

**Developing Evidence-based Leprosy
Information, Education, and
Communication (IEC) Materials for the
Cordillera Administrative Region (CAR)**

A Formative Research Report

**Prepared by a team of researchers from the University of the
Cordilleras (UC)**

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**Funded by: Department of Health – Cordillera
Administrative Region**

**August 2012
(Revised September 2012)**

LIST OF ACRONYMS

BB	Borderline Borderline
BHW	Barangay Health Worker
BI	Bacteriological Index
BL	Borderline Lepromatous
BT	Borderline Tuberculoid
CAR	Cordillera Administrative Region
DJNRMH	Dr. Jose N. Rodriguez Memorial Hospital
DOH	Department of Health
DSWD	Department of Social Welfare and Development
FAQ	Frequently Asked Question
FGD	Focus Group Discussion
HD	Hansen's Disease
IEC	Information, Education, & Communication
KAP	Knowledge, Attitude and Practice
KII	Key Informant Interview
LL	Lepromatous Leprosy
MB	Multibacillary
MDT	Multi-Drug Therapy
PB	Paucibacillary
RJ	Ridley and Jopling
TB	Tuberculosis
TT	Tuberculoid Leprosy
TV	Television
UC	University of the Cordilleras
WER	Weekly Epidemiological Record
WHA	World Health Assembly
WHO	World Health Organization

FOREWORD

Evidence arising from qualitative researches can greatly enrich our understanding about social issues existing in our society. Conducting such research however requires a great deal of critical, creative, philosophical, and logical thinking, so as to really come up with solid claims and provide invaluable insights about a particular social issue. These processes and requirements were precisely encountered when we analyzed gathered data from five provinces in the Cordillera Administrative Region, Philippines, regarding leprosy and its stigmatic effects on patients and their family members, community members, and health workers.

The team involved in this research has come from diverse backgrounds. Mr. Abner O. Lawangen obtained a degree in environmental science, and is currently involved in a local government unit. Mr. Ferdinand D. Lawan has a degree in political science, and currently teaches political science subjects at the University of the Cordilleras. Ms. Junelyn T. Tomin is a statistician with a degree in applied statistics, and is currently pursuing graduate studies in statistics. Ms. Ruby L. Estepa is a nurse, and had conducted together with her undergraduate peers, a phenomenological research as a requirement for her bachelor's degree. Finally, the fifth member is Mr. Danesto B. Anacio who aspires to be a specialist in the field of environment and social theories.

While it may be a fact that the researchers are not hard-core social scientists or social researchers, this does not mean that proper protocols and basic scientific methods, and equally important, ethics; were not followed during the study. On the other hand, to claim that errors were not made in the research would be outright hypocrisy.

The reader is then invited to continue reading this output of science and art about leprosy in the Cordillera region. This is also the result of a summarization of a huge collection of interviews and group discussions, and countless hours of being immersed with the data. It is assured that after poring through this report, insights about knowledge, attitudes, and practices related to leprosy in various communities in the Cordilleras will be given light. Secondly, key messages to correct identified misconceptions will be presented. Lastly, if not crucially, a challenge is given to readers to conduct further researches. The goal of a leprosy-free region will not be realized without sound and appropriate research.

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ACKNOWLEDGEMENTS

This report has been made possible through the funds provided by the Department of Health – Center for Health Development, Cordillera Administrative Region during the term of University of the Cordilleras Vice President for Research and Special Projects, Dr. Ruben C. Umaly.

The researchers are eternally grateful for the assistance and presence of the following personnel and departments during fieldwork procedures:

- Mr. Anthony Baigen and Dr. Antonette Agpas in Benguet.
- In Abra, Mr. Noel Martin served as a guide for the researchers in identifying and locating patients. The researchers lodged at the Provincial Health Team Office of Abra during fieldworks there.
- In Apayao, Dr. Estela Nicolas referred key personnel for in-depth interviews, as well as welcoming the researchers to lodge in her residence.
- Mr. Joseph Apatas was with the researchers throughout all the fieldworks in Kalinga. The researchers lodged at the Kalinga Provincial Health Team Office.
- In Ifugao, lodging was arranged through Ms. Hazel Domingo and Mr. Edwin Alipio. The guest house of the Ifugao Provincial Environment and Natural Resources Office also proved to be a homey place for an overnight stay.

The final research report has been reviewed by Mr. Cezario Joel C. Espejo and Dr. Cleofas M. Basaen of the University of the Cordilleras.

EXECUTIVE SUMMARY

The World Health Organization (WHO) passed a resolution in the year 1991 to eradicate leprosy as a public health problem by the year 2000. This meant that leprosy cases should be less than one in a population of 10,000. After this goal was achieved in the global level in 2000, a number of countries are still prevalent with the disease. Indeed, global averages for leprosy were less than one in 10,000, but not when averaged per country.

The Philippines is one of these countries, and as a result, the Department of Health (DOH) created a mandate to eliminate the looming health problem on leprosy by 2020. Thus, the DOH regional office of the Cordillera Administrative Region (CAR) sought the help of the University of the Cordilleras (UC) in conducting a research on leprosy and its related stigma in particular communities of CAR. In determining the knowledge, attitudes, and practices (KAP) of patients and their family members, community folk, and finally health workers, findings are summarized as follows:

1. Causes of Leprosy

There are varied answers as to what causes the disease, indicating that the causative agent of leprosy was not clearly defined among community members, leprosy patients and their family members. This ranges from having no ideas, to a kaleidoscope of ideas reflecting a blurred view on how leprosy is acquired. In general however, the concept of leprosy as a hereditary condition was emphasized. It was shown that health workers knew the causative agent of the disease, though further training is recommended to educate health workers, most importantly on the mode of transmission of leprosy.

2. Symptoms of Leprosy

The late symptoms of leprosy, described as rotting and smelly wounds, as seen among untreated patients were elucidated among the community members, patients and family members. However, the early stage symptoms were not known by most respondents but generally assumed as a skin aberration. Undetermined skin illnesses that may indicate early leprosy were generally treated as mere skin allergies or fungal infections. Ineffective treatment by anti-fungal and antiseptic creams and soaps would then trigger the patient for consultation and further evaluation. Although municipal doctors as well as leprosy coordinators, who usually confirm leprosy cases were observed to be equipped with sufficient knowledge and skill in diagnosing leprosy, midwives and barangay health workers lack skill and training in determining the early signs of the disease.

3. Prevention and Management of Leprosy

Health workers were the only well-informed individuals on the prevention and management of leprosy. A mixture of health teachings, hearsays, gossips and foretold stories from earlier generations and past experiences on managing

leprosy, in addition to facts about the disease, were reflected among community folks, patients and their family members. Such preliminary information was magnified, causing communities to practice extreme precautionary measures. Furthermore, main concern on the children's susceptibility on acquiring the disease was highly recognized and so, strict isolation was suggested.

4. Leprosy related Stigma

Leprosy related stigma was very much present, even among health workers. The mere presence of active lesions, characterized to be pustular (presence of pus), bloody and with stench smell, hinder the community members to mingle with leprosy patients. Moreover, even scars and diminished fingers, brought about by late treatment, were reported to have elicited fear of companionship among the community members. Though stigma was very much observed as evidenced by suggestive isolation of the patients, the extent of stigma is not conclusive in this study.

5. Interpersonal Relationships and Interactions

Patients were still allowed to join community gatherings such as religious and cultural ceremonies but were not permitted in prolonging their stay and in handling food to be served for visitors. Patients were observed to have accepted their status in the community but further evaluation on their definite responses may need further exploration.

6. Treatment and Medication of Leprosy

Once leprosy is confirmed, a Multi-Drug Therapy (MDT) regimen is instructed to be taken by the patient. However, due to known undesirable side effects of the treatment, some patients tend to stop the medication without any advice from the health worker. Most patients were reported as compliant and health workers have conveyed the importance of counseling and health education prior to the start of medication to achieve effective management.

7. Other Findings

There is no conclusive evidence to support gender related issues about leprosy. Although researches in other countries present gender discrimination as a result of having the disease, analyzed data is insufficient to reveal if such conditions are present in CAR.

In terms of IEC, oral presentations aided by printed IEC materials are seen to be more efficient than printed posters, leaflets or stickers alone. This also signifies the need for the production of IEC materials to aid campaigns in informing the public about leprosy.

Further analysis and data gathering are emphasized in determining data gaps from this report.

This revised edition was edited by Danesto B. Anacio.

INTRODUCTION

Leprosy or Hansen’s Disease (HD) has afflicted the lives of people since time immemorial. Dr. Gerhard Armauer Hansen, a Norwegian physician, discovered the causative agent of leprosy as *Mycobacterium leprae* in 1873. *M. leprae* is an acid-fast, rod-shaped bacillus, with a slow growth rate. Symptoms of the disease are generally manifested through the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes.

The World Health Assembly (WHA), the WHO’s decision-making body, passed a resolution in 1991 to eliminate leprosy as a public health problem by the year 2000. This meant that the disease should not be found in a single individual per 10,000 people. The resolution was deemed successful, that by the end of 2000, the global leprosy incidence rate was less than one case in 10,000 (WHO, n.d.).

Though leprosy was eliminated as a global health problem in 2000, averaging prevalence rates per country painted a contrasting picture. There are also countries where leprosy is highly endemic. In 2011, the WHO Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (plan period: 2011–2015) was actively promoted in countries where leprosy is endemic. It targeted highly endemic areas of Angola, Brazil, Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania (WHO). This strategy aimed at reducing the rate of new cases with grade-2 (visible leprosy-related) disabilities worldwide by at least 35% by the end of 2015 (Weekly Epidemiological Record [WER], 2011).

Table 1. Leprosy Case Detection in Selected ASEAN Countries*

Country	No. of new cases detected per year						
	2004	2005	2006	2007	2008	2009	2010
Indonesia	16, 549	19, 695	17, 682	17, 723	17, 441	17, 260	17, 012
Myanmar	3, 748	3, 571	3, 721	3, 637	3, 365	3, 147	2, 936
Philippines	2, 254	3, 130	2, 517	2, 514	2, 373	1, 795	2, 041

*Adapted from WER (2011).

There are still new cases being reported currently in each country, worldwide. For example in the Philippines, from years 2004 to 2010, around 2, 000 new cases were detected for each year (**Table 1**). A number of Philippine areas are said to be prevalent with the disease. The capital, Metro Manila, is said to have over 500 new cases in different health centers and hospitals. The provinces of Ilocos Sur, Tarlac, Nueva Ecija, Batangas, Cavite, Laguna, Quezon, Rizal – all in Luzon, and Tawi-Tawi in Mindanao are reportedly with high rates of the disease. Two major cities, Cebu City and Davao City, are also included in the list (“DOH: PH tops,” 2012)

The stigma associated with leprosy is very much recognized, even in the oldest civilizations of China, Egypt, and India (WHO). This stigma is usually associated with the disabilities resulting from patients who have not undergone treatment. Leprosy-

associated stigma also becomes an obstacle to the treatment of the disease, wherein patients become fearful about observed symptoms and thus hesitate to self-report their conditions to health authorities. In addition, even health-workers and community members may contribute to the felt stigma of patients.

In a vision to empower stakeholders and eradicate leprosy as a health problem in the future, the DOH-CAR funded a research to ensure that leprosy services are functioning efficiently at all levels of the health care system in the Cordilleras. Furthermore, it is hoped that the goal of eliminating problems caused by leprosy is maintained for many years to come. As a result, a multi-disciplinary team of researchers from the University of the Cordilleras (UC) was tasked to help fulfill this research need. This report presents findings from the said research which explored the knowledge, attitudes, and practices (KAP) of different communities in CAR regarding leprosy.

It is believed that determining the KAP of communities in the Cordilleras would help craft efficient information, education, and communication (IEC) materials for addressing stigmatic and non-treatment behaviors of patients. The evidence-based IEC materials would also enlighten family members of patients, communities and barangay health workers (BHWs) about leprosy, and thus be guided appropriately in preventing the spread of the disease.

METHODOLOGY

The Researchers

Determining the KAP of Cordilleran communities regarding leprosy requires a broad and varied perspective. This is due to the fact that there is a diverse and complex composition of indigenous and non-indigenous communities in CAR. A multi-disciplinary team would match this varied composition of communities in CAR. Team members are composed of a statistician, a political science major, an environmental science major, a nurse, and a social-environmental analyst.

The varying specialization promoted a complementary sharing of thoughts, point of views as well as perceptions of the data gathered. Personal biases were set prior to the conduct of data analysis and brainstorming was frequently done to elicit the genuine interpretation of the data. Moreover, data gathering experiences were shared as a group to summarize activities, to check missed out details, and to plan for enhanced data gathering procedure and analysis.

Research Framework

Data from participants were gathered using qualitative methods. The KAPs about leprosy were determined among research participants, and categorized according to causes, symptoms, prevention and management, stigma, interpersonal relationships and interactions, and treatment and medication of leprosy. In-depth interviews were used for community members, health workers, and leprosy patients. To enrich data sources, a set of focus group discussions (FGDs) were done with community folk.

All data gathered in this research utilized the basic interpretative qualitative framework. It concentrated primarily on the analysis of health workers, family members of leprosy patients, and the patients themselves. Researchers analyzed the situations these individuals have undergone as part of the DOH program on leprosy.

To support the concepts arising from gathered data, a grounded theory approach was used. This meant that the researchers went to the field with a minimal, or even an absent, set of assumptions. As a result, the participants' narration and statements were recorded first before forming opinions and theories afterwards. The discovery of data is emphasized; description and verification are given secondary priority (Merriam, 2002).

Research Participants

Participants were identified using stakeholder sampling and/or criterion sampling. In the circle of health professionals, participants were identified using stakeholder sampling. Health worker participants are involved in the administration and design of health services concerning leprosy. Meanwhile, the criterion sampling technique was used to determine former or current leprosy patients. Criterion sampling was

also used to identify individuals with at least one current or past immediate family member afflicted with leprosy.

In order to broaden data sources, the snowball technique was also used. This involved the identification of potential patients for interview as referred by health workers, community members, family members, and patients.

Research Locations

Based on records from DOH-CAR, locations were selected if at least one patient is currently based in a particular municipality. Five (5) municipalities and one (1) city in five (5) provinces were visited for data gathering (Figure 1), namely: Flora, Apayao; Bangued, Abra; Rizal and Tabuk City in Kalinga; Alfonso Lista in Ifugao; and La Trinidad in Benguet.



Figure 1. Provinces and locations (in dots) visited for data gathering
(Image adapted from Wikipedia)

Data Collection, Management and Analysis

A set of general questions served as a guide during key informant interviews (KIIs) and FGDs:

1. Identify factors that influence leprosy-afflicted patients in seeking treatment.
2. Determine concepts and beliefs of patients and their family members, community members, and health workers regarding leprosy using the following themes:
 - a. Causes of the disease
 - b. Symptoms
 - c. Transmission
 - d. Prevention
 - e. Treatment and Management
3. Determine needs of health workers to improve services on leprosy-afflicted patients.
4. Suggestions for IEC materials about leprosy

The researchers worked in partners in conducting KIIs and FGDs. After which, the researchers summarized the findings at the end of the day to capture the picture at its freshest state. Brainstorming to validate and identify key concepts was conducted. Planning to enhance interview and FGDs were consistently done all throughout the data gathering procedure.

A digital audio recorder, an audio-video camera, and a cassette recorder were used to store interviews; and proceedings from FGDs. Field notes and photographs were also used to strengthen observations and analyses.

Each interview was replayed from recordings for transcription. Subjective as well as non-subjective cues as manifested by the participants were all considered in the interpretation of data. Secondary documents (patient records in health offices and barangay maps) were also utilized. Questions were asked in *Ilocano*, the *lingua franca* of the Cordilleras.

Once all interviews were transcribed (converted to text), copies were given to all researchers for validation and reading. Researchers shared transcription tasks, as such; each researcher was thoroughly immersed in gathered data. One part of a transcribed interview is provided in **Figure 2**.

PATIENT [2] – RIZAL, KALINGA

1
2
3
4 **AOL:** [Introduces research project, seeks consent, wherein interviewee agrees in the
5 interview, and obtains profile of interviewee]
6
7 [chatter and signing of consent form]
8
9 **AOL:** Idi ba, anya ti kasla panang awat mo idiyay sakit nga diay? Idi pay lang ha-an kayo
10 nagpa agas.
11
12 **P2 KALI:** Idi damo enya, madik anmu nga kastoy. Itattan, nasugatak nga idi, ditoy.
13 Itattan, nagado napanak nga doctor, isaldak pay tal talon ko ah. [mumble]
14 Inbaga da, skin infection. [mumble]. Diay sugat ko, agala-ing ton nu kwan,
15 agsubli ton manen, medyo umangot. Mang ikwa ak ti uggot ti bayabas.
16 [chatter] Idi kinita na nga damo, kuna na nga diabetes. [chatter] Within three
17 months ak nga nagtum tumar, July, nastroke ak en. [chatter] Nu bumaba ngay
18 diay blood sugar ko. [chatter] Ta diay sintomas na gamin diay diabetes ko met
19 kwa, nu daytoy panag is istorya tayo ngay ket, bumababa met diay kwan.
20 Sabsabali ngay ti maibaga bagak en. Tapos nu daduma pay, mapal paling-etan
21 ak ngay? Mabasa amin ah nga t-shirt. [chatter] Inbaga piman ni sir HW2-Kali
22 ket, 'man tumar ka sin anuka.' Aguray ka ta illeppas ko lang daytoy tum
23 tumarek. [chatter] Idi inmay manen ni sir HW2-Kali en, ag riri ak metten ah,
24 'apay daytoy agas mo agkudekudek?' [chatter] Ngem tatta metten ket okay
25 metten. Ada ladtan ti talaga nga daytoy diabetes ko nga lumablaban. Lalo tatta
26 ta nalami-is, ag ut-ot. Ngem daytoy sabali nga sakit ko, ok metten. [chatter]
27 Daytoy lang, ag kara isbo ak. Ngem medyo mayat metten. Ok met panag is
28 isbok metten.
29
30 **AOL:** Ngem idi un una na 'nang, nu mang mangeg mu ti leprosy, anya ti kasla
31 mapanpanunot mo? [chatter]
32
33 **P2 KALI:** [chatter] Kasla duwa nga klase? [chatter] Diay maysa, ni Mrs. [name]
34 [chatter] Tatta, daytoy, observation ko ditoy bagik, okay metten. [chatter]

Figure 2. Part of an Interview Transcript

Transcribed interviews were then coded, wherein relevant data for crafting IEC materials were extracted and organized to reveal patterns, data sets, themes, and other issues. A part of a coded interview is presented:

Table 2. Part of a Coded Transcript

Category	Data	Quotes	Inference	Context
Knowledge on leprosy	Patient describes that there are two types of leprosy. One would be the type that she saw on a certain patient. The other type is the one that she has.	“[chatter] Kasla duwa nga klase? [chatter] Diay maysa, ni Mrs. [name] [chatter] Tatta, daytoy, observation ko ditoy bagik, okay metten. [chatter]”	There is an idea that there are different “types” of leprosy. However the types are actually different levels of complications caused by leprosy.	The patient concluded that leprosy “types” are based on visible skin symptoms. Her leprosy is “different” from that of another patient, since the symptoms of the latter are much more “serious” in comparison with symptoms of the former.

Leprosy medication side-effects	Patient experienced skin darkening, which was not experienced before medication, and red-colored urine. She then asked implications for the latter.	“Ay ha-an nga kastoy nga ngin mitim idi. Kuna met ni sir HW2-Kali nga maikat dayta. Uray umisbo ak gamin ket nalabaga. Kasla anya kwa na diay?”	Side effects cited by the patient were skin darkening and red-colored urine. She further raised concern over these side effects.	Information about leprosy side effects might not have been relayed to the patient.
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After interviews were coded, all transcripts were consolidated to organize recurring themes. A list of topics to include in the IEC material was also considered. A sample of a consolidated data analysis is presented:

Table 3. Part of a Consolidated Data analysis

THEME	BEHAVIORAL FINDINGS	CONTEXT (What they know)	IEC CONTENTS TO CORRECT BEHAVIOR
Symptoms	One patient said that her symptoms are different from another leprosy patient.	Her symptoms are different	Indicate symptoms (early and late)
Treatment and Medication	Only one of the two patients cited experienced side effects from the medical regimen.	Side effects cited by the 2 nd patient were skin darkening and red-colored urine.	Include all side effects of the medication

Finally, after data were consolidated, a final matrix was used to organize specific images and statements that need to be included in the proposed poster, flyer, and sticker. An example of the final data analysis matrix is presented below:

Table 4. Final Data Matrix sample

Data (from data analysis)	Statement (based on data analysis)	Message (single, clear, simple sentence in simple vernacular)	Image (description of image)
Symptoms	Leprosy is equated with an allergy and an assortment of symptoms that are not necessarily associated with the leprosy. Late stage symptoms and disabilities are also frequently cited.	Agrugi ti leprosy no makita daytoy tallo nga sintomas: 1. Ada parte ti kudil nga pumupuraw weno lumalabaga ken medyo bumubumlad; 2. Ha-an nga makarina nu ma egeman; 3. Awan buok nga agtububbo ken awan ling-et nga rumwa.	Image of a skin lesion that is whitish, reddish and elevated; with no sense touch; and without growing hair. Sweating is also absent in the skin lesion.

Findings from this research were solely based on interview transcripts, noted observations during the conduct of interview, and health records obtained during fieldwork.

Validation of Data

As mentioned earlier, the researchers were deeply immersed in the collection, analysis, and presentation of data. Furthermore, research meetings and post-interview meetings served as avenues for inter-researcher dialogue and discussion. The research methodology also ensures the validity and reliability of gathered data.

In addition, gathered data were triangulated with various participants to ensure uniformity and consistency. Interview transcripts were also triangulated with patient records and observations.

Ethics

Written consents were requested by some municipalities and were so provided. Most often, oral consent sufficed, as one participant was not comfortable affixing a written signature on the consent form.

The purpose and objectives of the study were presented beforehand to provide focus on the discussion. Introductions by the researchers were also done prior to data collection to condition participants into answering more definite questions pertaining leprosy. Permission on utilizing aids for recording the interview process was also presented to the participants and all but one agreed to the use of recorders and cameras. In this case, data gathering was simply aided by field notes.

Neither force nor deceit was applied to encourage the participants to partake in the study; and so neglect to answer the questions due to some personal reasons was very well respected. The participants were as well free to choose the interviewer according to their preference and depending on the researchers' availability. During individual interviews, requests on having a single interviewer were granted accordingly.

FGD and KII transcripts used alphanumeric codes in order not to reveal the location or identity of a particular participant. It was ensured that audio files were only accessed by the researchers and were not shared to anyone, even to health workers. Confidentiality and anonymity was ensured all throughout the data gathering procedure.

RESULTS AND DISCUSSIONS: A COMPARISON OF KAPs RELATED TO LEPROSY

This section discusses the KAP of participants, divided into six (7) categories, namely: (1) Causes of leprosy; (2) Symptoms of leprosy; (3) Prevention and management of leprosy; (4) Leprosy related stigma; (5) Interpersonal relationships and interactions between patients, community and family members, and health workers; (6) Treatment and medication of leprosy; and (7) Recommendations for leprosy IEC. A comparative analysis between patients, health workers, and community members/family members are done in each category in order to determine differences and commonalities.

All in all, a total of 50 data gathering sessions (FGDs and KIIs) were conducted in five provinces in CAR. The following table provides a breakdown of interviews and discussions conducted from January 2012 until the first week of February 2012.

Table 5. Interviews and Discussions Conducted in the Research

	Benguet	Abra	Apayao	Kalinga	Ifugao
FGDs and/or KIIs with Community Members	2	1	7	1	1
KIIs with Patients	3	2	3	2	5
KIIs with Family Members	1	3	3	0	3
KIIs with Health Workers	3	3	3	2	2
Total	9	9	16	5	11

Two of the interviews were excluded in the analysis. One patient in Apayao provided inconsistent, unrecognizable, and unintelligible answers, which was later revealed by neighbors and health workers that the said patient was suffering from a mental illness. Another patient in Kalinga was also not included in the analysis, as it was later determined in the interviews that his disease was actually a case of sebaceous cysts, and not leprosy.

1. KAP: Causes of Leprosy

There were various answers as to what causes the disease. Results indicated that the causative agent of leprosy was not very clear among patients, family members, and community members. In general however, the concept of leprosy as a hereditary condition was emphasized. It is given that health workers know the causative agent of the disease, though further training is still needed. The following discussions are given for each participant.

Patients

In tracing the history of the disease, a recurring theme of causation mentioned by interviewed patients was the issue of heredity. Attributing leprosy to “bad blood” or “inheritance” was consistent in data gathered. Moreover, heredity remained as the main causative factor as perceived by patients since the disease was traced from generations of one to two families in the community. Some patients have not as well settled for a family of their own due to the notion that leprosy may be acquired by their future children.

Further explanations as to how leprosy was inherited were not expounded by the patients but rather, it was strongly associated with historical events and cultural practices. Nonetheless, some patients denied familial history of the disease but admitted contact with a household member with leprosy.

Other reasons cited by patients as to how they have acquired the disease were linked to frolicking in swimming spots. Intake of hyper-allergenic foods such as sea foods, chicken with squash and fish pastes or sauce were as well mentioned to precipitate the occurrence of leprosy. Poor hygiene and unhealthy lifestyle were also mentioned as secondary factors that may aggravate the disease.

Family Members and Community Members

As consistent to the patients' beliefs, their family as well as the community members generally confirmed that leprosy is hereditary. However, confusion was evident on whether leprosy was passed through blood lines or that it was acquired due to prolonged contact with a family member. Both reasons have nonetheless convinced the family and community folks that leprosy may circulate within the family tree or the household boundaries.

The concept of curses and other supernatural consequences as a cause of the disease was only mentioned in Kalinga. A participant in the Kalinga FGDs explained that one family in the area acquired leprosy from bartering a considerable piece of land in exchange for a piece of clothing.

Health Workers

Health workers seemed to be well-informed of the basics of leprosy, such as the causative agent, mode of transmissions and treatment. However, “frontliners” of the health care system, namely the midwives and barangay health workers need to be clarified on leprosy being a droplet infection or through prolonged contact. Skin to skin contact was still taught by some health workers as the primary mode of transmission of leprosy thus, cleaning of the skin lesions are disregarded by some family members.

Moreover, health workers disclosed that there has been lack of focus on leprosy monitoring. Most activities prioritize more on maternal and child nursing as well as on outbreaks and communicable diseases. *Kilatis Kutis* or skin check-up caravans which are usually conducted once a year are currently not done regularly.

Implication of KAPs on Leprosy Causes

Participants associate leprosy with heredity, through observations that leprosy ran in families. Rafferty (2010) supports this concept in her research, as she concluded that in certain epidemiological settings, leprosy occurred in families to the extent that many considered it as an inherited rather than an infectious disease.

There is a high variation of answers from participants, particularly patients and their family members, and community members. One patient is clueless as to what or how she acquired leprosy, while community members would cite a variety of causes of the disease, including curses (*na-uyungan* or *na-gamud*); allergies (*kurikong* or *kukuttel*¹) as a result of eating fresh- or sea-food, or other allergy-inducing food; living or bathing in “unclean” or “dirty” environments or water bodies; or a combination of these perceived causes of leprosy.

In addressing misconceptions about the cause of leprosy, it is suggested that people should know that a bacteria is the causative agent of leprosy, specifically *M. leprae*, and NOT through eating certain types of foods or curses or anything else. A refresher lesson may be needed to update the health workers on the pathophysiology of leprosy.

1 = Terminologies of leprosy are not uniform. *Kukuttel* is understood as leprosy by some but not all. Others would even cite leprosy, *ketong*, and *kukuttel* to refer to different diseases.

2. KAP: Symptoms of Leprosy

Late symptoms as necrotic and stingy wounds that lead to loss of fingers and toes as well as deformed nose were primarily associated with leprosy. Most are however clueless on the early signs (white or reddish spots with no or scarce hair growth, no sweating and sensation). It was also noticed that leprosy was concomitant to general skin diseases such as swelling and pruritic (itchy) allergic reactions and fungal infections. With this belief, community members treat these lesions with anti-fungal and antiseptic creams. If symptoms are untreated by such regimens, leprosy is then entertained.

Diagnosing skin lesions are well performed and predominantly done by municipal doctors and leprosy coordinators through series of skin tests. Midwives and barangay health workers who handle case finding and home visitation activities usually fail to identify early symptoms of leprosy due to lack of training and practice on identifying the lesions.

Patients

Patients generally denied acquisition of the initial leprosy symptoms due to lack of knowledge and awareness of the disease. This may be attributed to two possible reasons:

1. Comparison between experienced symptoms and disabilities seen in other patients.

- As a case in point, one patient interviewed in Kalinga doubted that she had leprosy because she compared her symptoms with that of another person afflicted with leprosy. Apparently, this other patient had rotting feet and smelly wounds. This comparison between her white patches (initial symptoms) with that of another patient's (late symptoms), made her believe that her condition was not leprosy. Acceptance that symptoms indicated leprosy, and thereby seeking medical attention from health workers, came only after late stage symptoms manifested.

2. Dismissal of initial symptoms as mere allergies or fungal infections.

- Skin lesions are dismissed as mere allergies or fungal infections. This carefree attitude is further exacerbated when patients consult dermatologists, wherein the latter will prescribe the patient with anti-fungal ointments and medicinal soaps.

Family Members and Community Members

Family members usually cite symptoms seen during late-stages of the disease. Prior to the diagnosis of the patient, they treat observed symptoms as another type of skin allergy or a fungal infection. Some have associated biblical stories (e.g. Job) pertaining to leprosy as terminal punishment from God. It was evident that there is a lack of knowledge and awareness of how to identify leprosy apart from other dermatologic symptoms. The table below summarizes the symptoms of leprosy as shared by community members during FGDs.

Table 6. Leprosy symptoms as cited during FGDs with community members

Ifugao	Benguet	Apayao	Abra	Kalinga
- Collapsed nose	- Itchy skin	- Absence of	- Rotting skin	- Itchy skin
- Rotting skin	- Rotting skin	eyes, nose,	- Scaly,	- Reddish and
- Water-filled	- Water-filled	legs	peeling and	swelling skin
bumps	bumps, Pus	- Rotting skin	thickening	- Scaly, peeling
- Reddish and	can be seen	- Reddish and	skin	and thickening
swelling skin	- Allergy	swelling skin		skin
- Absence of	- Scaly, peeling	- Wounds that		- Shiny skin
sensation in	and	do not heal		
wounds	thickening	- Scaly, peeling		
- Scaly, peeling	skin	and		
and thickening		thickening		
skin		skin		
- Shiny skin				

Health Workers

Midwives, who are usually in the field and lead the barangay health workers during home visitations, have reported lack of training, knowledge updates and materials to aid appropriate information campaigns. Due to this fact, one midwife shared that they are not very confident when explaining leprosy facts to their constituents. Knowledge inadequacies among the front liners of health cause community members in preferring other health professionals outside their barangay in explaining leprosy. These conditions affect the demography of leprosy and alter

monitoring as well as follow-up check-ups since patients in one municipality tend to be counted in another municipality, as the case in Apayao.

Detection of the symptoms is one vital role of the health workers and as presented above, further education and training is necessary for health workers especially the midwives and barangay health workers. Even some doctors also need to be educated about leprosy symptoms. One family member said that a particular doctor in a private clinic initially diagnosed a patient to have some “special” kind of allergy, when it was in fact leprosy. Leprosy may only be one aspect of the various functions health workers have, but it must be emphasized that this disease also needs to be prioritized in order to be totally eradicated.

Implication of KAPs on Leprosy Symptoms

If causes are not clear among patients and their family members, as well as community folk; this applies the same for leprosy symptoms. It should be noted however that people are most aware of late-stage symptoms, which are usually said to be rotting, smelly, and disgusting wounds with no sensation. Initial symptoms however are not very much known, wherein symptoms of other skin diseases are cited together with known early symptoms of leprosy.

People should therefore know that the early symptoms of leprosy are (American Leprosy Missions [ALM], n.d.):

- hypo-pigmented (whitish) or reddish skin patches
- such patches feel no sensation, as such, it is not itchy
- such patches have no hair growth, or sweating

Naafs (2006) states that the generally accepted criteria for the diagnosis of leprosy are loss of sensation in a skin lesion to light touch, an enlarged nerve among all palpable peripheral nerves and a positive skin smear. Two of the three criteria are needed for the diagnosis of leprosy.

3. KAP: Prevention and Management of Leprosy

Preventing and managing the spread of leprosy are a mixture of facts and precautionary measures based in hearsay (“so they say”). Due to this fact, actual causes of the spread of the disease are made complicated, especially when some facts are magnified and exaggerated. This results in actions and practices which are not necessary in preventing the spread of the disease. It may as well be that certain beliefs about preventing and managing leprosy contribute to the stigma that leprosy is a highly communicable disease.

Some health workers suggest constant monitoring and counseling to patients and family members to prevent the spread of the disease. Counseling also helps correct misconceptions on how leprosy is transferred from one person to another. Again, the need to inform patients, family members, community members, and even barangay health workers (BHWs) about preventing and managing leprosy is emphasized.

Patients

The absence of visual symptoms among family members leads to patients in not practicing preventive measures. For example, one patient from Abra said that symptoms among family members should have been manifested upon infection. This view is also held by one patient in Ifugao, believing that the disease is not communicable, and thus preventive measures are not needed. Another patient in Benguet acts normally with the community, even allowing the granddaughter to sleep with her (patient) during sleep-overs.

Contrarily, one patient says that isolation can be one way of preventing the spread of the disease. The patient believes that interacting with other people, where sweat and blood can be touched by others, will spread the disease. Leprosy is highly communicable.

Some patients are however well informed, as they believe that medication prevents further transmission of the disease, and thus, they strictly comply with Multi-drug Therapy (MDT) treatment.

Family Members and Community Members

Leprosy is believed to be so infectious that transmission is readily and immediately manifested in those with whom the patient has close contact. Since family members are in close contact with the patient, they should immediately have symptoms of the disease, like rotting feet or smelly wounds. With this in mind, if such symptoms are not seen in family members, the patient is then seen to have no leprosy, but some other disease instead.

Other family members are puzzled as to how leprosy can be transferred. They know that leprosy is communicable but have scant understanding on how the disease can be specifically spread. As a precautionary measure, family members have separated the things, dishes or utensils of the patient inflicted with leprosy. Disinfection is another practice, wherein one participant in an FGD in Apayao said that she pours boiling water to surfaces that a patient has touched.

In addition to the practice of separating the things of the patient, and disinfecting surface areas that the patient has touched, other practices include AVOIDANCE of the following:

- Following the footprints of the leprosy patient,
- Hanging your clothes on a clothesline used by a leprosy patient,
- Sitting in places where a patient used to sit, and
- Direct contact with the wound of a patient
- Contact with the saliva and other body fluids of the patient
- Sharing of lime during betel chewing sessions with the patient
- Sharing bath soap with the patient
- Sex with the patient

Eventually, these ideas would imply that a patient should be isolated to further prevent the spread of the disease. Most FGDs revealed that patients should be isolated, separated or placed far away from the community.

In general, there is no clear idea regarding the transferability of leprosy. One participant says that the disease is transferable but another doubts, asking if patients had indeed infected other people. Misconceptions also arise when facts about how the disease is transmitted are partnered with the aforementioned “preventive practices.”

Health Workers

One health worker suggests that IEC campaigns to inform people are needed. In addition, IEC campaigns are also needed for BHWs because it is observed that BHWs are not that technically proficient about leprosy.

Two health workers in Benguet cited constant monitoring and counseling of family members and patients helps in preventing the spread of the disease. One should educate family members as to how to assist the recovery of the patient. In addition, since family members are always in close contact with the patient, family members should also be monitored for signs and symptoms of infection.

Health workers in Benguet and Kalinga also shared that some cases were detected when the patients sought treatment for some other disease, not for leprosy. One health worker in Kalinga shared that he would sometimes go to the public market and “scout” for people with visible skin problems. In one occasion, the health worker was at a pharmacy when he saw someone buying an antifungal soap. When the health worker saw the customer’s skin patches, the former invited the latter to the health center. The health worker then prescribed MDT after diagnostic tests resulted positive for leprosy.

Implication of KAPs on Leprosy Prevention and Management

Due that causes and symptoms are not clear among patients and their family members, and the community in general; preventing and managing leprosy is also not well understood. Participants would resort to maintaining a certain level aseptic or sterile environments (pouring hot water on surfaces) or isolating the patient’s belongings.

As for health workers, constant monitoring and detection of cases is very important for preventing and managing leprosy. Furthermore, health workers should note individuals acquiring the disease as a result of having contacts with newly diagnosed leprosy patients (Moet *et al.*, 2006):

- classification of the index (referring to the extent of the disease) of the patient;
- the physical distance of someone from the patient;
- age of the person;

- Genetic relationship (meaning family members), independent of physical distance

Even though there is no solid evidence as to how leprosy is transferred, the disease can be prevented by informing patients to cover their mouths when sneezing or coughing. Long term skin to skin contact should also be avoided, though this does not mean the family members should not touch patients (ALM, n.d.). If skin to skin contact is necessary to perform a particular action, then one should do so. These two practices should be explained orally to people by trained health workers.

Worobec (2009) shares that the modes of leprosy transmission are not well established, although a number of possibilities are cited:

- Exposure to nasal and oral secretions or droplets of patients harboring bacilli;
- Skin to skin contact;
- Congenital transmission from untreated patients;
- Dermal inoculation via tattoo needles;
- Infected soil or sphagnum moss; and
- Exposure to arthropod or animal vectors.

The fact that some cases are detected accidentally adds to the urgency that BHWs need to be very knowledgeable about leprosy in order to diagnose symptoms when patients seek consultation for diseases other than leprosy.

4. KAP: Leprosy related Stigma

The disease never fails to elicit stigma among patients, family members, community members and even health workers. Places associated with leprosy carry a certain amount of caution. People who have leprosy feel that they are being talked about in the community. Things and surface areas touched or owned by people who have the disease are seen to be infected with leprosy.

Patients

The primary stigma associated with leprosy for patients would be the fear of being humiliated because they have the disease. Due that leprosy is seen to be very serious and communicable, letting others know that one has the disease is not a very good move. Having the disease however, does not guarantee stigmatic feelings for patients.

Stigma may be absent however, as the case for one patient in Kalinga, wherein communities seek the patient's carpentry services, and that neighbors see the patient as kind and caring. This causes the patient to live his daily life normally, as if he has a disease that is just like any other common disease.

One should note that there is an initial non-fear of the disease, which may be a form of self-denial. This is revealed when one patient in Benguet stated that he does not

fear transmitting the disease, or that he does not fear being avoided by other people because he has leprosy. Later on in the interview however, the same patient says that he does not want people (including his family members) to know that he has the disease due to fears of rejection and humiliation. Another patient in Kalinga initially tells during the interview that she feels nothing about her leprosy, stating that one would just have to accept it and pray to God to be cured. She further states that her diabetes is much more of a concern, implying that she sees her diabetes as a heavier disease than leprosy. Later on, she reveals that her neighbors are telling other community members that people should avoid her because of her leprosy. This signifies that the patient had experienced being stigmatized by the neighbor's statements about her disease.

Stigma is also directed towards the disease *per se* (leprosy) and not the patient who has the leprosy. One patient compares that leprosy is worse than TB. Another patient says that leprosy is heavier than heart diseases. Though, not all patients view that leprosy is a very serious disease. One patient in Benguet views that TB is a much heavier disease, due to the constant coughing nature of TB.

Post-treatment stigma exists, as one patient is hesitant, though willing, to share her experiences. One patient recalled how she experienced community avoidance due to her leprosy. Although treated patients now function normally in the society, discussing past experiences may not be a casual topic.

Family Members and Community Members

Family members face a multitude of issues, and are equally affected with the patient by remarks from community members. There are instances when family members receive discrimination not only from the community (because they have a family member who has leprosy) but from the patient as well. The patient would sometimes accuse family members that they are ashamed of having a member with leprosy. As such, they receive remarks from the community, and sometimes, the patient.

Family members may experience pressure to observe "good manners" during community affairs. One family member in Ifugao shared that they told the leprosy-afflicted member to self-isolate during one community event due to issues raised by community members. Family members are emphatic with patients, and are hurt when they see or hear that their family member is the subject of discriminatory remarks. In some cases, they are altogether (patient and family member) avoided by community folk.

For family members who have been well advised by doctors that the disease cannot easily be transferred, they do not mind gossips in the community. As the case of one family member in Benguet, she instead informs community members that they should not fear the family member (afflicted with leprosy) because the family member is undergoing medication.

Community members on the other hand, fear infection at the same time compassion for leprosy patients. Most often, feelings of compassion is not enough to cover the stigma of infection. As such, the idea of isolating the patient is a necessary but painful measure for controlling leprosy.

Health Workers

Health workers won't deny that they feel fear, that they might have leprosy as a result of servicing leprosy patients. However, the dedication to eliminate leprosy as a health problem, as well as one's mission as a member of the health department, drives health workers to continue with the job. Sadly, not all their colleagues have the same disposition. It can be observed that some health professionals are still disgusted in working with leprosy patients.

It is assumed that health workers may also be delaying the stigma felt in the community, or diverting the stigma towards another concept. One health worker in Ifugao for example tells patients that their disease is a TB of the skin, instead of saying leprosy. Meanwhile, another health worker would rather say that it is HD.

Confidentiality about the identity of the patient is also practiced. It is believed by health workers that community members might ostracize the patient if it is made known that someone has leprosy.

Health workers are aware of the stigma existing in communities, especially in areas where a patient is currently residing. In addition, health workers would cite certain areas due that these are "endemic" with leprosy. A certain amount of caution is labeled for these areas, which may contribute to the stigma associated with leprosy.

Implication of KAPs on Leprosy Stigma

The fear of being humiliated due to some skin discoloration or condition is a double crimpler. First, it makes the patient hesitant about seeking treatment. Second, it reduces the productivity of the individual by affecting his/her self-confidence, and thereby causing problems on community relations. It could further lead the patient to isolate himself/herself from community affairs, or cause the patient not to share utensils, clothing, and other household items which are usually shared among family members in the household.

Leprosy stigma is simply a correlate of ignorance (Cross, 2006). Stating that leprosy is caused by a bacteria and not anything else is a critical message. One should cover their mouths when sneezing or coughing, as a lot of diseases, not just leprosy may be spread through the inhalation of respiratory droplets. The important thing is to state the facts about the disease. It should be noted however that stigma is hard to avoid, due to the following reasons, which is also cited in the research of Hussain and Roshan (n.d.), as observed during the FGDs and KIs:

Physical Deformities

The appearance of untreated patients having deformities and bad smells elicit fear among people. Such appearances may imply that something is dangerous about the person, which therefore causes stigma. It is believed that if the disease causes no physical deformities, stigma may be less or even be absent. It also follows that the level of stigma is directly proportional with the level of physical deformities seen. Visually seeing the wounds of the patient encourage ideas of isolating the patient from the community.

Threat of communicability

As community members see physical deformities in the patient, it follows that one might also have such deformities if s/he interacts with the patient. As such, instances which imply physical connection between an individual and the patient; like touching things which the patient have touched, using things which the patient have used, etc.; is avoided as much as possible. This stigma is also present among health workers, though health workers shared that such ideas would eventually fade away in time.

Threat of Social Avoidance

Notions of avoidance by the community and separation from family members as a result of having leprosy self-stigmatize the patient, and thus reducing normal interaction with the community.

Cross (2006) then proposes that the logical solution would be to enlighten people about the biological realities of leprosy. He cautions however, that rational explanations are inadequate in societies where cultural belief systems prevail. On the other hand, communities studied in this research suggest that cultural belief systems are open to rational and scientific explanations, and would thus be receptive about facts and rational explanations concerning leprosy.

The consequences of stigma often outweigh the physical affliction caused by the disease (van Brakel, 2003), as such, addressing misconceptions about the disease would therefore reduce, if not eliminate leprosy related stigma. Furthermore, the diagnosis of leprosy per se does not cause people to perceive any greater disadvantage than people diagnosed with other skin conditions, as also the case from the research of Boku *et al.* (2010) in Cebu.

The patient that feels no stigma may be due to the fact that there is a harmonious relationship among community members. This condition may as well be the synergistic result of: the patient applying his skills to perform jobs as requested by his neighbors; his hardworking/industrious attitude; and his kind disposition when interacting with community members. Imposing healthy body image counseling programs may help, as used by Guimarães *et al.* (2009), wherein body image enhancement, and coping enhancement programs were used to boost the well-being of one man diagnosed with leprosy.

5. KAP: Interpersonal Relationships and Interactions

Interpersonal relationships and interactions between patients, family members, community members and health workers are very much influenced on the existing stigma caused by the disease.

Patients

One patient complained that health practitioners were not friendly and accommodating. She further stated that a visit to a hospital proved not too good as hospital staff seemed snobbish and inattentive to her needs. Another patient shared that appropriate and well trained health practitioners should attend to her needs since she perceives that health workers are not well trained.

Patients may see health workers as “enemies” rather than friends if the privacy of the former is not respected. One patient in Ifugao aired his complaints, stating that during one check-up, health workers announced publicly that he is “positive” (with leprosy). The event greatly humiliated the patient, and even caused the patient to be not convinced about the news, especially that there is no laboratory result to indicate that he is indeed positive with leprosy.

Generally, it is ok that family members know that they are sick with leprosy. The case is different for one patient, who says that he does not want his family members to know that he has leprosy. The patient further implied that family members may not deal with him nicely as a result of having leprosy.

There was not enough information or counseling about the possible side effects of the medication. Patients are alarmed or frightened by the seemingly adverse effect of MDT medication. They need someone in authority, usually a doctor, whom they trust to explain the nature of leprosy competently and trustworthily. Some of the family members and patients doubted that they have leprosy when they feel that someone is not technically-competent or trustworthy.

Family Members and Community Members

In one FGD in Kalinga, participants were not afraid of some leprosy patients. They still interact with the patients and do not mind being neighbors with the patients. Another shared that because there are no positive findings from the clinic indicating that the patients indeed have leprosy, the participant is not fearful. But when another leprosy patient with more serious symptoms was mentioned, the participant said that she was fearful, and would thereby limit interacting with the said patient.

Community members see family members as the bridge for communication between the community and the patient. Community members state their desires for the patient to isolate himself/herself from the community, or to seek medication, through the family members.

Family members stay together with the patient despite the knowledge of his disease. One family member states that the disease did not affect the relationship of the

siblings. For example, a patient's brother ignored what the community was saying about the patient, since it is not him who has the disease in the first place.

People fear the patient but at the same time, would not want to offend the patient. They do not want to stigmatize the patient, and would thus aim to maintain normal interactions as much as possible. Some community members even allow patients to conduct chores, in this case, baby sitting. As shared by one participant during an FGD in Apayao, she allowed the patient to baby-sit for them. She wanted the patient to do the job, as the patient was also in financial need. However, after getting the baby from the patient, the mother (of the baby) bathed the child in water, in hopes that infection will be prevented. The mother would also pour boiling water to surfaces that the patient touched after the patient had gone away from their backyard.

Health Workers

Health workers in Kalinga and Benguet who served as leprosy coordinators for more than 10 years, said that patients relate well with them, as a result, they are inspired in doing their jobs. They further added that one gets along with patients through encouragement, not verbal berating.

Implication of KAPs on Interpersonal Relationships and Interactions

Stigma about the communicability of leprosy is a factor that greatly affects interpersonal relationships among the community, health workers, and patients and their family members. Another factor would be the attitude of health workers. If health workers are nice and respectful of the privacy of patients; they promote harmonious relationships. Otherwise, patients may see health workers to be outside the treatment process and thereby avoid communicating with health workers. The role of family members as a buffer for community-stigma is also apparent, thus, counseling regarding leprosy should include the family members of patients.

6. KAP: Treatment and Medication of Leprosy

Treating leprosy treatment is primarily through MDT. However, there are a number of issues encountered in treating the disease, as revealed in the following discussions.

Patients

A numbers of factors that discourage patients from completing their medication were revealed in interviews. One patient said that he stopped taking one tablet in the MDT because he observed that the particular tablet is making him weak. Other factors that halt the completion of MDT treatments include instances when symptoms apparently disappear after a few days into medication. The proximity of the health center is also an issue, wherein patients get discouraged when traveling considerable distances to the health center. Health workers are discouraged as well, if they would visit a patient in a far flung area. Lastly, the length of treatment is seen as a big priority to comply with. Six months of medication (at least), is discouraging

for patients as well as family members. Vices, especially alcohol-drinking for either a male or female patient, can also be a significant factor affecting medication.

Patients have also cited a number of instances that have encouraged them to comply with medication. The assurance of health workers that medication is free is one. Another encouraging factor is the assurance that medicines will cure the disease, and that they would not be infectious after constant medication. The disposition of the health worker is also a major factor for patients. A patient in Kalinga shared that the persistent encouragement of the health worker encouraged her to medicate. Patients also become more relaxed if news about them having leprosy remains confidential.

It was notable that patients would seek the services of the modern health care system and only consult “local healers,” if all else fails. It is a general practice that “modern” health services are sought first (whether in public or private clinics).

Family Members and Community Members

A primary concern for family members would be the length of the treatment, as well as side effects felt by the patient. This would sometimes cause family members to seek other treatments for the disease, or even advise the patient to stop medication.

The idea of bringing patients to leprosaria is very much open, as long as patients would be cured. Two names are commonly cited when it comes to leprosaria: Tala and Culion. Tala, Caloocan is the site of the Central Luzon Sanitarium of Dr. Jose N. Rodriguez Memorial Hospital (DJNRMH). It was established in 1940, to accommodate patients suffering from leprosy in the entire Luzon region in the Philippines (Dr. Jose N. Rodriguez Memorial Hospital, n.d.). Meanwhile, Culion, Palawan, was selected as a colony for leprosy patients in 1901 (Culion, Palawan, n.d.). Though, such establishments are no longer fulfilling their original purpose due to the advent of MDT, some family members, community members, and even patients still think that leprosy treatment is more appropriate (and maybe more efficient) in these areas.

Family members are relieved by the news that medication would render the disease non-transferable. Not everyone knows this fact however; as one participant in an FGD in Apayao doubted whether medication would indeed make leprosy non-transferable.

Aside from using drugs, community members also believe that using sulfur soap, keeping surroundings clean and tidy, washing hands after touching something, using boiled guava leaves to wash wounds, and using salted water for washing, helps in treating leprosy. The point is that one should try everything deemed curative to treat the disease.

Health Workers

As to problems concerning treatment, one BHW shared that due that the patient is located in a far flung area, she encounters difficulties delivering medicines. She would then resort to sending blister packs (MDT) through a courier. Another health worker in Ifugao states that the location of communities is a hindrance for delivering medicines and monitoring patients. In addition, some health workers cite that funds for transportation are lacking or inadequate.

A health worker in Abra estimates that about 90-95 percent of the general population is receptive to using MDT provided by the DOH. Well-off patients on the other hand would prefer consultation, and thereby medication, from private clinics.

It is also observed that the *Kilatis Kutis* program of the DOH is not conducted regularly. Such programs are said by health workers to be crucial for detecting a variety of skin diseases, as such; it is perceived that stopping the program may create further problems for preventing skin diseases.

Some midwives were not well versed with the MDT scheme for treating leprosy. The duration of treatment, as well as background on why treatment is a long process, is unknown for some midwives.

Implication of KAPs on Leprosy Treatment and Medication

Health workers should ensure that strict compliance in medication is followed in order to minimize the emergence of drug-resistant strains and ensure that treatment is successful (Worobec, Matsuoka et al., 2007). The health department should also be aware that drug-resistant leprosy strains have been present since the 1960s (Buckingham, 2006). Strict compliance also helps minimize relapse, or the re-occurrence of the disease (Kaimal and Thappa, 2009).

Counseling may offer help for promoting treatment behaviors for the patient. Gautam (2009) stresses that counseling regarding questions about the disease and its management, transmissibility of infection, side-effects of the drugs and self-care advice may ensure efficient treatment. If there is deficient knowledge about leprosy as a result of non-counselling, the treatment process may be affected (Nsagha, Bamgboye, and Oyediran, 2009). Furthermore, dealing kindly with patients could also empower them, boost their esteem, and may in fact be served social justice (Mendonça, 2011).

Faith in MDT as the cure for leprosy should be established among health workers. Maghanoy et al. (2011) present studies indicating the long term efficacy of the 1 year WHO-MDT for multibacillary (MB) leprosy patients, even in those with initially a high bacteriological index (BI). In addition, trainings on the duration of the MDT treatment and other information concerning MDT are needed for BHWs.

Treating leprosy apart from other diseases in separate programs may send messages to the public that leprosy is somehow different and more infectious than

other diseases. Dr. David Heyman (as cited by Rafferty), WHO Executive Director of Communicable Disease Programmes says that 'diagnosing and treating leprosy through the public health system is vital if we are to avoid continuing stigma and prejudice against leprosy patients. Continuing to treat leprosy patients through expensive and separate programs has been shown to be the wrong approach - for health systems and for the patients they look after.' Various researchers claim that separating leprosy services from other health services magnified leprosy as a health problem and thus contributed to the fear associated with it (Arole et al., 2002; Byamungu & Ogbeiwi, 2003; and Feenstra & Visschedijk, 2002; as cited by Cross)

The issue of side effects from MDT should be explained well to patients. Sehgal, Sardana and Dogra (2008) provide a list of side effects for each component of the MDT:

Rifampicin (RMP) side effects:

In addition to hepatitis, a common adverse effect, flushing, pruritus or sensation that causes the desire or reflex to scratch (1 month), dyspnoea or shortness of breath (3–6 months) and skin rash may occur. Intermittent therapy may lead to development of antigen antibody complexes leading to a flu-like syndrome, renal failure, thrombocytopenia and hemolytic anemia, warranting discontinuation of the drug. Toxicity is uncommon after 1 year of therapy. Reddish discoloration of body secretions is harmless, but occasionally alarming to the patient. The drug is teratogenic in animals, but safe in humans. RMP decreases the plasma level of dapsone, oral contraceptives and steroids. Rifampicin resistance is rare so far, described as a one step mutation localized to the *rpoB* gene. Its usual adult dose is 600 mg once a month orally on an empty stomach, while in children its dose is 10 mg/kg.

Diaminodiphenylsulfone (DDS, dapsone) side effects:

Besides, the skin rash and pruritus, nausea, vomiting, psychosis (200–300 mg), headache, insomnia, and blurred vision may necessitate its withdrawal. Hemolytic anemia, a dose related phenomenon, is of minor significance. Bone marrow usually compensates this in a short time. However, in patients with G6PD (glucose 6 phosphate dehydrogenase) deficiency, there may be a severe hemolysis. These patients are started on 25 mg twice weekly, and are gradually increased to 50–100 mg daily over 3–4 months. Hemoglobin of less than 8 g/dl is a contraindication to its use. Thrombocytopenia and methemoglobinemia may occur occasionally. Reversible motor neuropathy of the ulnar and median nerve may occur. Dapsone syndrome (6-week dermatitis) is a delayed hypersensitivity reaction characterized by fever, lymphadenopathy, hepatitis, and exfoliative dermatitis and is controlled by giving corticosteroids for 4–6 weeks and stopping dapsone. In the unlikely event of dapsone poisoning (1000–2800 mg), 1% methylene blue is given (1–2 mg/kg) as a slow IV drip until the disappearance of cyanosis. The widespread emergence of secondary and primary resistant strains of M.

leprae was reported, which led to the concept of prevalent MDT. Dapsone should be given as a single daily oral dose of 50 mg and 2 mg/kg body weight/day for a child. The repository compound acedapsone 4,49 diaminodiphenylsulfone, (DADDS) given as an injection of 225 mg every 75 days produces a satisfactory initial response and has been tried in several large programs. However, it is not recommended in routine use because it has lower plasma levels (0.02–0.1 mg/ml) than standard oral dapsone and because of the emergence of resistant strains of *M. leprae*.

Clofazimine (CLO, B663) side effects:

Skin pigmentation and abdominal symptoms may develop. The skin first becomes red, then brown and eventually blue-black. This pigmentation varies with the initial skin color, and pigmentation is more marked in areas of infiltration of the skin and photoexposed sites. It is reversible, and is a consequence of lipofuscinosis. Xerosis (anti-cholinergic effect), phototoxicity, acneiform eruptions, ichthyosis and pruritus are a few other cutaneous side effects. The conjunctivae become red, and the urine, sputum and sweat become pink. Transient discomfort and diarrhea because of irritation of GIT mucosa are its early untoward effect. Late effects are characterized by persistent diarrhea, loss of weight, cramps and abdominal pain. They are due to deposition of the micro crystals in the small bowel mucosa and mesenteric lymph node causing eosinophilic enteropathy. It is generally safe to restart the drug at a lower dose. Severe symptoms are uncommon, and fewer than 25% of patients develop any problem even at doses over 100 mg. The dosage used for MDT is well-tolerated, and has not shown significant toxicity. Moreover, CLO is a repository drug, stored in the body after administration and slowly excreted. It is given as a loading dose of 300 mg once a month to ensure that the optimal amount of CLO is maintained in the body tissue, even if patients occasionally miss their daily dose.

Why patients resort to other medications may be explained by the fact that even if such treatments do not cure leprosy, but such regimens were easing the pains and discomforts of the patient, they are perceived as worthwhile (Inglis, 2009).

The standard for identifying the level of the disease also needs to be clarified among health workers. One health worker in Kalinga is more familiar with the Ridley and Jopling (RJ) classification system developed in 1966. The RJ classification system identifies five leprosy groups depending on the patient's immunological response to the bacteria, extending from tuberculoid leprosy (TT), in which there is a strong cell-mediated immune response; a borderline group (BT, BB, BL); and lepromatous leprosy (LL), in which there is a very poor cell-mediated immune response. It may be helpful for health workers to use the simplified classification for treatment purposes defined by WHO. This separates the disease into paucibacillary (PB), (1–5 lesions) and multi-bacillary (MB) (6 or more lesions) leprosy depending on the number of cutaneous lesions (Manifold and Marshman, 2009).

An FGD in Kalinga revealed that one should approach the Department of Social Welfare and Development (DSWD) in managing leprosy patients. Due to such sentiments, the presence of DOH health workers in the community should be strengthened. Community members may seek the services of other departments (in this case, DSWD) for health related issues.

7. KAP: Recommendations for Leprosy IEC

Ideas on how to improve the system for managing leprosy were asked among the participants. What they wanted to know about leprosy was also sought during data gathering. These recommendations are presented in the following discussions, wherein answers are summarized from all stakeholders for each province.

Benguet

Participants wanted to know what are the causes, signs and symptoms, and practices that would prevent the spread of the disease. Some participants even wanted to know foods to avoid. They prefer illustrations as some are illiterate and would therefore not be able to read text. Someone should orally explain facts about leprosy. Although one respondent have observed past IEC activities were conducted in their community about dengue or family planning, IEC about leprosy could not be recalled.

Abra

Participants suggested that they need information emphasizing the transition from early stages to late stages of the disease. Invoking fear by showing consequences (graphically strong images) if early signs of leprosy are ignored is helpful to encourage people to undergo medication. They also prefer visual aids, e.g., pictures or images of early and late stages. Participants say that retention of the information is very high if they are able to see pictures or images or if they are able to watch these images, as some cannot read written materials about leprosy.

Health workers need trainings and seminars. One health worker confessed that she didn't have much training or updated knowledge and information about leprosy since she became BHW in 1991. Radio programs may also be one way to inform public about leprosy.

Apayao

IEC materials should emphasize that leprosy medication is given freely by the DOH as one participant in Apayao asked if leprosy medication is free.

Most community members prefer barangay assemblies and meetings for obtaining information about leprosy. TV and radio is not very common in the community, probably due to economic constraints and the absence of electricity. Furthermore, they said that not much attention is given to posters, probably again, due that the community prefer community assemblies.

Community members prefer hearing from the doctor, rather than the midwives assigned in the community. Reputation matters in communities. People who are in the higher levels of an organization's hierarchal structure, or people who come from the city, are much more preferred in the community. This phenomenon may be caused by health workers not establishing rapport with community members.

For health workers, trainings are needed to improve their performance and confidence, especially in assessing leprosy cases.

Kalinga

News about patients with leprosy is spread in the community via gossip and hearsay. Information about leprosy can be spread through the community by word of mouth. The power of community gossip may be the key in eliminating leprosy stigma. For example, educating the community, especially in rural areas, about leprosy may be more effective if it is done through public presentations. On one side however, stigmatization may be also spread rapidly through community gossip.

People from the "region" are viewed as ones with authority. For example in Kalinga, the community may have perceived that the researchers were from the regional office, and we were thus seen to be credible and trustworthy. People "outside" can be seen as authoritative and credible.

One health worker suggests that posters should contain pictures of the different types of leprosy.

Ifugao

The communities are uninformed about the disease. It is crucial to educate the people and empower them through proper education to understand the disease and to act appropriately. One patient is willing to share experiences and advise "leprosy suspects" to seek treatment

The community preferred radio and TV (Radyo Bayan) for IEC campaigns. The people would like to see pictures of symptoms, causes, medication and the early and late signs of the disease. Information about leprosy can also be spread through the community by word of mouth.

One health worker recommends that the IEC material be in Ifugao or Ilocano to be easily deciphered by the people. Private institutions (e.g., La Sallete) doing extension programs should also coordinate with the local health units during leprosy-related activities.

CONCLUSIONS

Conclusions are presented according to key issues on KAPs, key messages for eliminating leprosy as a health problem, and thematic conclusions for sustaining the goal of a leprosy-free CAR. Furthermore, conclusions derived from this report will be the basis of future IEC materials intended for CAR. It is hoped that the truth about leprosy will set constituents in the Cordilleras free from the stigmatic prison created by misconceptions about leprosy.

Causes of Leprosy

Most people are not aware of what causes leprosy. As for health workers, they know very well that leprosy is caused by bacteria. Nonetheless, IEC campaigns should target health workers, as well as the general public.

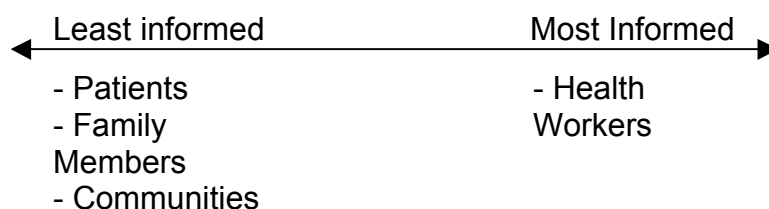


Figure 3. Least informed and most informed groups about the causes of leprosy

In summarizing findings for creating IEC materials for leprosy, the following table is presented:

Table 7. Message and image for correcting misconceptions about the causes of leprosy

DATA	STATEMENT	MESSAGE	IMAGE
<p>CAUSES/ORIGIN:</p> <p>1. Most patients, family and community members perceived that leprosy is caused by:</p> <p>a. intake of some foods or substances such as fish, contaminated foods and liquor;</p> <p>b. swimming in streams or ponds</p> <p>c. touching belongings, wounds, or surfaces touched of a person</p>	<p>There are misconceptions about the true cause or origin of leprosy that need to be corrected.</p>	<p>Leprosy is caused by an infection with the bacteria called <i>Mycobacterium leprae</i>, and spread through respiratory droplets from an untreated person with leprosy.</p> <p><u>Tagalog:</u> <i>(Ang leprosy o ketong ay sanhi ng isang mikrobyo na kung tawagin ay Mycobacterium leprae. Ang mikrobyo na ito ay</i></p>	<p>A picture of a person who is infected with leprosy is coughing/sneezing resulting to blowing of respiratory secretions/droplets indicated by tiny round objects. The resulting droplets will be emphasized as the source of leprosy.</p>

- with leprosy.
- d. genes (hereditary)
- e. supernatural beings activities such as spirits or a curse

daladala ng isang taong hindi nag gamot laban sa leprosy. Naikakalat ito sa pamamagitan ng ubo o bahin ng isang taong hindi nagpagamot

Ilocano:
(Ti leprosy weno ketong ket magapo iti mikrobyo nga Mycobacterium leprae. Daytoy nga mikrobyo ket maala iti maysa nga tao nga han nag-agas kontra ti leprosy. Maiwaras daytoy nga sakit nu ag-uyek weno ag-baeng ti tao nga han nag agas.

Symptoms of Leprosy

People are very much aware of late stage symptoms of leprosy but are not knowledgeable about initial symptoms. Hearsays have been health workers' greatest challenge in delivering accurate health teachings. This then suggests constant monitoring and counseling to patients and family members to prevent the spread of the disease. IEC materials should state early symptoms of the disease (Table 8) in order to diagnose and treat leprosy as early as possible.

Table 8. Message and image for correcting misconceptions about leprosy symptoms

DATA	STATEMENT	MESSAGE	IMAGE
SYMPTOMS:			
1. Most patients, family and community members assume that the symptoms of leprosy is often serious, they would see:	There is partial knowledge about symptoms of leprosy. There recognition of symptoms in the late or advance stages but there is limited awareness of the early signs which are usually associated with ordinary skin	Initial symptoms are: (1) Pale or reddish skin patches, macules or blemishes or flat spotted markings in the skin usually whitish or reddish; (2) loss of sensation, (3) absence of growing hair or sweating in said skin patch. If left untreated, symptoms can further develop into weakness, rotting wounds and numbness of toes, fingers, and nose)	Early symptoms of leprosy: hypo-pigmented or reddish lesions, spots, or blemishes in the skin; with text indicating that no sensation is felt on such lesions. Text should also
a. nodules and deformities in the face and extremities			
b. rotting of or serious lesions or ulcerations in the extremities			
c. amputations			
2. Most patients and		<u>Tagalog:</u> <i>(Ang ketong ay nagsisimula sa isang maputi o mapulang batik o marka sa balat na walang</i>	

<p>family members can hardly distinguish early signs of leprosy with that of ordinary skin problems.</p>	<p>problems.</p>	<p><i>pakiramdam at kadalasan at hindi tinutubuan ng buhok o nilalabasan ng pawis. Kung hindi nagagamot ang mga pangunahing sintomas na ito, lalala at magkakaroon ng panghihina o kayay pamamanhid ng mga kalamnan, paa, at kamay, at pagkaroon ng mga sugat na hindi naghihilom.)</i></p>	<p>indicate that these have no hair growth or sweating. Pictures of severe lesions and disfigured toes, fingers, and faces will be shown when MDT treatment is not sought.</p>
<p>3. Most patients believe that the symptoms they have are mere allergic reactions or skin irritations such that they did not seek immediate medical attention. Although some would seek medication, they would consult doctors for skin allergies or fungal infections, but not to check if it is leprosy.</p>		<p><u>Ilocano:</u> <i>Ti ketong ket agrugi iti maysa nga napudaw wenno nalabagga nga marka wenno pantal iti kudil. Daytoy nga pantal ket ha-an makarikna, ha-an nga tubtubuan ti buok, ken ha-an nga aglingling-et. Nu ha-an nga ma-agasan dagitoy umuna nga sintomas ket mabalin nga agkakapsot, mabegbeg dagiti lasag, ima ken saka, ken agkaroon ti sugat nga ha-an umimbag.</i></p>	

Transmission of Leprosy

It is not known by many that the most probable mode of transmitting the disease is through inhaling respiratory droplets or through prolonged skin-to-skin contact with an untreated person. As such, the following message (Table 9) should be relayed in the leprosy IEC.

Table 9. Message and image for correcting misconceptions about leprosy transmission

DATA	STATEMENT	MESSAGE	IMAGE
<p>TRANSMISSION: 1. Patients, family and community members view that leprosy can be transferred through: a. direct or close contact with the patient (skin to skin contact or open wounds) b. inhaling of droplets</p>	<p>There is a correct notion that leprosy is transferable but there are misconceptions as to the specific mode of its transmission from one person to another.</p>	<p>Leprosy is spread through respiratory droplets from an untreated person with leprosy. Prolonged contact with infected persons who are not undergoing multi-drug therapy (MDT) also spreads the disease.</p> <p>Patients are not highly infectious and become noninfectious only after a few</p>	<p>(Image is similar with Table 7)</p>

General safety precautionary measures are sometimes applied in exaggeration to prevent and manage the disease. Isolation of the patient, including his/her personal belongings and maintaining a clean environment (at times, disinfecting what the patient had used), are general practices. Again, most are not aware on properly managing and preventing the occurrence of the disease (Figure 4). Health workers are knowledgeable about modes of transmission, and are thus guided accordingly as to the prevention and management of the disease and patients. In order to inform patients, family members, and communities in preventing leprosy, Table 10 shows key messages to correct misconceptions.

Table 10. Message and image for correcting misconceptions about leprosy prevention and management

DATA	STATEMENT	MESSAGE	IMAGE
<p>PREVENTION:</p> <ol style="list-style-type: none"> 1. A few family members separated things used by the patients with the rest of the family and tried to avoid having close contact with patient. 2. Most family members are aware of possible transmission but do not know what specific precautionary or preventive measures to be undertaken 	<p>Since the incubation period can take several years, the best way to prevent the disease lies in the early diagnosis and treatment of those individuals suspected or diagnosed as having leprosy, thereby preventing further transmission of the disease to others.</p>	<p>If initial symptoms are observed, one should immediately consult the nearest clinic or hospital for diagnosis. If it is confirmed as leprosy, one must comply strictly with medication.</p> <p><i>Tagalog</i> (<i>Kung pantal sa kutis ay nakikita, sa health center agad magpakonsulta. Kung may ibinigay na gamot, pagkuha nito ay huwag malimot</i>)</p> <p><i>Ilocano</i> (<i>Nu ada pantal iti kudil nga makita, idiy kaasidegan nga health center agpakonsulta. Ited da nga agas para kanyam, panang tumar ken panang palpas ket ha-an mo nga liplipatan.</i>)</p>	<p>A picture of infected person taking the MDT with the full support of family members, further indicating that the person should not be dreaded but assisted in the medication process.</p>

Leprosy-related Stigma

Stigma is inevitably interlinked with the disease. The expression of stigma varies however, as community members may still seek patients to conduct particular chores or services due to skills that the patient possesses. Measuring the level of stigma cannot be truly concluded from data gathered, albeit, it can be surmised that leprosy stigma in CAR is dependent on: (1) one's knowledge about symptoms, communicability and treatment about the disease; and the (2) the physical condition of the patient, symptoms seen on the patient or symptoms seen and felt by the patient.

Interpersonal Relationships and Interactions

Patients still see themselves to be interacting normally with family members, the community and health workers, only that a comment may occasionally be heard about their condition. However, stigma of being humiliated; ignorance of leprosy facts; and the attitudes are factors limiting the existence of interpersonal relationships and interactions among patients and their family members, community folk, and health workers.

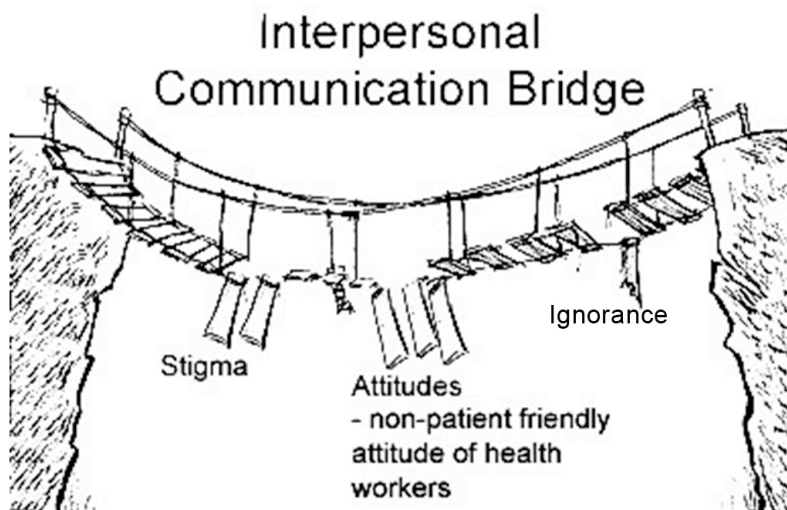


Figure 5. Factors affecting interpersonal relationships and interactions involved with leprosy (Image adapted from Gerry Davis, <http://gerrydavis.blogspot.com>)

Treatment and Medication

Counseling patients to comply with medication is very important for ensuring treatment. Strict compliance with medication should be enforced in order to avoid relapse of symptoms in patients. Health workers should encourage patients to continue medication in spite of side effects or even if symptoms seem to disappear. One should also not factors which encourage or discourage treatment, as presented in the following table:

Table 11. Factors affecting patient’s compliance to medication

Treatment and Medication Encouraging Factors	Treatment and Medication Discouraging Factors
<ul style="list-style-type: none"> - Assurance by the health worker that MDT will cure the patient - Assurance by the health worker that the patient will not be infectious once undergoing medication - Persistent encouragement of health worker - Support of family members to the patient - Good relations with health worker - Assurance of confidentiality 	<ul style="list-style-type: none"> - Side effects (skin darkening, red-colored urine, weakness, body-discomforts) - Interruption of MDT supply - Far-proximity of health center - Rapport not established between patient and health worker - Length of treatment - When symptoms disappear

Gender Issues in Leprosy

Unfortunately, gathered data is not conclusive as to indicate if women or men are more affected by the disease or not. FGDs and KIIs did not reveal whether a man or a woman afflicted with the disease is treated differently by peers, family members, community members or health workers. In addition, data cannot conclude which gender is more compliant in finishing medication. A quantitative research would be a more appropriate method for determining gender related issues about leprosy in CAR. What is clear in the mean time is that the disease affects everyone.

Conducting IEC

All the communities studied for this research indicated that they would prefer oral explanations about leprosy in addition to printed IEC materials. The presence of IEC materials is greatly needed to supplement understanding of the causes, prevention, treatment, and management of the disease.

Value of Research

More research is definitely needed to address the goal of a leprosy-free CAR.

1. Assessing the impact of the *Kilatis Kutis* program
 - Determining whether the program has been efficient in detecting leprosy and other skin diseases could provide implications for budgetary allocations.
2. Creating a manual for health workers dealing with leprosy patients
 - Although publications from WHO are available for guiding health workers in achieving a leprosy-free community by 2015/2020, a localized version of a leprosy-manual for health workers would be helpful.
3. Case studies for a specific social unit
 - Future analysis could be done using a case study analysis. This is due to the fact that this report concentrated on using the basic interpretative qualitative framework for ease of explaining gathered data, as well as to present findings in a concise but accurate manuscript.
4. Crafting modules and strategies for educating health workers
 - Seminars and trainings for health workers in handling patients with leprosy are very much needed in order to ensure that leprosy is properly controlled and managed. Health workers should have a complete understanding on the causes, prevention, management, and treatment of leprosy. Conducting such seminars however should be assessed through research and feasibility analysis.

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