Africa because of the severity of the African epidemic, the politics of the HIV/AIDS issue, and the fact that HIV/AIDS seems to be highly stigmatised in the region. However, the relative 'lack of scientific research on the manifestations of HIV/AIDS-related stigma in [Sub-Saharan Africa still] presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS related stigma' (Lorentzen & Morris 2004:27).

The problem of HIV/AIDS stigma in Africa has been raised in related research on barriers to testing, treatment, care and adherence, on quality of life, and on social responses to HIV/AIDS. It is important to understand HIV/AIDS stigma in relation to the broader social, political, economic and cultural context, and to address stigma as one of a number of causes of discrimination, reluctance to test, therapeutic non-compliance, and so on. First, however, it is, however, essential to clarify exactly what we mean by stigma, how it arises, and how it works, so that we can suggest ways of reducing its negative impact on society. Important recent work on HIV/AIDS stigma in South Africa includes Posel (2004), Kalichman & Simbayi (2003, 2004), Patient & Orr (2003), POLICY project (2003a), Stein (2003), Shisana & Simbayi (2002), Jennings et al. (2002). Research on HIV/AIDS stigma in other African countries includes ICRW 2002, Muyinda et al. 1997, Bond et al. 2002, and several Bergen University theses: Lie (1996 cited in Lorentzen & Morris 2004), Oduroh (2002 cited in Lorentzen & Morris 2004), and Lorentzen & Morris 2004.

In order to conduct this literature review, we compiled a database of recent academic work on disease stigma across various disciplines and across different medical conditions (although we focused on HIV/AIDS). Our database (which currently stands at over 3,000 entries) is not yet fully comprehensive, nor yet fully representative of the admittedly meagre amount of current African research, but it provides a good general overview of the available material.

This paper critically reviews academic

literature on disease stigma that can help us to:

1. Develop more sophisticated theoretical approaches to understanding stigma in southern Africa,
2. Develop research methodologies to better understand the historical and cultural specificity of stigma, and its impact on the treatment and care of PLHAs in southern Africa, and
3. Inform the development of better anti-stigma interventions in southern Africa.

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Anwei Law, IDEA: "One of the things I've noticed, and we brought it up in Brazil, too, was that when people do social science research papers, they use quotations from people who have had leprosy, but usually don't use their names. Usually this is said to be out of ethical considerations. However, I think that when dealing with issues of stigma, one has to rethink this. I just saw a paper on stigma and HIV/AIDS that identified someone simply as 'a woman from Thailand' – it's possible that the women requested this, but equally likely that the researcher suggested this. In any case, it serves to increase anonymity, which perpetuates stigma. I think that the people doing social science research need to really think about this. We have seen that identity is a critical part of eliminating the stigma and when you do not attribute a quote to a person, you are taking away their identity, which might also be regarded as unethical. It's a challenge. It's important to guard privacy as requested by a person, but important not to encourage anonymity, which only adds to the stigma."

Jose Ramirez, Jr., IDEA USA: "A scientific . . . method [hasn't been] developed yet that will measure stigma because there are so many differences in language, in culture, in geography, in laws, so it's really very hard. In my opinion, stigma is actually an act of rejection or labelling or unexplained fear of a person or even of oneself because . . . . we learn about stigma even before we're diagnosed."

Amar Timilsina, IDEA Nepal: "When I was nine years old and was going to school, I used to have needle pricking competitions among my friends, because of my loss of sensation . . . . When I eventually started the treatment, my suffering started because other people came to know that I was suffering from the disease. When I went back home and started going back to school again, they refused to have me in the class. So I was thrown out of the school as well as from the community. I was compelled to forsake my family and the love of the village where I was born and brought up . . . . I made up mind to commit suicide several times, but by the grace of love and good support from the hospital and staff I got additional energy to tolerate the pain and wait for the bright future . . . . Slowly I started getting the dignity back into my life. I got married, I have two children and am now the General Secretary of IDEA Nepal."

Jaimie Tomas Cabeto, ARPAL/IDEA Angola: "In 1978 I started hearing and learning about people affected by leprosy. We were children and as we saw those people in the leprosarium we thought that was something very odd, very strange . . . . It took a long time for the doctors to find out what I had. I went to several clinics, saw several doctors but they couldn't tell what I had . . . . When the health professional told me the diagnosis, I was crushed. I started taking the treatment but I was afraid of telling my family I had the disease. As time went by and as I got involved in the Association of People Affected by Leprosy, ARPAL, in Angola, I started feeling courage to speak about the disease and to tell my family about the diagnosis."

Rev. Albrecht Hahne, South Africa: "If you look at the term stigma, it is a mark. If I look at my hands, they are marked hands. If I look at my face, it's a marked face. In other words, I can say whatever I'd like, but I will always have to live with this mark. I can tell other people that that mark is nothing, but every morning I get up I see that mark. Every day that I get dressed, I am reminded of that mark. The stigma is part of my life, of my existence. If I try to shy away from that, I actually need to try to shy away from a part of my existence . . . . That'll to my mind be a decimation of my own life. I would return my life to nothingness . . . . I myself have come to this point that I accept the stigma of my life. . . My life is a life marked by leprosy . . . .

"If society is not prepared to accept us as what we are, society is not worthy of us . . . . I firmly believe that this, my life as it is, is a unique life given to me by my Creator, I call him God. He said this life is going to be so valuable that I will put everything into this life that is necessary for this life to develop to what it is . . . . All of you know I'm a pastor of a Christian Church. I've led three churches, one church of over a thousand people and I must tell you, there was not one house into which I couldn't go. At the moment I'm leading a church of over 500 people; there's not one house that I cannot enter. I believe the main thing . . . . is to say I accept what I am and with what I am, I will move out into society. If you have to run away, run away.

"Are we going to return into a cocoon of silence, cover everything up, don't talk about it, or are we going to share it with the society where we're going to live. We share it. Let us bear this mark, this stigma, with courage. Let's face the world with courage. And we can help others to come to terms with the facts of their lives."

Breaking the Silence: Women & Stigma

Zoica Bakirtzief, American Leprosy Missions, IDEA Brazil: "Let's say a woman is dependent on her husband for income, dependent on her husband for housing and for providing for her children and her future and old age. If that husband rejects her and she's also unskilled and doesn't have other resources, that's a survival threat. It's not a simple threat. So would you ask her to disclose her diagnosis? I'm just posing a question. Maybe the issue, perhaps, is not to have women so vulnerable to such situations, such as a disease. Economic power and independence, the possibility to not depend upon others for one's own survival, it's a basic need for women and for men. So we have to consider the economic aspect of rehabilitation as an important issue in human rights because it has to do with survival, and if you are faced with the threat of survival, it's very hard to cope with anything else. It's a burden too hard to bear."

Zilda Borges, Brazil, IDEA Latin America: "We know that women have been discriminated against in many parts of the world . . . . in relation to employment, income, and participation. We also know that many women have fought for their rights all over the world to overcome discrimination. I have met women with their heads bowed down, women who are part of the women's movement, or other social movements, but who do not speak about their experience with Hansen's Disease. I have also met women with their heads held up high, who speak with people in the community about the disease. But the number of women who have their heads held up high is much smaller those who bow their heads.

"In the work I do amongst women, I give priority to the women who are living in silence. The methodology that I found to address their silence was to promote meetings. One woman, two women, three, four, five, that's all. The groups are different, one from the other, and we've had groups that merged into other groups. The goal is to get the women involved and engaged and merged into other social movement groups."

Mimi Badamuti, Sinikithemba HIV+ Choir, South Africa: "The question is, is the stigma ever going to end? That's the question I ask myself every day. Every time you are talking about HIV and AIDS, people, they think you are talking about a wild animal that can pounce on them, attack them and kill them instantly. But it's not. I've got a great experience about stigma, because in our country, here in South Africa, we are labelled. It's none of anybody's business that you are HIV positive or HIV negative, but people think it's their own business . . . . the main problem is with us women. Once you disclose your status to your partner it is the last time you hear from him. He goes, he disappears. Sometimes, most of us women, we find out when we are pregnant that we are HIV positive, and the man is leaving you because you just told him that you are HIV positive . . . . Once the man is gone, sometimes you are not working, you are unemployed. You have no one else to buy formula for the child. You are not supposed to breast feed the child, what will happen after that? The child will be malnourished and she or he will have nothing to take into her stomach or his stomach. "For me, I was fortunate enough that my family was so supportive to me and even now they are so supportive to me even though I am HIV positive. And I was fortunate enough that the girl that I give birth to is HIV negative. She is now 7 years old and she is healthy, she looks nice, she is big, she is beautiful like her mother. So for us women, we must stand up, we must break the chains, we must break the silence, and speak out . . . . For me, I live positively with my status, I reduce stress, I talk to my virus. I tell my virus that if it kills me, we are both going down together . . . . So women, men with HIV/AIDS and leprosy, let us stand up and fight together, and fight these diseases . . . . and fight stigma, discrimination."

Culture, Identity & Stigma: The African Experience

Dr. Jean-Paul Bado: French Colonial Africa

In the nineteenth century, many explorers in their reports pointed out that they discovered many affected by leprosy in Western Africa who carried out different social activities, and even married (sometimes with many wives). For many ethnic groups, those with leprosy lived in societies without ostracism, except in some region of Dahomey (currently Benin and the northern Ivory Coast) where those with the signs of the disease were banished by their societies and more directly by their family. With the development of the colonial economy, the colonial administration decided that those with the disease became more and more an obstacle to its development plans. In French Sudan (and other colonies, just after the International Conference of Leprosy in Strasbourg), certain administrations expelled many affected by leprosy from colonial towns for different reasons. They were arrested for begging, which was forbidden by the colonial administration. Dr Marchoux, who had been studying the disease since 1897, managed to convince those in charge of health in the French colonies to build a modern leprosarium for people with leprosy in French Africa. In 1931, the French Western Africa health policy makers created "service de lutte contre lepré". Three years later, they built the *Institut Central de la Lepré* which was unveiled in 1935. Those affected by leprosy had a centre where specialists in biomedicine tried to understand all the mechanisms of their disease and treat it. The fight against leprosy was also a fight for everyone."

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Linda Beer Kumwenda. "To save our Empire's Children ". Mission Leprosy Settlements in Northern Rhodesia.

This image, taken from a missionary journal published in 1907, portrays the accepted view of the engagement of missionaries with leprosy: the necessity for a dual healing, and the association of leprosy with sin.

Whilst this image and much other archival evidence can lead to the conclusion that missionaries did target people with leprosy, placing them within what has been described as a 'total institution', and thereafter attempted to reconstruct them, a closer examination reveals a more nuanced trajectory in Zambia. In this brief presentation, I show through the examination of specific stations involved in such work such as that carried out at Chitokoloki, by the Christian Missions in Many Lands; Mbereshi, where leprosy work was forced upon the London Missionary Society; and Fiwila – the 'village of mercy' run by the Universities' Mission to Central Africa that missionaries in Zambia did not target Africans suffering from leprosy. Additionally, whilst they did use the opportunity provided by settlements for evangelism, they generally found that the work was, evangelically speaking, uneconomic – and did not enlarge their settlements until 100% funding was provided by government – and this at a time when treatment could be given on an outpatient basis, and opportunities for social reconstruction no longer available. Indeed, whilst some missionaries applied damaging labels to those under their care, others saw beyond the disease to the person. Yet others changed their stance over time. Local attitudes to leprosy confirm Iliffe's statement that African reactions are diverse. The Luvale people in the area around Chitokoloki, for example, did not appear to have negative attitudes towards leprosy, whilst the marginality experienced within the Lala community around Fiwila was such that, on being called to sort out a marital dispute Chief Shaiwila remarked, 'These people are already dead. How can a dead man or woman be divorced or marry?'

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Illuminating Ourselves: Redefining Traditional Images

Open discussion – The role of images and language in the formation of attitudes.

Achievements of people affected by leprosy or living with HIV/AIDS, past and present, as a means of challenging stereotypes and the stigma that is perpetuated by them.

From Ingeborg Grytten (Author, Norway, 17th century), to Akashi Kaijin (Poet, Japan, early 20th century) — to the Music of Bacurau (Brazil) and the Poetry of Antonio Borges, Jr. (Brazil) — to the Sinikithemba HIV+ Choir.

Images of Dignity – Pamela Parlapiano

Sunday, February 6 – Human Rights

Alhaji Shehi s/Fada, IDEA Nigeria: "This is the new era for people affected by leprosy that is marked by freedom, from hardship to freedom: What I will say is that in every country we [must] unite ourselves, help each other, cooperate. In Nigeria before, we were not cooperating . . . . but as IDEA came, we began to cooperate amongst ourselves. So let us cooperate, unite, and then face the government . . . . to fight for our own rights."

Artur C.M. de Sousa, MORHAN, Brazil: "Bacarau was one of our founding members. His vision was that of a humanitarian nature. So when he founded MORHAN, 25 years ago . . . . He used to say that we were supposed to bring other social issues to be discussed within the movement . . . . When I met him in Rio De Janeiro, it was a cold, rainy evening. And he pointed at a child who was covered under newspaper sheets on the street. And he also pointed to a car that had had a rain protection cover. And he said—We were supposed to fight against any form of social injustice. Because the same situation, same conditions that cause leprosy discrimination, were the same conditions that made our society protect a car more than a child.

We have 40,000 new leprosy cases per year [in Brazil]. And we have to think that Hansen's disease is part of a group of diseases that are neglected. They have the following characteristics – low political engagement, little information, little power by the groups of affected persons . . . . the poorest or the lowest social strata are the most affected by these diseases, and they are more de-habilitating or incapacitating than deadly."

Professor Bernardino Fantini, Director, Institute of History of Medicine & Health, University of Geneva. Health and Human Rights.

"This paper discusses the history of relationships between health, disease, and human rights, and divergent ideas about what human rights are, and how history can integrate personal experiences and the memory of individuals, groups, and institutions. It started with a definition of history as a way to build up our personal and social identity, to preserve our memory, which is the basis of our personal and collective identity, to recognize our being part of a social group and of the whole humanity, to acknowledge that we all share ideas, ways of thinking, psychological attitudes, theoretical constructs, artistic perceptions, and moral and religious beliefs. It acknowledged that for the whole of human history, infectious diseases killed, disabled, and disfigured. They had and have the capacity to destroy, destabilise, and profoundly modify populations, but they also produced and still produce psychological and moral consequences such as fear or terror, abandonment, exclusion, discrimination, and stigma, but also solidarity, compassion, and mutual help.

Leprosy is a paradigm of a global disease, a paradigmatic experience for looking to the relation between global health and human rights. The memories of what the disease has been and of the human experiences of diseased persons are of fundamental importance in the understanding of the social attitudes towards other diseases, like HIV/AIDS. Many historical examples, including the history of leprosy, show that global health (health for all in the world) will be the result of social action and the empowering of individuals to pursue their own safety and self determination.

Human rights are not abstract nor only the result of legislation or public statements. They refer to the respect for the individual as a person, for his or her dignity, and the right to pursue his or her life. The "right to health" means the right of each member of humanity to realise his or her own potential in life, and this means also the obligation of the national and international authorities to ensure this realisation of potential, even in conditions created by disease or disability.

In centuries past, health was considered as a product of other, more fundamental rights. It was believed that economic growth, scientific progress, education, information would be enough to ensure health for everybody (for example the hygienic movement of the nineteenth and twentieth centuries). Once considered as disappearing threats, infectious diseases have come into prominence in global health with the emergence of new viral and bacterial agents; the spread of resistance to common antibiotics; the devastating impacts of new epidemics from "old enemies" such as cholera, plague, dengue, foot-and-mouth disease, BSE; and resurgent infections of "silent" or "neglected" diseases such as malaria and tuberculosis. Those active in health care can no longer simply act alone without regard for the many other issues and others involved. Health inequities are widening and in global health, millions continue to die from diseases of poverty, despite the accumulation of impressive knowledge and modern technologies.

Historians want to know the social and cultural determinants of this tragic paradox. Human rights are not only the "world of the individual person", but are the result of social conquest, collective initiatives, as the potential for life of each individual becomes connected to interpersonal relationships and social contexts. A human right is individual, but the defence and implementation of those rights are necessarily collective. Strategies for health and human security depend upon individual and collective action. Health equity is the fundamental value underpinning global health; it is both intrinsically valuable, as well as instrumental in achieving human freedom. The globalisation of health responses must be based on the value of equity, on the diffusion and application of knowledge, and on moral indignation over injustices associated with health."

Ensuring the Rights of Humanity: Discussion

Chairs: Professor Bernardino Fantini & Dr. P.K. Gopal

Panel: Alhaji Shehu Sarkin Fada, Chamada Abibo

In Conclusion: History as an Agent for Social Change

Chairs: Prof. Megan Vaughan, Zilda Borges and Anwei Law

Professor Megan Vaughan, Smuts Professor of Commonwealth History, Cambridge University, U.K.: ". . . though I've spent some years reading in the history of medicine and the history of leprosy, it really is genuinely true, I couldn't have learned anything that I've learned in the last 2 days if I hadn't been here, listening to peoples' stories, so it's really a privilege for me . . . . when you hear about the history, the stories that we've been listening to, you wonder if we learn anything from history at all . . . . It's really rather depressing in some ways but there are also some more positive aspects of this.

I want to start by just saying something about the history of slavery, partly because we're here on Robben Island, but also because I think there are some parallels . . . . one might draw. We all know that in the history of slavery is a history of struggle. It is a history of struggle against the deprivations and stigmatization . . . . What slaves were deprived of were their names, their families, their languages . . . . [and] perhaps most importantly of all, their histories. So part of the struggle against slavery and within slavery was to recover a history, but integral to the struggle against slavery was always in the telling of stories. It was always telling your story, telling the story of your people, telling the story of your resistance. And again these stories took different forms but they were very important in the struggle, in the oppositionist movement, in the struggle in slavery.

People who had been slaves whose ancestors had been slaves felt they carried a stigma of slavery. Slavery is not a disease but it's a social condition that can give you a stigma. And they also found that there were other more complex forms of social and economic discrimination that they were faced with. They were faced with racism . . . . they were faced with economic deprivation, they were faced with the fact that they couldn't get proper jobs, they were faced with a lack of education, all those things we know about.

If there are any lessons to be drawn from this then I think for me what I've learned from listening to you all is how you found strength in unity within this organization, IDEA. And I think this is a very interesting case of a very successful, political and advocacy organization from which other organizations dealing with other issues may well want to learn.

I've also been incredibly impressed by the ability of people from such diverse places facing quite diverse kinds of struggles to come together and give each other support and move forward."

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US-Japan Meeting, 2005

Il-1 at the Early Stage of Monocyte Differentiation to Dendritic Cells Impairs Functional Activities of Dendritic Cells

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ABSTRACT

Mycobacterium leprae initially infects monocytes and produces various cytokines, but the role of these cytokines on the precursors of dendritic cells (DCs) is unclear. *M. leprae*-infected DCs were differentiated from monocytes treated with low levels of IL-1β (100 pg/ml), and the functions of these DCs were evaluated. IL-1β treated DCs were inefficient in activating autologous T cells. Although these DCs presented *M. leprae* antigens, the percentage of DCs expressing high levels of CD86 and CD83 Ag was reduced. When LPS, peptidoglycan or *M. bovis* BCG was used as stimulator, IL-12 production from these DCs was significantly reduced, although monocytes treated with other cytokines (TNF-α, IL-6 or IL-10) did not have such effect. We can conclude the IL-1β, at the early stage of DC differentiation, impairs DC function. Therefore, clear understanding of the immune responses will be vital to the design of vaccines against mycobacterial infection.

Dendritic Cell Maturation is Suppressed by *Mycobacterium Leprae*

Rose Ann Murray and Gilla Kaplan

Public Health Research Institute, Newark, N.J.

ABSTRACT

To better understand the host innate immune response to mycobacterial infections, we are exploring the effect of *M. leprae, M. bovis* bacillus Calmette-Guerin (BCG) and *M. tuberculosis* (TB) on antigen presenting cell (APC) maturation. Dendritic cells (DC) are especially good APC, being able to prime naïve T lymphocytes against particular antigens at proximal lymph nodes. However, to function optimally, blood DC must be matured by exposure to stimulatory cytokines and/or the antigens that induce these molecules. We have infected monocyte-derived immature DC with *M. leprae,* BCG or TB and examined the extent of DC maturation, as evaluated by phenotypic surface changes and immune response gene expression. Our results suggest that BCG and TB both stimulate phenotypic and genotypic DC maturation but BCG is much more efficient. In contrast, *M. leprae* appears to inhibit DC genotypic maturation without affecting DC maturation marker expression.

Polymorphism of the 5′ Flanking Region of the Il-12 Receptor β2 Gene Partially Determines the Clinical Types of Leprosy through Impaired Transcriptional Activity

Hideki Ohyama[1], Koretsugu Ogata[2], Tazu Takeuchi[3], Yasushi Uemura[4], Masataka Oyama[5], Masako Namisato[6], Nahoko Kogoe[1], Naoko Yamada[1], Nobuyuki Terada[1], Sho Matushita[4]

[1]Hyogo College of Medicine, [2]Shimadzu Corporation, [3]Okayama University Graduate School of Medicine and Dentistry, [4]Saitama Medical School, [5]Nagasaki University Graduate School of Biomedical Sciences, [6]National Sanatorium Kuryu–Rakusenen

ABSTRACT

Polymorphisms on the 5′ flanking region of *IL12RB2* were analyzed to determined possible immunogenetical factors affecting the establishment of clinical types of leprosy. Several SNPs, including –1035A>G, –1023A>G, –650delG and –465A>G SNPs, were detected on the 5′ flanking region of *IL12RB2*. Frequency of haplotype 1 (–1035A, –1023A, –650G, –464A), which exhibited the highest frequency in the general Japanese population, was significantly lower in lepromatous patients as compared with findings in tuberculoid patients and healthy controls. Reporter gene assays using Jurkat T cells revealed that all haplotypes carrying one or more SNPs exhibited lower transcriptional activity as compared with haplotype 1. These results suggest that SNPs in the 5′ flanking region of *IL12RB2* affect the level of expression and may be implicated in individual differences in cell-mediated immune responsiveness to mycobacterial antigens, leading to lepromatous or tuberculoid leprosy.

Inhibition of TNF or LTa Impairs *Mycobacterium Leprae* Growth in Mouse Foot Pads and Is Accompanied by Dysregulated Granuloma Formation

Deanna A. Hagge[1], Bernadette M. Saunders[2], Gig Ebenezer[3], Vilma Tulaga[1], Nashone A. Ray[1], Warwick J. Britton[2], James L. Krahenbuhl[1] and Linda B. Adams[1]

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ABSTRACT

TNF and lymphotoxin-alpha (LTα) are key cytokines in cell mediated immunity against intracellular pathogens. To study their role in experimental leprosy, *My-*

cobacterium leprae foot pad (FP) infection was evaluated in TNF knockout (TNF$^{-/-}$) and LTα-deficient chimeric (LT$\alpha^{-/-}$) mice. In both TNF$^{-/-}$ and LT$\alpha^{-/-}$ mice, *M. leprae* growth was augmented compared to control mice. Histopathologically, TNF$^{-/-}$ mice developed more extensive and diffuse lymphocytic infiltration compared to control mice. In contrast, few lymphocytes were present in LT$\alpha^{-/-}$ mice. Upon *M. leprae* inoculation, there was a delayed early response in FP induration in both strains; however, induration in TNF$^{-/-}$ mice rapidly increased to levels higher than controls while LT$\alpha^{-/-}$ mice could not sustain induration. Flow cytometric analyses of isolated FP cells demonstrated elevated percentages of CD3$^+$ T cells in TNF$^{-/-}$ mice many of which expressed CD69. Expression of various Th1 cytokines and chemokines in established granulomas were similar or elevated in TNF$^{-/-}$ compared to control mice, but LT$\alpha^{-/-}$ mice demonstrated 5–25 fold lower levels of expression. These studies indicate the critical but independent roles for TNF and LTα in orchestrating and maintaining an appropriate T cell accumulation within the microenvironment of the *M. leprae*-induced granuloma.

Nerve Damage in a Mouse Model of *Mycobacterium ulcerans* Infections—Detection of *M. ulcerans*-specific DNA from micro-dissected nerve tissue

Masamichi Goto[1], Kazue Nakanaga[2], Junichiro En[1], Thida Aung[1], Tomofumi Hamada[1], Shinichi Kitajima[1], Norihisa Ishii[2], Suguru Yonezawa[1], Hajime Saito[3]

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ABSTRACT

Buruli ulcer is a chronic painless ulcerative skin disease in tropical and subtropical zone caused by *Mycobacterium ulcerans*. Recent histological and ultrastructural studies have clarified direct intraneural invasion of acid-fast bacilli and vacuolar change of Schwann cells in *M. ulcerans*-inoculated mice. In order to further investigate the mechanism of painlessness, nerve tissues were selectively cut out from the histological specimens by a UV-laser micro-dissection system, and PCR technique was applied. Intraneural bacilli were proven to possess *M. ulcerans*-specific DNA sequences, but not *M. leprae*-specific DNA sequences.

Advances in Molecular Epidemiology of Leprosy

Miyako Kimura[1], Nathan A. Groathouse[1], Kiran Madanahally[1], Becky Rivoire[1], Xiaoman Weng[2], Huan-Ying Li[2], Juan Camilo Beltran Alzate[3], Nora Cardona-Castro[3], Robert H. Gelber[4], Sang-Nae Cho[5], William C. Black[1], Patrick J. Brennan[1] and Varalakshmi D. Vissa[1]

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ABSTRACT

In order to monitor and break the cycle of transmission of leprosy, a better understanding of the source and chains of *M. leprae* infection by means of molecular epidemiology is necessary. Since *M. leprae* cannot be grown *in vitro* and the DNA recovered from clinical samples such as skin biopsy is valuable, we first established multiple locus variable number of tandem repeats analysis (MLVA) as a method of strain typing in four clinical *M. leprae* strains grown in armadillo host. This approach involved the screening of 25 short tandem repeat (STR) loci, resulting in the discovery of polymorphisms at 13 loci. Subsequently, MLVA was applied to additional archived armadillo-derived clinical isolates from leprosy patients from eight countries for a total of 21 reference strains, and to recent clinical isolates from Colombia, the Philippines and China. These data were analyzed according to parsimony principles to discern genetic diversity and phylogenetic relationships. MLVA has been shown to be a practical and effective method for *M. leprae* strain typing and classification.

What is Needed to Improve Diagnostics for TB and eprosy?

Mark Perkins

Foundation for Innovative Diagnostics

ABSTRACT
Case detection is a major problem for the control of both leprosy and tuberculosis, and the need to detect drug resistance continues to rise. In countries where these diseases are coming under control, the need for accurate tests for latent infection is also pressing. Significant advances have been made in unraveling the genome and proteome of both *M. leprae* and *M. tuberculosis,* and a number of promising new diagnostic targets have been identified. These targets are now being explored for their relevance to the development of clinical tools for the detection of latent infection, active disease, and pathogen drug resistance. The path from reagent discovery to useable diagnostic is a long one, however, blocked by a number of financial and logistic as well as technical obstacles. This talk will put the search for novel TB and leprosy diagnostics into context, highlight the priority needs, and discuss knowledge gaps that stand in the way of development of tests that are ideally suited for the intended settings of use.

Genotyping of *Mycobacterium leprae* by variable number tandem repeats and its application for molecular epidemiology

Masanori Matsukoa[1], Zhang Liangfen[1] and Teky Budiawan[2]

1)Leprosy Research Center, National Institute of Infectious Diseases, Tokyo, Japan 2)Leprosy-TB Program, Health Service, North Sulawesi, Indonesia

ABSTRACT
The transmission mode of leprosy was examined by application of polymorphism of short tandem repeat (STR) in *Mycobacterium leprae* genome. To substantiate polymorphic loci from STR as promising candidates applied for the molecular typing tools in leprosy epidemiology, 44 STR loci including 33 microsatellites and 11 minisatellites were investigated among the 27 laboratory maintained strains. Not all STRs were expectedly polymorphic. Thirty-two out of the 44 loci were polymorphic. Nine polymorphic loci were suitable for identifying genotypes according to the discriminatory capacity, stability and reproducibility. All the strains were classified into independent genotypes by the selected 9 polymorphic loci. Three multicase households were submitted to molecular typing. Two *M. leprae* isolates obtained from one family contact cases could be divided into different genotypes by these polymorphic loci. The transmission of leprosy by some infectious sources other than the multi-bacillary case in the same dwelling was strongly suggested.

Identification of Specific Proteins and Peptides in *Mycobacteruim Leprae* Suitable for the Selective Diagnosis of Leprosy

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ABSTRACT
Abstract. Comparative genomic analysis of the *M. leprae* genome has identified 1604 open reading frames, as well as 1,130 inactivated genes (pseudogenes), and up to 165 genes with no homologues in *M. tuberculosis*. Diagnosis of leprosy is a major obstacle to disease control, and has been compromised in the past by the lack of specific reagents. We have used comparative genome analysis to identify genes that are specific to *M. leprae,* and tested both recombinant proteins and synthetic peptides from a subset of these for immunological

reactivity. Four of the unique recombinant proteins (ML0008, ML0126, and ML2567) and a panel of 58 peptides were tested for IFN-γ responses in PBMC from leprosy patients and contacts, TB patients and endemic and non-endemic controls. The responses to the four recombinant proteins gave higher levels of IFN-γ production, but less specificity, than the peptides. Of the 58 peptides tested, 35 have showed IFN-γ responses only in the paucibacillary leprosy and household contact groups, with no responses in the TB or endemic control groups. Four of the six 9mer peptides tested also showed promising specificity, indicating that CD8 T cells epitopes may also have diagnostic potential. Those peptides that provide specific responses in leprosy patients from an endemic setting could potentially be developed into a rapid diagnostic test for the early detection of leprosy and epidemiological surveys of the incidence of leprosy, of which little is known.

Isothermal Amplification and Molecular Typing of the Obligate Intracellular Pathogen *Mycobacterium leprae* from Tissues of Unknown Origins

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ABSTRACT

Molecular based diagnostic and epidemiology studies require sufficient amounts of high quality DNA. Routine molecular-based epidemiologic methods have not been applied to the obligate intracellular organism *Mycobacterium leprae* because it is difficult to obtain genomic DNA template from clinical materials. Accordingly, we have developed a method based on isothermic multiple displacement amplification, which will finally allow access to quality DNA template. In this report, we evaluated the usefulness of this method in error-sensitive, multiple feature molecular analyses. Using test samples isolated from host tissue, we also evaluated amplification fidelity, genome coverage and regional amplification bias. The fidelity of amplified genomic material was unaltered and while regional differences in global amplification efficiency were seen using comparative microarray analysis, a significant degree of concordance of amplified genomic DNA was observed. This method was also applied directly to archived tissues for the purpose of molecular typing *via* short tandem repeats. This study demonstrated that whole genome amplification can be coupled with error-sensitive molecular-based typing methods on low copy number sequences from clinical biopsies of obligate intracellular pathogens, such as *M. leprae*.

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The Alternative Sigma Factor sigE and Stress Responses in *Mycobacterium Leprae*

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ABSTRACT

Mycobacterium leprae lacks a functional heat shock response mechanism which appears to relegate it to peripheral regions of the body including peripheral nerves. The alternative sigma factor SigH orchestrates the heat shock response by inducing *sigE* and *sigB* gene transcription and their respective heat shock regulons in *M. tuberculosis* (*Mtb*). However, *M. leprae*'s *sigE* and *sigB* genes are transcriptional unresponsive during heat shock conditions. A likely mechanism for this heat shock defect is the lack of a functional *sigH*. However, no recombinant protocols exist for *M. leprae* to directly test this hypothesis. Therefore, we studied the functional capability of SigE of *M. leprae,* using surrogate genetics in a *sigE* knock-out mutant of *Mtb* (ST28) con-

taining a functional *sigH*. The SigE of *M. leprae* restored the ability of ST28 to respond to heat shock and detergent stress and restored its ability to grow in human macrophages providing direct evidence that the SigE of *M. leprae* is functionally capable of regulating specific stress responses and indirect evidence that the lack of a protective heat shock response and potentially other environmental stress responses in *M. leprae* is at least partly due to the lack of a functional *sigH*.

Lepra Reactions After Multidrug Therapy for Multibacillary (MB) Leprosy

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ABSTRACT

There are two distinct, commonly occurring, immunologically-mediated reactional states in leprosy which complicate its course, account for considerable morbidity, including neuropathy, and are the major reason for patients on chemotherapy to seek medical attention—lepra type 1 reactions, reversal reaction (RR), and lepra type 2 reactions, ENL, mediated respectively by Th1 and Th2 responses. In this study we evaluated in MB patients the incidence, severity, and duration of lepra reactions one and two years after the completion of 1-year WHO MDT (139 patients) and 2-year WHO-MDT (295 patients) and compared those results. We have found for the first time that in MB patients lepra reactions commonly persist even after the completion of MDT, occurring 48% of the time in the first 2 years after the currently recommended 1-year regimen and are of considerable severity and duration. Also, the incidence, severity and duration of lepra reactions and the frequency of neuritis were consistently greater after the completion of 1-year MDT than 2-year MDT, and lepra reactions and these complications more frequent in those with a high bacterial burden. Since a major goal of WHO MDT is to reduce the duration needed to care for leprosy patients to a period sufficient to complete MDT, our findings suggest this is not feasible without courting the significant morbidity from lepra reactions observed in this study.