

A MULTIDISCIPLINARY STUDY OF STIGMA AMONG THE TAUSUG IN THE PHILIPPINES

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Hansen's Disease or leprosy brings stigmatization from others and the sufferer himself. The process may be overt or covert with behavioral and psychological/emotional manifestations. A study among the Tausugs of Mindanao using a psycho-linguistic analysis of interviews, along with a psychological test and the use of archival data, among others, brings to light various perceptions, reactions and beliefs regarding causation as well as coping styles of hansenites, their kin and community members in an attempt to develop more culturally sensitive and appropriate educational materials for an HD control programme.

Introduction

The view that health problems are both socio-cultural and medical has led to the recognition of the role that the social sciences can play in disease control, particularly when the availability of modern drug therapy is not the main problem in arresting or eradicating a prevalent disease such as Hansen's.

In the Philippines, the mere mention of leprosy brings on shudders, nervous laughter, a call on the almighty for mercy or some other reaction indicating fear, squeamishness or a strong aversion to anything related to this unfamiliar sickness. Although Hansen's Disease (HD) was documented in the Philippines as early as the 17th century by the Spanish colonizers, little is known about this most dreaded disease. Some people believe that HD is legendary while others believe it was eradicated some time ago. Only a small number of medical personnel

trained specifically for its control are able to diagnose HD. This scant knowledge of HD has cloaked it in mystery, perpetuated a fear of it and resulted in the strong stigmatization of hansenites.

Stigma refers to the complete or partial discontinuance of the relationships between hansenites and non-hansenites and attendant social acts directed at the hansenites. Stigma/stigmatization results from a lack of knowledge of HD and is largely responsible for this lack of knowledge.

The assumption of this study is that the stigmatization of HD works in some way against effectively controlling and treating the disease. Consequently, this study sought answers to several related questions among the Tausug, an ethnolinguistic group in the Philippines. Why is stigma attached to HD? What are the manifestations and effects of stigma on the sick? What is the significance of stigma management in relation to disease control programmes? Does the medical staff contribute to the perpetuation of stigma and in what ways could the knowledge of stigma help in the improvement of disease control?

The study uses a multidisciplinary approach to examine the manifestations of stigma, its effects on the sick and the community and the coping mechanisms of the sick and their relatives among the Tausug. It was hoped that the knowledge gained could be used to prepare and disseminate culturally sensitive educational materials for an effective HD control programme. To this end, the study concluded with some recommendations for improving the design and delivery of the HD control programme.

Objectives and Research Design

The specific objectives of the study were:

1. To describe and analyze stigmatization and stigma management in relation to leprosy as manifested by the Tausug.

2. To arrive at a body of knowledge to be used in the educational materials and medical staff training of the disease control programme of the Tausug and input into the national control programme.

To meet these objectives, a multidisciplinary approach which included historical investigation, a psycholinguistic analysis of taped oral data and psychological testing and analysis was developed.

Language is an effective source of information because factual information can be gathered from it. But often, the covert messages, thoughts, emotions and perceptions expressed by the speaker's unconscious use of certain lexical and syntactic forms can be more revealing. An analysis of these linguistic forms reveals the more sensitive views of the informants. The results are often more informative than can be obtained from observation or from structured interviews for statistical or quantitative analysis.

For this study, information was gathered through unstructured interviews with hansenites, relatives, medical personnel, other members of the community, folktales and historical documentation about HD. The interviews were conducted in Tausug by the principal researcher and research assistants. The interviewers attempted to elicit information indirectly by inquiring about daily activities, friends, likes and dislikes, desires, fears and aspirations. Direct questions or questionnaires were not used as Filipinos in general do not respond favorably to these.

Interviews were conducted individually, especially with hansenites, or in groups of two or more. Group interviews encouraged spontaneous responses and discussion from which group opinion or norms were revealed.

In addition to the interviews, unobtrusive observations were made of the relations existing between hansenites and the family, medical personnel and the rest of the community. Data from folktales and historical documents were obtained from the community and from neighboring islands and ethnolinguistic groups (1).

The manifestations of stigmatization are expressed either overtly or covertly. Both external and internal stigmatization (self-stigma) are expressed overtly. Some manifestations such as fear, squeamishness, revulsion or disgust may be expressed covertly. The stigmatizer may unconsciously manifest stigma and at the same time deny his feelings. This type of stigmatization is revealed in the language of the stigmatizer.

An analysis was made of language structure such as sentence phrases and lexical forms which expressed perceptions of HD and reactions to the disease in terms of stigma, self-stigma and coping. The informant's choice of structures conveyed overt messages and revealed the covert perceptions and emotional state they were in. The different terms used to indicate the disease were analyzed for types of reactions. The competing terms, archaic forms and innovations used by the informants indicated the change in the intensity of stigma and the coping mechanisms used.

Historical documents were also examined to provide a perspective of HD and its spread in the country. Accounts of its spread and the establishment and progress of the control programme at the national level and in the Tausug community were discovered. Both primary and secondary sources were utilized in reconstructing the historical account of HD and stigmatization. Documentary evidence of stigmatization helped shed some light in the change in manifestations and intensity of stigma. These historical facts were verified by the etymological information found in dictionaries and by comparative linguistic evidence.

Site Selection

The selection of the Tausug for this study was based on three factors: HD prevalence rate, linguistic reasons and the scarcity of studies on HD among their group.

Historical documents show that the Mindanao Treatment Station, a skin dispensary, was established in Zamboanga, Sulu Province, in

1930. As reported in the Memorandum for Treatment Stations and Dispensaries (May, 1931) two treatment substations, Lanao and Cotobato, had been organized. This suggests that HD was a significant and persistent health problem in the area. The language, customs and beliefs of the people in the regions provide cultural evidence that a considerable period of time of HD prevalence must have elapsed to allow the development of such adverse and entrenched attitudes towards HD.

Table 1 indicates that of the provinces with prevalence rate records for HD, Sulu shows the highest rate - 3.89 per 1,000. In March, there were a total of 2,061 registered out-patient cases in Sulu, 1225 active and 836 "floating" cases. Ilocos Sur which is populated by the Ilocano, one of the largest ethnolinguistic groups in the country, shows the next highest rate. Ilocanos populate Ilocos Norte, La Union and Abra provinces which also are among those with the highest prevalence rates. Despite the fact that the Ilocanos (cf. Valencia, Ventura and Paz, 1984, 1986) are a larger and more widespread group, it was decided that it would be beneficial to study a group that had not been studied for HD.

Table 1. The Top Ten Provinces in the Philippines with the Highest HD Prevalence Rates, 1985*

Provinces	Prevalence Rate/1,000 pop.
Sulu	3.89
Ilocos Sur	3.74
Batanes	2.80
Ilocos Norte	2.55
Palawan	1.77
Metro Manila	1.61
La Union	1.37
Abra	1.20
Rizal	1.11
Cebu	1.08

* From the Annual Report of the Leprosy Control Service, Ministry of Health.

Stigmatization by the Tausug

Earlier in the paper, stigma was described as the complete or partial discontinuance of the relationships between the hansenite and non-hansenites and attendant social acts directed at the hansenite. To understand stigmatization by the Tausug, it is first necessary to comprehend their perceptions of HD, its causes and the transmission of the disease. This knowledge is required before we can understand causes of stigma, the manifestations and effects of stigma and the strategies used for coping with the disease.

When symptoms thought to be HD were observed in an individual, stigmatization became operational. It was the perceptions and beliefs of the individual or the community rather than the medical diagnosis which triggered stigma. These perceptions, along with traditions and norms, form the group's attitude towards HD and hansenites.

Figure 1. Ideology of Stigma Diagram

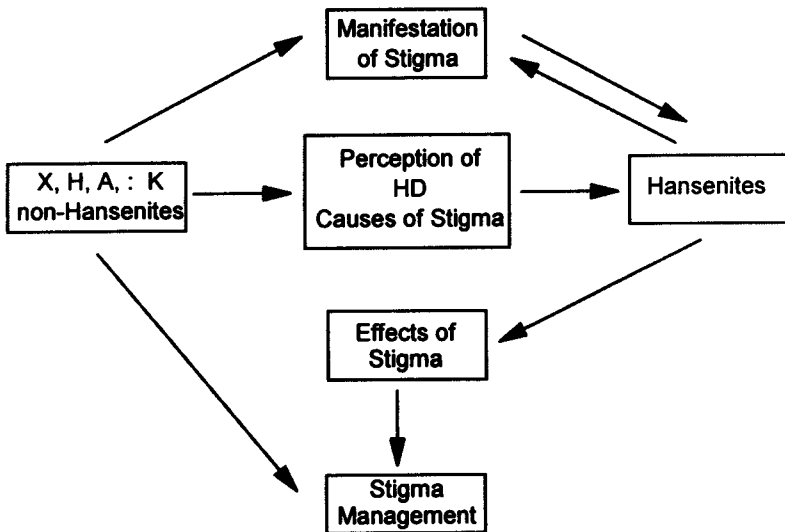


Figure 1 illustrates stigma manifested by non-hansenites and hansenites. Hansenites manifest a stigma directed towards themselves, hence the double arrows directed to and away from them.

The effects of stigmatization on the hansenite reflect the manner in which they coped with stigmatization. In some ways, the close relatives of hansenites found themselves in situations where they too had to cope with stigma. This is illustrated in Figure 1 by the broken line that separates kin (K) from the rest of the non-hansenites in order to indicate their stigma management.

The Language of the Tausug

Since all thought, sentiments and aspirations are expressed in language, language is the most credible source of information. Certain linguistic structures emphasize, clarify and complete the message sent by a speaker. These structures allow and are often responsible for the successful reception of the message by the listener.

In the Tausug language, stigmatization can be better understood by the following syntactic structures.

1. Particles. These linguistic forms reveal the mood of the speaker and give added meaning to the emotion expressed by the speaker.

*I just only stay outside because I now cannot go to our house,
(they) just come to see me already...*

“Only” and “already, now” were used repeatedly to emphasize the change in the relationship between the hansenite and the rest of his family. Other particles used were “really”, “just”, “like”, “as if”, “it seems,” “maybe”, “might”, and “also”.

2. Fixed/set phrases. These consisted of expressions and exclamations that revealed strong reactions. They were often introductory phrases that were used to show the speaker’s position on the matter.

*If you ask me/As far as I know, it seems not...Let it go away!
God forbid. God’s will.*

3. Substitutes and fillers. Substitutes such as pronouns and acronyms were used in place of terms for HD, hansenites or a symptom

of HD to avoid using the actual term, usually as a result of fear or stigma. Fillers were used when a speaker hesitated or wished to avoid saying something.

You would think one would not do what's this, would not go near people.

... because people would what's this, they also (would do) like that.

4. Quotes. Speakers resorted to quoting people of authority or elders to give credence to what they were saying. At times, this was done by implying that what they were saying was common knowledge. This was usually in the form of direct or indirect quotes or sentences which contained "they/he, she said/say." This strategy communicated the caution felt by the speaker in revealing the information in the message.

Eh, from what I hear, they say that it is leprosy.

It is said that their ancestors were cursed.

5. Metaphor. This strategy of using metaphors was used when the speaker sought clarity in describing something or when he was deeply bothered by the topic. In describing the reaction of the people he met on the street, an informant said:

...like they flew as if with wings.

Some informants described HD as "octopus like." A hansenite vividly described his symptoms using metaphors which alluded to objects in his environment.

It was round like a seashell. A kind of shell. Here on my foot. Then it was gone. It came out on my ears. My ears became big already, like a snail.

6. Direct responses. Responses which did not answer a question indicated a studied avoidance of the topic being discussed. For example,

when a hansenite was asked how his disease interfered with continuing relationships with his friends, he suddenly said that death would solve all his problems.

Of course we are all afraid of those who have that sickness. But up to the present, nothing has happened. If I were afraid of contamination, I would not have taken on the responsibility of one who is sick.

The Tausug term translated as responsibility actually means “to carry on one’s back.” This revealed how the wife felt about caring for her hansenite husband. She expressed a feeling that she was duty bound, a responsibility she felt she had to meet. Another wife expressed her faith in medicine. This faith helped dispel her fear.

Medicine, there’s medicine to cure it.

Squeamishness/Revulsion

Squeamishness towards the disease was quite common due to physical symptoms such as rashes, watery pustules, bumps and the more serious deformities exhibited by the hansenites. This reaction was different from the fear of physical deformities discussed above. Squeamishness or revulsion was an immediate reaction on contact or to direct experience with HD or hansenites. Fear of physical deformity was not the result of any direct experience but was brought on simply by the knowledge that it could happen.

The next sample illustrates stigmatization brought on by squeamishness or revulsion. The use of “that thing” or “what/how do you call it” as a substitute for the term for HD or as a filler to bide time while thinking what to say next, communicates the uneasiness brought on by this fear.

An informant expressed his revulsion at the idea of touching or shaking the hand of a hansenite in this manner:

I might shake hands but that is my feeling about it, I might shake hands...I might shake hands but even if he were a friend with that, that is only his hand...that is a little bit (part of his hand). You see it would (have to) be a friend, but it wouldn't be like from my heart (sincerely) that is wholeheartedly.

The repeated phrases, use of fillers “that thing” and his decision to shake hands if the hansenite were a friend, but qualifying that he would only hold a portion of the hand and would not do it with sincerity, aptly communicated his squeamishness or revulsion towards the hansenite.

Customs and Beliefs

Certain customs and folk beliefs were partly responsible for the attitude of the Tausug towards HD. The belief that the disease was highly contagious was probably the basis for the folk belief that HD originated in the “Northern part of Jolo” ie. some distant place. The belief that the disease was the result of a curse or a punishment from the Almighty was often expressed by the informants, especially by the hansenites and their kin. The rituals used by folk healers to “cure” HD were dreadful enough to cause stigma and manifested the severe treatment hansenites expected from the community. Many of the rituals amounted to virtual punishment for what some hansenites perceived to be a situation beyond their control.

As part of their notion of contamination and transmission of HD, the Tausug believed it was necessary for the corpses and belongings of hansenites to be burned.

Folk or indigenous cures were used extensively and were usually the first treatment sought for most ailments. It was only when the condition of the patient seemed hopeless that medical help was sought at the skin clinic or sanitarium. The strong faith in indigenous medicine and the failure of these cures was partly responsible for the perception that HD is incurable.

Perceptions of HD

The analysis of language and linguistic structures revealed the Tausug's perceptions of HD, its causes and transmission. These perceptions are important to understand the reasons behind its stigmatization. For instance, the Tausug perceived the disease as a dirty sickness.

Eh, (one) becomes dirty with that sickness. Eh, even if (one) gets well, it will not be the end of it.

HD was consistently described as a Tausug word meaning to corrode, disintegrate, be eaten into, gnawed or to wear away gradually. This word aptly depicts the perception that the disease inevitably leads to frightening deformities.

HD was often identified as a "melting/disintegrating sickness." The verb form in this case designates a progressive aspect.

Causes our flesh to disintegrate.

...so long as it causes melting/disintegrating like that (of) the hands, feet, they say it is leprosy.

This perception had economic implications contributing to the attitude which nurtured stigmatization. Most informants expressed anxiety over the disabling effect of HD which they believed incapacitated and prevented them from earning a living.

The Tausug believed that HD was caused by either natural or supernatural causes. The natural causes included things taken internally such as chicken, salt or salty water. One common belief on causation is the concept of *kagaw*. The concept of infection is related to this belief.

The Tausug believe that HD is caused by a germ. Although they do not conceive of the germ as a microbe, they believe that the *kagaw*, a minute insect-like organism enters the blood stream and causes the ill-effects of HD, especially the rotting of flesh. A similar concept was

found among the Subanon, an ethnolinguistic group located in an adjacent area southwest of Zamboanga. According to the Subanon, the germ is of different colors causing different types of HD and exists in a certain variety of bamboo.

The Tausug believe that HD is highly transmittable because the *kagaw* can crawl easily from one host to another. Conversing or shaking hands with a hansenite, buying from the same store, bathing in the same place or just being near a hansenite exposes one to the *kagaw* and HD.

The Tausug also believed HD had a life of its own. In describing their symptoms, a number of informants referred to their sickness as a living organism, as in the following example.

(It) disappeared, the moving thing died. When I grew older, it moved/lived (again).

The data show that poor health habits were perceived as one of the reasons for the disease spread. More prevalent was the belief that chickens were instrumental in the transmission of HD. The informants reasoned that since chickens were allowed to roam around freely, they could eat anything including human feces. In all probability, chickens picked up the *kagaw* which was then transmitted to humans through chicken meat and eggs.

Infection was considered more virulent for those with open wounds. The belief that HD was the result of neglected skin ruptures indicated that the disease was progressive and even terminal. A number of informants reported that HD started as a wound and then spread to the rest of the body.

It started as a wound on the foot...then it climbed to my face.

Many informants believed that HD was caused and transmitted genetically through the blood.

If you have the same blood, (you will get) that sickness. If you do not have the same blood, even if you embrace night and day, nothing will happen.

Having weak blood, which actually means being weak or unhealthy, made one susceptible to the disease.

Besides the natural causes of HD, supernatural causes such as fate, spirits or curses were revealed in the data.

Eh, I was probably destined by the master.

I think it was planned by Almighty God that I would get sick like this.

The Causes of Stigma

The data showed that the causes of stigmatization among the Tausug were fear, squeamishness, customs, folk beliefs and lack of knowledge.

Fear

The fear of the disease was expressed in strong terms. It was considered by some to be second only to death. The mere mention of HD brought on responses such as:

I don't know anything (about it) and I'm afraid (of it).

God forbid, no, let it go away.

The fear of HD was based on the fear of contagion of physical deformity, of the loss of the ability to earn a living and of ostracism. Mainly because of the concept of the *kagaw* which was believed to be highly mobile, a strong fear of contagion was noted in two groups of informants: the associates of the sick (A) and those who knew no one with HD (X). The two other groups, the hanzenites (S) and their kin (K), did not express the same fear. Hanzenites no longer had this fear and their kin expressed a fatalism rooted in their religion and acceptance of God's will.

The perception that HD is dirty or causes one to be considered dirty adds to this fear. The following excerpts show the fear of contagion of what is perceived to be a dangerous and incurable disease.

I'm afraid of him because (of) that, I know (it) is dangerous. It's really very contagious because my mother said it takes a long time to cure that sickness. It doesn't get cured (even if you cure it), it (stays) in the blood and in the veins/nerves. What are called kagaw eat (drink) human blood. Even you put them in boiling water, they don't die.

Another fear, the fear of physical deformity, was intensified by the belief that the deformity caused by HD was inevitable, irreversible and permanent.

Customs and Folk Beliefs

Indigenous healers were often consulted and rituals and offerings to the spirits made often. One ritual cure practiced by the Tausug is based on the concept of the *kagaw*. This organism was believed to feast on fresh blood. A cow was slaughtered and its entrails removed. The patient then crawled into the slit abdomen. Attracted by the fresh blood, the *kagaw* would leave the patient and transfer to the slaughtered cow. After a short while, the patient was taken from the abdomen and the cow along with the *kagaw*, presumably, burned.

A man sick with leprosy should kill a cow. My father was a healer. He would slaughter a cow. Put the one sick with leprosy inside the cow, afterwards when he gets out, the cow is burned so that the kagaw was left inside. My father healed two women sick with leprosy (in this).

Another ritual called *kaja* was an offering of chickens, coconuts and gantas of rice, eleven of each, and a sum of money. The offering included prayers and was performed on top of a mountain.

Lack of Knowledge

The prevalent reason for stigmatization was ignorance or lack of knowledge of the disease. All the other causes of stigma, except to a lesser degree squeamishness, can be traced to ignorance of cause, transmission or cure of HD. The hansenites and their kin did not exhibit this as much as the other two groups.

Manifestations of Stigma

The stigmatization of HD by the Tausug was manifested behaviorally and psychologically. Behavioral manifestations included ostracizing or isolating acts which were observed in the communities under study. The psychological or mental manifestations were gleaned from the language data and the results of the psychological testing.

The Tausug maintain strong clannish ties. This was a consideration in an individual's relationship with friends or relatives who were hansenites. In general, the closer the relationship, the weaker the stigmatization was manifested, at least overtly. Often, continued association with hansenites was done grudgingly or conditionally by relatives or friends.

Figure 2. Intensity of Stigma

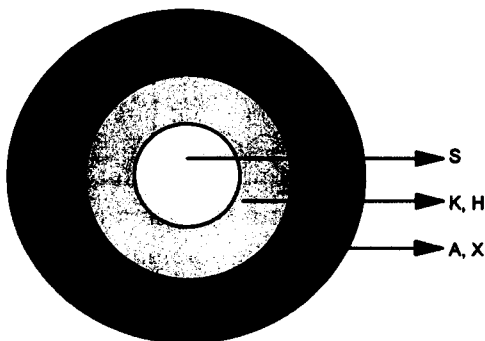


Figure 2 illustrates the intensity of stigmatization relative to the social and interpersonal relations of the stigmatizer and the stigmatized. The darkest shaded area represents the A (associates) and X (those who do not know a hansenite) members of the community. The lighter shaded section represents the K (kin of hansenites) and the H (health staff) members, and the lightest shaded area represents the S (hansenites). Self-stigma (cf. Section on self-stigma below) accounts for the shading of S which was observed to be much weaker than that coming from other stigmatizers.

Behavioral Manifestations

The behavioral manifestations were either overt acts directed at the hansenites or rituals and practices of the group towards hansenites. Acts such as covering the nose with a hand in their presence, teasing, laughing or jeering at them were practiced by children or young adults who belonged mostly to the X group in the community. More serious acts of ostracism or isolation which signified strong stigma were also gleaned from the data.

Serious HD cases such as those with ulcers, clawed hands and other deformities were severely ostracized. The Jolo Sanitarium's social worker stated that these hansenites were treated like outlaws. It was not unusual for them to be denied public transportation so that relatives had to pick up their medication from the skin clinic.

At the community level, isolation of hansenites was either a group or an individual act. Communities of hansenites and their families have grown outside both hospitals in Jolo and Zamboanga. The hansenites in these communities were patients who had been discharged from these hospitals and those who were not eligible for admission to them. Due to ostracism, they preferred to live in these communities with others of their kind and avoid stigmatization. It was often the case that their immediate families came to live with them.

Several customs practiced by the community promoted the isolation of hansenites. One was the building of a separate house for the hansenite usually located within the yard of the main house.

The only one close to him was his mother. His mother is the one that takes him his food in a small house... which was made for him near the fence... there she takes him his food.

He doesn't mix with others (socialize) anymore. People don't speak to him, for (its) truly contagious. Meanwhile, a house was built for him far away. We who lived nearby (neighbors) avoided eating chicken, eggs, water (bathing).

The hansenites feared unemployment which contributed to building stigma. The prospect of an unproductive future caused depression and at times motivated attempts to keep their sickness a secret. An informant expressed her belief that HD was not contagious but then contradicted herself by saying that she would not hire a hansenite.

If you don't have the same blood as they do, even what you do, you won't (get it)...It's hard to have them here (hire them) with a child (in the house). I will not get (hire) one if I know he is sick.

Psychological/Mental Manifestations

Linguistic evidence of the Tausug's stigmatization of HD was easy to discover. The terms they used to refer to the disease indicated psychological or mental manifestations of stigma. The term for HD in Tausug is *ipul* but this was studiously avoided because of fear that mention of the word could cause contamination. The strong aversion to the effect of HD on appearance or squeamishness triggered by the term resulted in several substitutes for the term.

One substitute was the term *leproso* from the Spanish *lepra*, or English "leper". The terms "leprosy" and "leper" may be highly stigmatized in English-speaking communities but these and *leproso* were used by the Tausug precisely to avoid the indigenous and more emotional *ipul*. Because these are foreign and foreign sounding, they are free of negative connotations. Borrowed terms neutralize the negative effect which the indigenous term may connote.

Other terms which indicate strong stigma were used. The least negative of these terms is derived from the root "sickness". This seemed merely to state "having the sickness" but the fact that "the sickness" was invariably understood to be HD said a lot. The term was also considered derogatory. Four other terms use the noun "sickness" along with a descriptive word: "sickness (that) melts/disintegrates/rots/ or wears down", "bad sickness", "sickness which cannot be named", and "different/strange sickness". All four are terms indicative of the attitude towards HD. The first one showed the fear of physical deformity. The next two connoted fear of something evil or unmentionable. The last one hinted of mystery; it connoted something beyond specific labeling.

Self-stigma

As part of the community, the hansenite possessed the same attitude towards HD as the rest, subjecting himself to some degree of self-stigma. This often diminished after the hansenite realized or accepted that he had HD (see Fig. 2) and learned to cope with it. Initially, the hansenite subjected himself to some degree of self-isolation. Some hansenites manifested this overtly by keeping to themselves, hiding or avoiding strangers. This was also manifested covertly in the language they used in speaking about themselves.

There were two linguistic strategies used by informants which contained self-stigma. The first was avoiding the name of the disease and using attributes. "The sickness", "that sickness", "different sickness" were the expressions used in lieu of the word for HD. The second strategy was the substitution of the first person singular pronoun "I" and "I (enclitic form)" with other pronouns, usually the plural forms "you and I (exclusive)" or "we", by hansenites when talking about their sickness. This would deflect attention away from the self (singular) by seeming to include others (plural).

Our sickness is like the one in Pasalobong.

The following excerpts describe self-stigma as observed by informants from the K (kin) and A (associate) groups.

He just sits around the house that way. That's it, he just stays at home. He doesn't have work anymore because he can't get any kind of work. Whatever work, people will not what's this, not even minding chickens, if they find out they will not buy (from him) because they are careful that they (the chickens) may have eaten that, yes, the excreta, which they say has those (germs).

My friend Tagaran, I think she's from Alu, she often covers her head (and face) with a towel, it's like what you would say...damaged (already), and even her little fingers. The thing on her body at times, she wears long clothes, she lengthens them like that to hide that (thing).

The language in this last example illustrates the self-stigma of a hansenite and stigmatization from a non-hansenite. The informant clearly revealed her attitude in the use of the filler “that thing”, by avoiding the mention of the symptoms “the thing on her body”, and by avoiding the term HD and substituting “that (thing)”. The description of the hansenite’s manner of dress illustrates self-stigma.

The Impact of Stigmatization

The Tausugs’ perception of HD and the causes and manifestations of stigmatization have been discussed. A logical sequence to this is to examine the effects of stigma on the hansenites and the rest of the community. The data show that the negative impact of stigma on hansenites and non-hansenites resulted in the breakdown of social norms highly cherished by the Tausug. Relationships within the extended family suffered to the extent that often, the patients could only interact with members of their immediate family. Relationships within the peer group were also strained although efforts were made to avoid shaming the sick member of the group. Confrontational situations were avoided as much as possible. This often resulted in the

isolation of the stigmatized. The hansenites showed their bewildered emotional state by constantly questioning “Why do I have the disease? What is to become of me?”

Life Event Stresses

The results of the psychological testing shed light on the effects of stigma. The purpose of the psychological testing was to identify the stresses which underscored the impact of stigma. The tests showed that hansenites were most distressed by life events related to HD. They ranked these in the first 10 of a list of negative events which they considered most stressful.

The male respondents ranked “Seeing my spouse get stabbed by an enemy” as 1 with a 98 value but the succeeding ranks 2 to 8 were all stressful events suffered as a consequence of HD. The female respondents on the other hand ranked the negative events related to HD 1 to 9 with “Death of my grandmother” intervening as rank 8. These stressful negative events are listed by rank and value in Table 2.

Table 2. Negative Life Events

	Male		Female	
	Rank	Value	Rank	Value
My shame and sorrow about the disease	2	96	4	85
Getting sick with leprosy	3	95	5	84
When my sickness (leprosy) gets worse	4	90	9	75
People avoid me because of my illness	5	86	2	87
Hearing negative remarks about my illness	6	85	1	89
People tease me about my illness	7	84	3	85
Borrowing a lot of money because of my illness	8	83	6	82
Inability to earn a living because of my illness	10	80	7	76
When my back gets swollen because of my illness	16	66	11	72

The females generally had lower estimates for negative events. This could mean that they were more conservative in quantifying their experiences than male respondents. However, the female respondents gave higher values to the events related to the need for affiliation, demonstrating that they value this more than the men. Another

interpretation could be that the women were able to handle the stresses that came with HD better than the men and therefore did not perceive these stresses as negatively as the men did.

Emotional Effects

Other emotional effects of stigma were hopelessness, anxiety, melancholia, wistfulness, bitterness, resentment and a determination to get well. One of the most common was the feeling of hopelessness. This was particularly expressed in relation to attaining goals.

If I didn't become sick like that, I would have finished my course. My ambition was to become a teacher. If I didn't become sick, I think my future would be very very good.

Understandably, the hansenites suffered melancholia. This was usually expressed along with the lament over the loss of friends.

I have no more friends since I have had this sickness. My only friends are my relatives.

Another common lament was not being able to go to the mosque.

Since I became sick like this, I no longer go to the mosque because I am ashamed (to face) my friends and others.

Often, along with a deep sadness, was a desire for what the hansenites perceived to be beyond their reach.

My heart is sad. I want to become clean like I was before. Even if I am now old, I want to be without sickness, unusual/unmentionable sickness.

My ambition/desire is to become like everyone else, (that is) also my children.

Bitterness and depression were effects caused by the belief that HD was not only a punishment for a transgression but that it was almost impossible to cure. Despite this attitude, the Tausug still called upon God for help.

Our family lived at a distance. Every time I went to the well, the people (there) would whisper, "Don't what's this (go there), that sickness is contagious." It affected me, deep in my heart I was very sad. I did not tell my father because I feared that my father would get his knife to hack them. I just let it go. "Never mind", I said to myself, "If sickness was truly given to me by God, then may you (plural) become like me."

The language of the informant in the last example depicts the progress of her emotions from unhappiness at being ostracized to suppressing her desperation by simply resorting to tears, then trying to cope by venting her resentment in a curse.

In this example, the hansenite uses two words for "whisper". One of the words incorporates the Tausug word for rumor. The use of both terms emphasizes the act itself and also indicates that she considered the whispers as rumors and idle talk. Unlike other informants, she did not simply say "God made me sick." She chose to say "...the sickness was given to me by God", implying that she had to bear what was given specifically to her by God. The strategy she had chosen to cope with stigma was expressed by her vindictive curse.

Stigma Management

Different coping strategies come into play when stigma has to be confronted. These are best understood from the point of view of the sick and of those who deal with them.

Acceptance

One way of coping is by accepting the consequences of stigmatization and trying to live as normally as possible. This is illustrated in the following excerpts by a hansenite who chose to ignore the heckling and teasing and to continue to attend school.

Even in school, there are those who already think badly of me, but I no longer bother about them. I just let it go.

In some cases, patients were resigned to both their condition and the attitude of the community towards them. This was expressed in terms of being patient and accepting what may come. They learnt to live with stigma, evading and avoiding confrontations with possible stigmatizers.

If I weren't sick like this, I desire (deep in my heart) to go to school so that I can be employed. Up to the present, I haven't gone to school because I am sick. I'll just wait for whatever work comes (my way). I just have to be patient.

Converging in Communities

The hanšenites who manifested self-stigma by self-isolation coped with their predicament by converging in communities just outside the walls of the sanitarium where they were able to avoid stigmatization.

Denial

Another form of coping was to deny knowledge of HD.

Me, I am not sick. I'm normal.

Some patients explained their presence in the skin clinic as seeking treatment as a precaution against catching the disease. The records showed however that they were actually active cases.

I don't think I am sick with what they call leprosy. I only do this/come here as a precaution.

Fatalism

Influenced by their religion, fatalism was often an attitude the Tausug used to cope with their predicament.

I have nothing to blame (for this), in reality, it's God who made me sick like this.

What can we do, never mind. Nobody (would) want this to descend (on himself). This is like *sukat*.

Sukut is a ritual offering to the spirits. The informant considered his sickness as something demanded by the supernatural, therefore it was his fate. Note the choice of "to descend", which could have been expressed by a word meaning to become sick or to have HD.

Belief in the Power of Prayer

Closely related to fatalism is the belief in the power of prayer. For those who believed HD was sent by God or was a curse, a supernatural cure such as prayer was credible. The dominant religion is Islam. Prayer is part of the fabric of daily life. Turning to prayer and with great faith in this as a solution, the sick and their families were able to cope with their problems.

The cure for it is forgiveness and prayers, for the one cursed and for the one who cursed (him).

Belligerence

The relatives of the hansenites usually coped with stigmatization by resorting to fatalism, acceptance or secrecy. But quite a number faced the problem with belligerence and threats of violence. The mother of a hansenite claimed that no one dared mock her daughter. It was often the case that the neighbors preferred to avoid trouble, hence they were careful with what they said in case they angered the hansenite's family.

Medical Staff

To complete the picture of stigmatization among the Tausug, it was important to study the attitude of the medical/health personnel (H) in the community who were involved in the treatment and rehabilitation of the hansenites. Although a number of the personnel were not Tausug, they could speak or at least understand Tausug.

Because of the strong stigmatization in the areas studied, it took a knowledgeable and dedicated staff to work with HD patients. Most of the H informants expressed satisfaction with their work and said they had no desire to change work or be transferred to another type of work.

Almost all of the H informants got their training on the job. They had no specialized training on HD or on how to deal with hansenites and had practically no knowledge of the epidemiology of the disease when they started. Some of them had subsequently taken seminars on HD. Despite this, they developed into efficient health providers with a reasonably positive outlook towards HD and hansenites.

Most of the health informants felt they had a mission to fulfill. This was to prevent the disease from progressing in their patients and to rehabilitate the physically deformed. They felt it was part of their duty to give hope to their patients.

Despite the sincere, conscious and overt efforts of the medical/health staff to help the patients and to avert stigma, some problems persisted. Having been exposed to the community or possessing the indigenous cultural norms, the H informants manifested traces of stigma.

In their place of work, staff members were at ease and seemed free of stigmatization, but once outside the sanitarium or clinic, they were careful in referring to their work. When asked if they would not mind having hansenites as household help, their answers were not categorically "yes" or "no" and used a strategy of avoidance.

The staff members referred to those patients who no longer showed symptoms of HD as "clean", implying that those with HD were "dirty". This was in consonance with the Tausug's perception of the disease as dirty.

Their close association with hansenites exposed these personnel to stigmatization. It usually came in the form of light teasing such as "You have it, don't you?" In fact, most members of the community avoided the sanitarium for fear that if they were seen coming out of it, they would be suspect.

The doctors at the skin clinics and sanitarium complained that patients came to them only after being treated for skin ailments such

as allergies by doctors who could not diagnose the disease correctly. Usually, these doctors had not seen a case of HD and could not recognize one when they did. If these doctors suspected their patients were hansenites, they postponed or avoided telling them the truth because of the strong stigma their patients would have to suffer.

Conclusions and Recommendations

The purpose of this study was to describe and analyze stigmatization in relation to Hansen's Disease (HD) among the Tausug and to arrive at a body of knowledge which could be used in local and national health education, medical staff training and disease control. By applying a psycholinguistic, historical and psychological approach to the problems of HD stigma among the Tausug, the study documented the processes of stigmatization, its causes and manifestations as well as the impact and management of stigma of hansenites, non-hansenites in the community and the medical staff.

The study revealed that stigmatization was the consequence of the reactions and attitudes of the community to HD and to those who are sick. The factors responsible for this attitude, its manifestations and its effects form the Tausug's ideology of stigma. This ideology can seriously mitigate against successful treatment of HD unless recognized and included in health and education programmes.

On the premise that the ideology of stigma is key to communicating pertinent information effectively to targeted groups in the community, a knowledge of the ideology of stigma will be of great assistance in developing educational materials and health programmes that ensure a more effective means of controlling the disease. Educational materials based on this knowledge should dispel the fears and negate the misleading perceptions and beliefs which have prevailed and supported the group's attitude towards and treatment of HD. At the same time, positive factors in the belief system of the Tausug can be utilized in giving credibility and relevance to the material. These positive factors which the Tausug will recognize,

understand and relate to, can be used as starting points in organizing educational materials.

Concept of Kagaw and the Perceptions of HD

The concept of *kagaw* could be capitalized on in health programs since it reflects, in some way, the scientific concept of the micro-organism and should not be dismissed as mere superstition or ignorance. Educational materials on causes and transmission could use this term and build on the idea that the organism does cause HD.

Among the Tausug, *kagaw* could also be used to dispel the perception that HD is brought on by supernatural causes such as fate, spirits and curses. Since it is living organisms that cause HD, they can be killed. Further, educational materials can demonstrate through this concept that HD is not a highly contagious disease by disproving the strength of the *kagaw* and countering the belief that it is practically indestructible or that it can crawl rapidly from one host to another. It can be emphasized that the strength of the *kagaw* could be reduced by faithfully taking the prescribed medicine.

Perceptions of HD Transmission

The Tausug's perceptions on HD transmission all relate to the actual means of transmission, prolonged contact. The perceptions that HD is transmitted by poor health habits, neglect of skin ruptures or because of weak blood all reduce to a poor state of health. Undoubtedly, anyone in a poor state of health is susceptible to disease. Transmission by heredity and by contact with hansenites, the other Tausug perception of transmission, are closely related since contact is sure to happen when a family member has the disease. Educational materials using the Tausug's perceptions of transmission would be credible and more easily accepted.

Fear of HD and Stigmatization

The fear of HD and of stigmatization should be addressed when fashioning educational material for HD control. For example, the strong fear of physical deformity which is perceived to be inevitable with

HD should be given special attention. This could be dispelled by highlighting the advantages of early detection and stressing that deformity comes with the neglect or delayed treatment of HD which are often due to the denial of the disease or to ignorance.

The study also suggested that hansenites, unlike non-hansenites, did not fear HD itself. Having the disease without any sudden crippling deformity or disfigurement did not terrify them by the anticipation of what might happen. The slow progress of the disease conditioned the hansenite into adjusting to disablement. Several hansenites, in fact, expressed a preference for HD over diseases like cancer and tuberculosis. What the hansenites actually suffered was fear of stigmatization which often gave rise to self-stigma. In some cases, self-stigma even preceded stigmatization from others.

Acceptance and Coping

It is imperative that educational materials on coping with stigmatization be fashioned in a positive and productive manner. Hansenites and their families tend to cope with stigmatization by secrecy and avoidance. The disadvantages of this manner of coping and the advantages of facing HD as early as possible should be emphasized. This does not mean coping by resigning oneself to stigmatization. Rather, it means that any sign of the symptoms should alert one to seek medical help and after a positive diagnosis, should spur one to pursue medication.

The results of the psychological testing of life events suggest the necessity of developing intervention strategies accounting for ethnic and sex differences. Patients, medical workers and the rest of the community must be appraised of the psychological factors attendant to understanding HD. The negative stressful events rated high by the respondents indicate that the problems related to these events have to be addressed in the educational materials on causes, transmission, cure and on coping with stigma. The positive stressful events, on the other hand, give clues to the general aspirations of hansenites. Educational

strategies which could inspire hansenites to attain their aspirations despite their sickness have to be found.

Medication Effectiveness and Use

A relevant and simple presentation of the drugs needed for medication should be developed. The scientific and generic names of the drugs are strange, foreign sounding and therefore difficult for the Tausug to remember. The Tausug informants identified drugs by color and size rather than by name.

The Tausug also conceptualize time in chunks rather than in units (hours, days, weeks). Time is reckoned by relating events to the position of the sun, light of day or in relation to seasons and predictable events. It was observed that instructions for drug intake in the usual Western manner were difficult for the Tausug to internalize. All of these items have to be considered when giving instructions for medication.

A careful explanation of possible reactions to the drugs must also be made. Often, the patients concluded that such a reaction was a failure of the drug to cure and felt that the drugs only aggravated their suffering. Many hansenites stopped medication due to this. In the educational materials, the language used to describe the reaction to drugs should utilize the words the Tausug use to describe their symptoms. This would facilitate their understanding of what they can expect after taking the drugs. Realizing the effectiveness of the drugs (through proper information) would help convince the hansenite that getting cured is the best way to overcome stigmatization.

Importance of Family Affiliation and Religious Culture

The study established that stigmatization is relative to the degree of kinship and social affiliation. The lesser the degree of kinship or social affiliation, the greater the stigma. Within the family, which included the nuclear family and close relatives, isolation when practiced was not complete or strictly followed. Ordinarily, a separate house was built for the hansenite within the premises of the home, but some families let the hansenites live among them. Interaction within the

family was maintained with awareness, tolerance and care. If any aversion was felt towards the disease and the sick, members of the family were careful not to show it.

Strong family ties often lead to the overprotectiveness of the hansenite by the family. This needs to be addressed in the educational material. The family must be convinced that their help and support could mean the eventual cure of their relative. The study showed that in some cases, relatives were often instrumental in convincing the hansenite or the suspected HD case to seek treatment. Some relatives even took on the responsibility of picking up the medication or accompanying the patient for periodic check-ups.

Strong stigmatization was practiced outside the family. This was tempered only by fear of reprisals from the relatives of the hansenites and by religious beliefs.

Language and Training

In addition to developing appropriate educational materials for the community, the study revealed the need for enhancing the knowledge of the medical/health staff on the stigmatization of HD. The Tausug's ideology of stigma, knowledge of their perceptions, psychological factors responsible for their attitudes, along with a history of HD and its control would be useful material for upgrading and for orientation seminars for health providers and new recruits. Such knowledge should equip them with an understanding of the behavior of the patients.

Future Research

The conclusions and recommendations of this report resulted from a study of the Tausug and are pertinent to this group. Nonetheless, the recommendations without the details specific to the Tausug could be applied to a national control programme if further similar research on HD and stigma could be conducted in other areas where HD is highly prevalent. A comparative analysis of the results of these studies

should then be made to determine specifically what can be applied to the national control programme.

Finally, it would be interesting and useful to know the results of studies related to stigma on other stigmatized diseases.

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Notes

1. The study was originally planned for twenty-four months. Due to problems related to data gathering, such as travel difficulties and informant accessibility, the completion of the research was delayed by several months. The collection of data lasted more than the estimated six months. Although most of the research team lived in the research sites, the rest had to travel to the areas by plane or boats on very erratic schedules.

Another problem was informant accessibility. Some of them could only be interviewed in the evenings. Due to the unrest in the area, it was often inadvisable to go out after dark. The unrest was due to the revival of traditional family feuds and the occasional raids of rebel troops.

2. The original Tausug is not included here but is available in a complete project report submitted to WHO.

3. Another skin clinic is located in the center of the city and is run by the City Health Office of Zamboanga.

One of the largest sanitarium, the Culion Leper Colony, was established on the remote island of Palawan.

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