

GLOBAL PROGRAM MANAGERS MEETING ON
LEPROSY CONTROL STRATEGY –
WHO SEARO
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“STIGMA AND DISCRIMINATION: A CHALLENGE TO DISEASE CONTROL”

by Jose´ Ramirez, Jr.

Good ^{morning,} ~~afternoon.~~ ^{dia} ~~tarde.~~ Buenos ^{dia} ~~tarde.~~ Howdy.

Today is a great day in the World of Leprosy as the number of new cases diagnosed with Hansen’s disease (HD) continues to be less and less. It is also a wonderful day because of the giant steps the World Health Organization has taken to address issues that go beyond the general physical treatment of Hansen’s disease.

However, there is also sadness in the World of Leprosy. The level of discrimination against persons affected by leprosy has not declined along with the downward spiral of new cases.

This discrimination translates to stigma. Stigma, in my opinion, is an act of labeling, rejection or unexplained fear of a person. Stigma is generally defined by researchers and sociologists, in particular Goffman, as a process that evolves into a devalue of a group. Stigma is a derivative of a Greek word meaning scar.

With the common use of the “l” word, or leper, persons affected by leprosy have become branded with a scarlet letter; a scarlet letter and stigma that have existed for over 40 centuries and approximately 100 generations of families who have been exposed to the myths about leprosy.

The “l” word has the power to resurrect painful experiences. One is the ~~seventeen~~ reactions (ENL) that can and do occur while one is undergoing treatment. Second is the emotional trauma of watching friends and family members say they believe God punishes those who commit unknown sins, with leprosy.

Our choice of beliefs, and words we use, has a huge impact in determining how we think about others, and how we see ourselves in a mirror.

My comments today are not intended to reiterate the work done on stigma by such notable researchers as Bassegy, Cornelje, Heijnders, Hotez, Tsutsumi, van Brakel and Weiss.

My comments today are designed to build upon the enormous data already collected on stigma; my professional knowledge of trauma, depression and corresponding stigma; and my personal knowledge about stigma. By addressing these three areas in a collective manner, the challenges of disease control can be viewed with different colored lenses. Hopefully this view will result in actions that can assist in lessening stigma and the barriers which impact the non-compliance of treatment prescriptions.

Improving Quality of Services

One of the strategies addressed in the document on "disease burden" refers to potential ways to improve the quality of services for persons affected by leprosy. This discussion can start by tapping into the vast amount of information available on stigma research, primarily collected via interviews. These efforts have attempted to identify or measure different levels of stigma. The outcome has consistently identified factors related to many emotions, including depression, self image, stress, and familial relationships.

Documentaries, media interviews, personal memoirs, oral histories and stigma surveys have one thing in common; the resurrection of past emotions which elicited tears and periods of suicide ideation. The emotions are oftentimes symptoms of vicarious traumatization, and post traumatic stress disorders. These emotions may not manifest to observable behaviors for many years, but an interview or informal conversation may trigger a painful and tearful memory. Many of these emotions have been described as "self-stigma," and this in itself is a label that is stigmatizing.

The emotions associated with trauma are well documented in the surveys on stigma. This information has resulted in a belief that only persons affected by leprosy can provide the empathy, compassion and counseling needed by others with a similar diagnosis. However, persons affected by leprosy may not have the desire nor required training to assist others to overcome emotional pain and confront the myths and misunderstandings about Hansen's disease that add fuel to the flame of stigma.

So, are we suppose to assume that there is no one willing to tackle the challenges of serving as a mentor to others? Not at all! There are many individuals, whether in large metropolitan areas or remote villages, with the desire to be a first responder. A first responder is an individual with the commitment to be trained on a special task or issue and then use those talents to assist others in a time of crisis. Basic clinical tools can be enhanced via collaborative efforts with local clinicians or universities who would have a general knowledge about labeling.

Similarly, the World of Leprosy needs a group of trained first responders, regardless of their personal impact by HD, to address the emotional needs of the individual and family affected by this illness. Members of this meeting would not go to a mechanic or electrician if confronted with congestive heart failure. You would not do this even though a repairman and surgeon are both trained to "fix things." The level, and type, of training makes all the difference in the world. *Additionally, the involvement of both genders is essential. The contributions of women are evident*

Persons affected by leprosy, with a new and empowering label of first responders would be in a position to take the steps necessary to overcome stigma when dignity and respect are missing. Dignity and respect can be restored through the organized efforts of education, counseling and the art of listening. The first responders would become impartial and trained listeners who could import clinical knowledge needed for this process to be successful. An empowered body can positively impact the spirit and infrastructure of a community, resulting in quality services.

at this meeting, but not from women affected by leprosy.

Equity, Social Justice, Human Rights

The actions related to equality, social justice and human rights are critical factors in any discussion related to "disease burden" and stigma. There are four forces that must be addressed, in order to understand their impact on the long-term survivability of stigma. These forces include: religious influence, institutional mind-set, labels of self-stigma, and a lack of partnerships. These forces contribute to the resurrection of stigma, and to the challenge of disease control.

Early this year, Mr. Sasakawa, the WHO Goodwill Ambassador for Leprosy Elimination, was able to secure a written commitment from internationally renowned religious leaders to address the issues of stigma. This was an impressive and important achievement and one that has the potential to touch the lives of many throughout the world.

However, within three weeks after the unveiling of this important signed document, the Global Appeal, many religious faiths celebrated their service with a reading from the Book of Leviticus – "...the man who bears the sore of leprosy... shall cry out 'Unclean, unclean'..." Regrettably, sermons sprinkled with sin, punishment and the "I" word were repeated thousands of times throughout the world. Regardless of the level of inspiration, or lack of inspiration from the speaker, the listener will record the "I" word in their mind and thereafter associate it with sin. This is passive listening, but the influence of religion is actively working every day. Therefore, change will likely need to start at the local level with on-going visits to the local spiritual leaders.

A second force which impacts stigma and disease control is something I call the institutional mind-set. There are four words that seem to be ingrained in the minds of many who work in the world of leprosy. These words are leprous, the "I" word, patients and colony.

The first two "I" words and their facsimiles are never described as anything other than negative terms in all dictionaries of the world. These terms may be historically accurate in the manner that they were originally written, but they do not belong in today's research papers, every day conversation, jokes modern day literature, and definitely not in the written or verbal language of presenters at an international conference to discuss Hansen's disease, or its accompany stigma. Was the "I" word not banned from the world of leprosy at the 1948 International Leprosy Congress? That was 61 years ago.

On October 11, 2009, all of us in this room and everyone we work with, or serve, will have the opportunity to reactivate the 1948 resolution, and to reverse the Law of Silence. The Law of Silence refers to the silent approach of allowing the media and others to use the "I" word without objection. The "I" word will be widely resurrected when the media scandalizes the canonization of Father Damien by automatically linking him to the "I" word. We should remember not to be silent on October 11, 2009, nor any other day that the "I" word is used.

The word patient is defined as "an individual under medical care." Those affected by leprosy become part of the incidence when first diagnosed, then part of the prevalence when placed under treatment, and finally a RFT (released from treatment) when MDT works its magic. However, it appears that in the world of leprosy, once a patient, always a patient – never a person with a unique identity. An individual who suspects they might have Hansen's disease may not wish to seek treatment for fear of being labeled a patient and the "I" word for a lifetime.

Diacone, which eventually became Dapsone, was introduced to the world a few years before the war. Obviously, the cure of leprosy has taken less time than the cure of stigma.

The definition of colony ranges from “a mass of microorganisms” to “a sub-group of persons institutionalized away from others such as in a ‘leper’ or ‘penal’ colony.” The word colony segregates, literally and figuratively, persons affected by leprosy. We should all recognize that people live in communities, large and small.

Research is an important component of science, be it physical or behavioral. The two, however, need to have a better mix, like almonds and chocolate. These distinct properties can create havoc, but the two properties can also create beauty. Therefore, researchers must avoid the label of “self stigma” and instead segregate the data from stigma surveys into a base that can be used by counselors to address the emotional needs of persons affected by leprosy.

Equity in the world of leprosy must move from intent to action, from words to deeds, and from vision to actual policy.

Role of Person Affected by Leprosy

The document prepared for this meeting addresses the importance of partnerships as it can facilitate the attainment of “mutual goals” while fostering a sense of “trust and respect” with a joint achievement on “policy development.” However, the man-made force of partnerships has not consistently resulted in the active participation of persons affected by leprosy. This has been due, in large part, to the lack of co-ownership of policy implementation. The lack of knowledge by persons affected by leprosy about business-like protocol have also contributed to this limited involvement in partnerships.

In many cases, the opportunity to be part of a partnership has been stopped at the door to the board room. This has occurred at a time when the board room needs to be redecorated with a shift in attitudes and perceptions. The board rooms of anti-leprosy organizations should look at their membership and evaluate the manner in which they can separate themselves from silent partnerships to active ones. An educational stipend to teach a person affected by leprosy on the intricacies and unique nuances of boards can pay huge dividends in the long run.

Even though stigma is difficult to remove, there is at least one strong indicator that self determination, or caring for self physically and emotionally, is starting to blossom. For the first time in many years, there is an abundance of very competent and active individuals being nominated for the Wellesly Bailey award. This award is presented to one woman and one man affected by leprosy who has been influential in creating positive change. In fact, two of the recipients of this prestigious award are in the audience today. These opportunities to work collaboratively must continue in order to impact the cessation of stigma. → They are Dr. P.K. Gopal and Zilda Borges

A presentation first made at the 15th International Leprosy Congress in Beijing, China, titled “People Affected by Leprosy as Working Partners”, exemplifies the importance of partnerships. That presentation focused on the limited vision of many, or symbolically, the lagophthalmos of stigma. This limited vision has prevented all of us from transforming the cycle of exclusion to one of inclusion.

The Eye of Exclusion is represented by four concentric circles with the person affected by leprosy in the middle. External, and man-made forces, such as education, language, media, health and politics may gradually exclude the individual from the process of policy development, their community, and family.

This exclusion can eventually reach the point where the individual refuses to comply with prescribed treatment plans to address his physical and emotional needs.

Conversely, the Eye of Inclusion represents an individual empowered to think and act like a person with a purpose, an identity, a name. The individual becomes a part of the family, the community, and the larger system.

Today is a wonderful opportunity to turn the corner and become less labeling, more inclusive, less fearful and better partners to decrease stigma. Our collective actions can make a difference in assisting others to make a commitment to accept the approved prescription for treatment and concurrently lessen stigma.

Our group must be willing to deliver the message that, while those affected by leprosy have varying degrees of physical scars, all ^{have} the same deeply embedded scars in their souls. These scars though can be used as stepping stones to reach the highest level of treatment, and then the door of success – being free of leprosy.

These ideas may not be new to this audience, but it is important not to dismiss their significance. These ideas of “community inclusion,” “emotional well being,” expressions of “opinions” with policy makers, and the end to “discrimination” and stigma just became law in Japan on April 1, 2009 in Act #82, an Act on the Promotion of Hansen’s disease Issues. The Global Program Managers may not have the means to initiate similar legislation, but I am confident that the commitment to attack stigma is very much alive.

In summary, stigma can be lessened and participation in treatment enhanced by identifying, and then attacking, stressors which contribute to the nutrients that feed the seed of stigma. These stressors include, but are not limited to: language – labels in religion, research and treatment; partnerships – delete exclusionary practices and add inclusionary ones; and counseling – make available trained professionals who can act as first responders to the emotional needs of those affected by leprosy.

Today truly is a wonderful day.

Thank you, Gracias.