An Exploration of the Involvement of People Affected by Leprosy in Case Detection Activities in South Sulawesi Province, Indonesia

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52th International Course in Health Development
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A thesis submitted in partial fulfillment of the requirement for the degree of

Master of Public Health

By

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LIST OF ABBREVIATIONS

BPJS	*Badan Penyelenggara Jaminan Sosial* (The Social Security Administration)
BTKL Makassar	*Balai Teknik Kesehatan Lingkungan* (Bureau for Environmental Health Technique) Makassar
CDC	Center of Disease Control and Prevention
DG DP & C	Directorate General of Disease Prevention and Control
DP & C	Disease Prevention and Control
DHO	District Health Office
PHO	Provincial Health Office
HC	Health Center
G1D	Grade 1 Disabilities
G2D	Grade 2 Disabilities
HIV	Human Immunodeficiency Virus
ICF	Intensified Case Finding
LEC	Leprosy Elimination Campaign
MoH	Ministry of Health
MDT	Multi Drug Therapy
NCDR	New Case Detection Rate
NHI	National Health Insurance
NIHRD	National Institute of Health Research and Development
NLCP	National Leprosy Control Program
NLR	Netherlands Leprosy Relief
PHO	Provincial Health Office
PerMaTa	*Perhimpunan Mandiri Kusta* (People Affected by Leprosy Association)
PLHIV	People Living with HIV
Posyandu	Pos Pelayanan Terpadu (Intergrated Health Post)
PNPK	*Pedoman Nasional Pelayanan Kedokteran* (National Guidelines for Medical Services)
Puskesmas	Pusat Kesehatan Masyarakat (health center)
RFT	Release From Treatment
RVS	Rapid Village Survey
SCG	Self-Care Group
SHG	Self Help Group
TAG	Technical Advisory Group
TB	Tuberculosis
UHC	Universal Health Coverage
WHO	World Health Organization

ABSTRACT

Background:
Indonesia has the world's third-highest number of leprosy cases. The number of new cases detected has been stable for the past 15 years with around 17,000-20,000 cases per year. Therefore, it is important to explore whether involving People Affected by Leprosy in case detection activities can be one possibility option

Objective:
To explore the involvement of People Affected by Leprosy in case detection activities in order to increase early case finding and provide evidence-based recommendations to National Leprosy Control Program – Ministry of Health

Methodology:
The methodology of this study consists of two components: the analysis of secondary data and a literature review. Piot's Model was used as the framework for analysis in this study.

Data from secondary data was not analyzed statistically due to poor quality the data. The outputs of the project haven't shows a big difference in the program achievement. Supporting factors identified in relation to their experience being affected by this illness: increasing the community awareness through delivering information on leprosy, identifying leprosy suspect cases and refer it to health workers and motivating patients to finish their treatment completely. Obstacles identified are generally People Affected by Leprosy doesn't have enough confidence and an adequate ability to deliver information on leprosy. There were limited international literature and publication on good practices in the other diseases.

Conclusion and Recommendation:
The recommendations are: to develop, provide and socialize a clear recording, reporting, monitoring and an evaluation system; to develop a clear national guideline and IEC materials prototype for non-health educational background and to involve People Affected by Leprosy through routine case management by health center

Keywords: People Affected by Leprosy, empowerment, case detection activities, Indonesia

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INTRODUCTION AND ORGANISATION OF THIS THESIS

Indonesia carries one of the heaviest burdens of communicable and non-communicable diseases globally, with one of the largest population at risk. National strategies and policies have been developed. However, Indonesia still faces many challenges to achieve the goal of the controlling of communicable diseases, particularly leprosy.

Indonesia has achieved the elimination of leprosy at national level in 2000. However, from 2001 until now, the leprosy situation in Indonesia has remained stable around 17,000-20,000 new cases. The Road Map of the Leprosy Control Program in Indonesia has targeted to achieve the elimination of leprosy on a sub-national level at 2019. One of the challenges identified is empowerment of the community and people affected by leprosy.

Society is the leading guard which will first recognize disease occurrence and impact. Potential groups in society, which have an important role, are religious leaders, village health volunteers, People Affected by Leprosy and community leaders. Some studies show that routine passive services in the health center cannot describe the actual number of cases in the field. Usually there is a significant difference between the number of cases detected passively in the health center and the number of case detected actively outside the building. This proves that there are a number of patients who are not detected by health workers in the field.

After graduated from Medical School, I worked on a remote island in the Riau Archipelago for 1 year. I joined the Ministry of Health of The Republic of Indonesia since 2010 as staff member in the Sub directorate of Leprosy and Yaws Control Program. In my work, I always have a special interest in the empowerment of People Affected by Leprosy, which is still stigmatized and marginalized in the community in Indonesia.

This thesis is addressed to the Ministry of Health, local government and stakeholder related which can be used in their program to strengthen People Affected by Leprosy's role in the leprosy control program. This thesis consists of seven chapters.

Chapter one consists of background information including information about leprosy, Indonesia, South Sulawesi Province, National Leprosy Control Program, Leprosy Situation in South Sulawesi Province, People Affected by Leprosy and about the project. Chapter two consists of problem statement, justification, objectives, methodology used and framework for analysis. Chapter three consists of results, finding and analysis. Chapter four consists of good practices from other diseases. Chapter five consists of discussions, conclusion and recommendation.

CHAPTER 1
BACKGROUND INFORMATION

1.1 LEPROSY

Leprosy is a chronic, infectious disease caused by a bacillus, *Mycobacterium leprae* that multiplies slowly. The incubation period of the disease is on average 5 years. However, it can take as long as 20 years for symptoms to appear. Leprosy mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract and also the eyes. In most patients, early leprosy presents as macular and hypo pigmented lesions. The lesions may also be red in light-skinned patients or coppery in dark-skinned patients. A very important characteristic of leprosy lesions is the impaired sensation or anesthesia (1,2,3).

WHO classifies leprosy related impairment into three grades:
Grade 0: no impairment
Grade 1: loss of sensation in the hand or foot
Grade 2: visible impairment.

Leprosy is curable and treatment provided in the early stages prevents disability. Untreated, leprosy can cause progressive and permanent damage to the skin, nerves, limbs and eyes. Although not highly infectious, it is transmitted via droplets, from the nose and mouth, during close and frequent contact with untreated cases. Early diagnosis and treatment with Multi Drug Therapy (MDT) remains an important component in leprosy control programs (1,2,3,4).

Since 1995, the WHO provides MDT treatment, free of charge, to all leprosy patients in the world. MDT is a simple yet highly effective cure for all types of leprosy and has cured around 16 million patients over the past 20 years. Leprosy control programs have improved significantly at national and subnational level. Active case finding activities, including health promotions, Leprosy Elimination Campaigns (LEC), Intensified Case Finding (ICF) and Rapid Village Surveys (RVS) have been introduced in most endemic countries. Primary leprosy services are usually integrated into existing general health services. Many efforts have been done but still there was around 200,000 new cases detected each year (1,2,8).

Recently, The Global Leprosy Strategy 2016-2020 was launched in New Delhi on 20 April 2016 which aimed on a leprosy-free world. A leprosy-free world defined as a situation where there is zero morbidity, zero disabilities and zero social consequences due to leprosy in the community. The strategies developed through three pillars consist of strengthening government ownership coordination and partnership, stop leprosy and its complications and stop discrimination and promote inclusion. The principles of the Global Leprosy Strategy are initiating

action. This involves plans of action, specifically for the developing country, ensuring the accountability. Those things mentioned above done through strengthening monitoring and evaluation in endemic countries and promoting inclusivity through establishing and strengthening partnerships with stakeholders, including persons or communities affected by leprosy (9).

The International Leprosy Summit - Overcoming the Remaining Challenges in Bangkok (July 2013), was participated by representatives from the Ministry of Health (MoH) from 17 countries, high endemic for leprosy, from all WHO regions. During the Summit, the Bangkok Declaration towards a Leprosy-Free World was signed by all participants to reaffirm their political commitment and guidance towards a world free of leprosy. In the Bangkok Declaration a Global Target was formulated: to reduce the number of leprosy patients with Grade 2 Disabilities (G2D) at the moment of diagnosis to less than < 1/1,000,000 by the year 2020 and to achieve elimination (a prevalence rate of less than 1 per 10,000 populations) at sub-national level by the year 2019 (10).

1.2 INDONESIA AND SOUTH SULAWESI PROVINCE

1.2.1 Geography

Indonesia is located in South East Asia with Jakarta as the capital city. It lies between two continents (Asian and Australia) and two oceans (Pacific and Indian). It is 1,913,578.68 square kilometers and the largest archipelago in the world with 17,504 islands. These islands are scattered along both sides of the equator line. The five largest islands are Sumatra, Kalimantan, Papua, Sulawesi and Java. Indonesia shares land borders with Malaysia, Brunei Darussalam, East Timor and Papua New Guinea and maritime borders with Malaysia, Singapore, The Philippines, Palau and Australia (11).

Figure 1 Map of Indonesia (12)

Since it is located along the equator line, the country has a tropical climate which has a wet and a dry season. Temperatures vary little throughout the year; the average daily temperature range is 18.20–40.30 °C. The humidity is generally high with an average around 80% (11,13).

The size, climate and geographical condition have made Indonesia become the country with the second highest level of biodiversity in the world after Brazil. Flora and fauna are a mixture of Asian and Australian species and the distribution are divided by the Wallace Line. Approximately 50% of the country is covered by forests (11,14,15).

South Sulawesi is one among 34 provinces in Indonesia (11). South Sulawesi Province located in the southern peninsula of Sulawesi Island with Makassar as the capital city. It is 45,764.53 square kilometers. It share land borders with several provinces: Central Sulawesi, West Sulawesi and South East Sulawesi. This province also surrounded by Gulf of Bone, Strait of Makassar and Flores Sea (11,16,17). Temperatures in South Sulawesi vary little throughout the year; the average daily temperature range is 19.50–35.60 °C. The humidity is generally high with an average around 78.20% (11,13,17)

Figure 2 Map of South Sulawesi Province (18)

1.2.2 Demography

Indonesia has a total population of 237,641,300 based on the Population Census of 2010 and by 2015 was projected to be 255,461,700 with an annual population growth rate of 1.38 %. Indonesia is the fourth most

populous country in the world after China, India and US in 2014. In 2013, 49.75% of the total population is female and 50.25% is male. Life expectancy in 2015 was 70.1. Indonesia currently possesses a relatively young population, with a median age of 28.4 years (2015 estimate). Population children of under 5 years old in 2014 is 23,313,000 and under 15 years old is 71,950,000 while population of women 15-49 years old is 67,520,000 (11,19,20).

South Sulawesi Province has a total population 8,520,304 in 2015 with sex ratio of 95.4% (11,16,17). Life expectancy in 2014 for South Sulawesi is 67.69 for male and 71.59 (11)

1.2.3 Socio-cultural

Indonesia is a very diverse country in ethnicity and linguistics with around 300 distinct native ethnic groups. There is total of 1,068 different local languages, while there were 742 of them have been mapped.167 languages have been researched and 176 have not been researched. The official language is Bahasa Indonesia which is primarily used in commerce, administration, education and the media (11,21,22).

Indonesian constitution stipulates freedom of religious choice and the government officially recognizes six religions, which are Islam, Protestant, Catholic, Hindu, Buddha and Confucius. The country has the world's largest Moslem population which comprises 87.2% of the country population (11,21).

South Sulawesi Province has four main ethnic groups which are Buginese, Makassarese, Torajan and Mandarese. Buginese is the largest ethnic group in South Sulawesi Province. There is total of 8 different languages, while there were 7 of them have been mapped (16,21,22).

1.2.4 Economy

In Indonesia, both government and private sector play an important role in the economic sector. Indonesia has the largest economy in South East Asia. Based on data released by World Bank in 2015, its GDP Growth Rate is 4.7%, GDP per capita is USD 3,347 and GDP (PPP) per capita is USD 10,157. According to data in 2015, 28.5 million Indonesian populations lived under the poverty line (11,23).

Indonesia has extensive natural resources, including crude oil, natural gas, tin, copper, and gold. Palm oil production is important to the economy of Indonesia as the country is the world's biggest producer and consumer of the commodity, providing about half the world supply. In an attempt to boost the domestic mineral processing industry and to encourage exports of higher value-added mineral products, the Indonesian government implemented a ban on export of unprocessed mineral ores in 2014 (11).

The Human Development Index (HDI) is a composite statistic of life expectancy, education and income per capita indicators. Based on UNDP reports in 2014 Indonesia ranks at 110th among 188 countries. In 2015, 28.5 million Indonesians lived under the poverty line. Poor people were defined as people whom the average of monthly expenditure is under the poverty line. The unemployment rate in Indonesia as per August 2015 is 6.18 (11,23).

In 2014, the highest HDI of districts/ municipality of South Sulawesi Province is 79.35 (Makassar) and the lowest is 61.45 (Jeneponto District) (17). Purchase Power Parity of districts/ municipality of South Sulawesi Provinces ranges between 6,214 and 15,079 (17). The provincial minimum wage of the province in 2014 is 1,800,000 IDR which is higher than national minimum wage (1,506,231 IDR). The unemployment rate in South Sulawesi Province as per August 2015 is 5.18 (11).

1.2.5 Education

The National Education System which was established through Law No 20/ 2013 stipulated that the education system in Indonesia consists of formal education, non-formal education and informal education and that all three can be complementary and enriching. Levels in the formal education consist of primary education, secondary education, and tertiary education. Non-formal education defined as education outside formal education which can be structured and tiered. Usually non-formal education is in early childhood and basic education such as learning to read Quran in the mosque, Sunday school at church, also includes a variety of courses such as music lessons. Informal education defined as family education and environmental learning activities which is done independently with full responsibility. The results of informal education was recognized at the formal and non-formal education after students pass the exam in accordance with national education standards (11,24).

The education system in Indonesia stipulated a compulsory education for twelve years. The enrolment rate in 2011 is 94% for primary education, 75% for secondary education, and 27% for tertiary education. By 2015, there were 176 state and 3,742 private universities in Indonesia. The literacy rate in 2015 is 97.43% in urban setting and 92.91% in rural setting (11,24). According to data published by Ministry of Education and Culture, there are 211,299 schools, 2,907.055 teachers and 44,565,592 students in Indonesia as per August 2016 (22).

Expected years of schooling in South Sulawesi is 12.90 years (2014) which have increased compare to 2010 which was 11.47 years (17). According to data published by Ministry of Education and Culture, there are 8,990 schools, 127,132 teachers and 1,703,187 students in South Sulawesi Province as per August 2016 (22).

1.2.6 Governance

Indonesia is a republic and democratic country with a presidential system based on the Five Principles (Pancasila). The political system in Indonesia is based on the Trias Politica principle or separation of legislative, executive, and judicative power (11).

Indonesia has started to implement decentralization system since 1999. Regional autonomy is part of the implementation of decentralization system. Regional autonomy defined as where district and cities have their rights, authorities, and obligations to set up and manage their own affairs and interests of local communities in accordance with the legislation. There were several legislation on regional autonomy that have established including Law No.22/1999, Law No.32/2004, Law No.12/2008, Law No. 23/2014 (25).

Central government headed by a President which is elected through general election once in five years. Local government consists of province and districts/ cities. Province functioned as an administrative layer between central government and districts/ cities. Province has its own governor and legislative bodies. District and city have its own Head of District and Mayor, and so as legislative bodies. Governor, Head of District, Mayor and legislative bodies are elected through local election once in five years. District and city is divided in to sub-districts. Sub-district is divided in to villages. According to national data released in 2016, there are 34 provinces, 416 districts, 98 cities, 7,071 sub-districts and 81,936 villages (11, 25).

Among 34 provinces in Indonesia, 5 provinces have a special status. Aceh has a special status since they implement sharia law as the provincial law. Special Region of Yogyakarta which is a sovereign monarchy within Indonesia. Papua and West Papua have special autonomy region. Jakarta have status as Special Capital Region of Jakarta (11,25). In South Sulawesi Province there are 21 districts, 3 cities, 306 sub-districts and 3,033 villages (11,16,25).

1.2.7 Health System and Financing

Health services in Indonesia are structured in five levels: central, provincial, district, sub district and village. The first level in primary care is the health center (*Puskesmas*) which is located in the village. The health center has a referral system to the district, provincial and central which provides the secondary and tertiary level. Based on the National Survey 2013, there are 9655 health centers, 1562 public hospitals and 666 private hospitals. 57 of them were special hospitals and central hospitals.

Percentage of birth with medical assistance in 2015 is 91.51%. According to immunization coverage (given to children under five) on 2015, measles have the lowest coverage compare to BCG, DPT,Polio which was 71.63%. Total Fertility Rate of Indonesia and South Sulawesi Province in 2012 is 2.60. Infant Mortality Rate for the country in 2012 is 34 while in South Sulawesi Province it is 25. Infant Mortality Rate for the country in 2012 is 43 and in South Sulawesi Province it is 37. In 2015, Infant Mortality Rate of the country is 23 per 1000 live birth (11,26,27,28,29).

Universal health coverage defined as all people get access to health care they need including promotive, preventive, curative, rehabilitative and palliative health services. These services provided needs to sufficient quality to be effective without ended to a financial hardship for the user (30,31).

Indonesia has targeted to achieve Universal Health Coverage (UHC) in 2019 (26,32). Since January 2014, a national institution named The Social Security Administration /*Badan Penyelenggara Jaminan Sosial* (*BPJS*) was formed to be in charge of National Health Insurance (NHI) in Indonesia (32). Furthermore, national laws have been established on NHI since 2004. The law for National Social System 40/2004 stated that health insurance for the entire population and in 2011 this legislation was strengthened by Law No.24/2011 on national agency for health insurance (33).

UHC comprises three main things. The first one is equity in terms of access to health services. As per April 2016, Indonesia has reached more than 50% coverage (165,789,580 memberships of 254,862,034 populations). The second thing related to the quality of the health services provided which is should be good enough to improve the health of the people who receive the services. The third one is protection for the people who received the services against financial-risk (34).

1.3 National Leprosy Control Program

Although elimination of leprosy at the national level had been reached in 2000, until now in Indonesia there are still 13 provinces with 121 districts where the prevalence rate is more than 1/10,000 population. Since 2000, the number of provinces and districts who reached elimination at sub national level, (provincial and district) are slowly increasing. The numbers of districts who have not reached elimination are 162 of the total 487 districts in Indonesia. Now a few more districts have been added and total numbers of districts are 511. Efforts to eliminate leprosy in districts will be encouraged by achieving the elimination at the provincial level.

Table 1 Leprosy Trend in Indonesia 2000-2015

Year	Registered Cases	New Cases	Grade 2 Disability Cases		Child Cases		MB Cases	
			Total	%	Total	%	Total	%
2000	17,539	14,697	1,231	8.38	1,499	10.20	11,267	76.66
2001	17,712	14,722	1,300	8.83	1,466	9.96	11,314	76.85
2002	19,855	16,253	1,251	7.70	1,449	8.92	12,398	76.28
2003	18,337	15,913	1,275	8.01	1,676	10.53	12,223	76.81
2004	19,666	16,572	1,430	8.63	1,763	10.64	12,957	78.19
2005	21,537	19,695	1,722	8.74	1,790	9.09	15,639	79.41
2006	22,763	18,300	1,575	8.61	1,905	10.41	14,750	80.60
2007	21,430	17,723	1,527	8.62	1,824	10.29	14,107	79.60
2008	21,538	17,441	1,668	9.56	1,987	11.39	14,328	82.15
2009	21,026	17,260	1,812	10.50	2,073	12.01	14,227	82.43
2010	19,741	17,012	1,822	10.71	1,904	11.19	13,734	80.73
2011	23,169	20,023	2,025	10.11	2,452	12.25	16,099	80.40
2012	22,390	18,994	2,131	11.22	2,191	11.54	15,703	82.67
2013	19,755	16,825	1,677	9.97	1,996	11.88	14,062	83.42
2014	19,948	17,025	1,596	9.00	1,894	11.00	14,213	84.89
2015	20,154	17,489	1,705	9,7	1,957	11	14,775	84

Source: National Data

One of the causes is lack of sustainable existing leprosy control programs in each district. This has been reflected as an unstable number of new leprosy cases detected through active findings which funds were made available for the implementation of the control program in the district. This is contrary to the biological fact that the incubation period of this disease requires a long continuity of the management of leprosy cases in the district from year to year. The remaining challenges for the districts include non-reporting of cases as a whole due to difficult to reach areas or have not been visited by leprosy technical officers regularly. This has resulted in a continued transmission of leprosy in the areas.

Recent challenges, faced by the National Leprosy Control Program and intervention efforts to overcome those challenges are:

a. Policy support and partnerships

Political supports from local government are needed for the leprosy control program especially in the era of decentralization, in order to ensure the sustainability of activities and implementation of control programs in the areas. Expected supports are to ensure availability of funds and human resources (trained leprosy technical officers). Some districts have not allocated adequate funds for leprosy control programs since the leprosy was not being prioritized. These districts have reported high number of new cases with high disability rates where adequate case detection, preventive and promotive activities need to be implemented. In addition, high displacement of trained leprosy technical officers and lack of leprosy technical trainings conducted by the provincial health offices, are causing problems to the sustainability of leprosy control program implementation. Advocacy to

stakeholders at the district is an effort to improve and maintain the sustainability of the leprosy control programs through the alignment of policies and adequate budget allocation to support the programs. In the areas of decentralization, advocacy is a priority for high endemic districts that have the resources, but are not being allocated optimally for leprosy control programs.

Partnerships, with professional organizations to support the leprosy control programs, have also become a necessity, as goes along. Referral services for the treatment and reporting of cases with complications, have already run well in some places, but still have encountered challenges in other places. It is important to develop the standards for leprosy case management. This will be very important in leprosy case management in the health care facilities.

Based on Regulation by Minister of Health No. 1438 in 2010 about the Medical Service Standard, in the area of National Health Coverage, disease management must have National Guidelines for Medical Services/ *Pedoman Nasional Pelayanan Kedokteran (PNPK)* including leprosy. To support a comprehensive and standardized leprosy service, *PNPK* of leprosy is needed. *PNPK* will be developed by The Indonesian Dermatology and Venereology Association, Indonesian Rehabilitation Medical Association and Indonesia Orthopedic Association. In addition, to strengthen the support of professional organizations in the district, it requires a Memorandum of Understanding (MoU) between the Directorate General of Disease Control and Environmental Health and professional organizations.

Leprosy problems are not only health related aspects but also social, economic and human rights. Partnership is needed with the Coordinating Ministry of People's Welfare, Ministry of Social Welfare, The Indonesian National Commission on Human Rights and other ministries/ institutions of Indonesia. This partnership will encourage the implementation of a comprehensive service for People Affected by Leprosy.

b. Case Finding and Case Management

Early case detection and prompt treatment is the main strategy of the leprosy control program. However, detecting cases through passive services in health centers and hospitals are difficult to be implemented well, since stigma is still high, and community knowledge of leprosy is still low. Case detection through active case findings becomes an important activity, especially for high endemic areas. Active case finding activities are suggested through the Leprosy Elimination Campaign (LEC), Rapid Village Survey (RVS), Contact Survey and suspect case detection by village health volunteers/ communities.

Several active case finding activities showed significant results through the increase in new case detection.

Case management should be supported by the availability of Multi Drug Therapy (MDT) in health centers and hospitals. Good management of the MDT will ensure the availability of drugs, for leprosy patients, timely in health care facilities so that leprosy patients don't drop out. Current reporting systems and the distribution of MDT from the central to the provinces, districts, hospitals and health centers still need improvement. Currently, not all hospitals are able to coordinate well with District Health Office (DHO)/ Provincial Health Office (PHO) for the availability of MDT; therefore, a policy from MoH is required which will be developed from the national agreement.

c. Disability prevention

The Bangkok Declaration 2013 achieved an agreement that each country is targeted to achieve a G2D rate below 1/1,000,000 population by the year of 2020. A high proportion of visible defects (G2D based on WHO criteria) in Indonesia, 8.7 per 1,000,000 populations in 2012 is a challenge for the National Leprosy Control Program. Defects in leprosy show a delayed discovery of cases which are associated with the lack of knowledge in health workers and a low awareness of the community in recognizing early signs of leprosy. Stigma against leprosy in the community causes the patients to hide themselves and to not seek treatment. Information, Education and Communication (IEC) activities on leprosy in the community are required. Activities that positively impact are based on the evaluation of the program, including the dissemination of posters, leaflets in public places, outreach to the community, socialization to religious leaders/ community, serving public service advertisements on television and radio. It is expected that, through IEC, community awareness and participation, participation will increase and ultimately take part to promote self-screening actively to healthcare facilities when early signs of leprosy are found. Not all the reasons, for delayed case detection, were identified and would gain a solution, so that it is necessary to conduct operational studies to provide input to the program in reducing the number of disabilities in leprosy.

As per historical aspect of the disease, disability in leprosy may occur after treatment through a reaction mechanism which is not detected and handled properly. Patient/ family’s knowledge, the availability of disability aids, health worker’s skills, default case tracking and a clear referral system, became determining factors in the success of prevention of further defects on leprosy.

d. Capacity building for leprosy technical officers

High displacement of trained health officers, in the field and expansion of regional areas, became currently one of the challenges for the National Leprosy Control Program. The above situation demanded the increasing need of trained health officers. Leprosy training for medical doctors, district leprosy technical officers and health centers health workers administered by the Sub directorate of Leprosy and Yaws with financial support from WHO and Netherlands Leprosy Relief (NLR). During the last few years, training was facilitated by National Leprosy Training Center, national and regional facilitators who have joined the Training of Trainers.

Compared to the number of health centers that reported leprosy cases, the number of medical doctors and leprosy technical officers who were trained per year are still not adequate. This happened due to a limited training budget support from donors, which is not sufficient enough to fund the needed training in the field. In 2015, funding of training sources from the national budget revenue expenditure will cooperate with the Agency for Development and Empowerment Human Resources of Health of the MoH and the Provincial Health Training Center.

Some of the potential health workers, who have been identified and have a significant role in the health program are; provincial technical officers, district technical officers and health center health workers; and medical doctors in health centers and hospitals, temporary employed medical doctors, intern medical doctors, family physicians and a dermatologist. While for complication management expertise is needed in other specialties such as medical rehabilitation and orthopedic.

e. Empowerment of the community and the People Affected by Leprosy

Increased efforts in promotion, prevention and rehabilitation of leprosy require the participation of the community. Society is the leading guard who first recognizes disease occurrence and impact. They also know how to mobilize resources to tackle the disease. Potential groups in society, which have an important role, are religious leaders, village health volunteers, People Affected by Leprosy and community leaders. Some studies show that routine passive services in the health center cannot describe the actual number of cases in the field. Usually there is a significant difference between the number of cases detected passively in the health center and number of case detected actively outside the building. This proves that there are a number of patients who are not detected by health workers in the field (35,36,37,38,39)

Since 2015, leprosy was included as one of the indicator of National Medium Term Development Plan 2015-2019. This was a huge step for

National Leprosy Control Program in Indonesia. Leprosy is one of Neglected Tropical Diseases in Indonesia which didn't get too much attention compare to other program. The government paying serious attention on the target of as stated in the National Road Map to eliminate leprosy in Indonesia at the sub national level by 2019. As the impact of being one of the indicators of National Medium Term Development Plan 2015-2019, there is an increasing in budget for leprosy control program. As the consequences to that, NLCP together with Expert Committee and stakeholder related have to push theirself to develop innovative program which will give an impact to the program achievement. In the era of decentralization with the regional autonomy in district/ city level, there must be a good collaboration between central, provincial and district/ city (37,38,39).

1.4 Leprosy Situation in South Sulawesi Province

Table 1 Leprosy Trend of South Sulawesi Province 2011-2015

Year	Registered Cases	New Cases	Grade 2 Disability Cases		Child Cases		MB Cases	
			Total	%	Total	%	Total	%
2011	1,252	1,338	162	12.17	83	6.20	1,128	84.03
2012	1,177	1,160	126	10.86	72	6.21	987	85.09
2013	1,133	1,172	110	9.39	70	5.97	1,035	88.31
2014	1,139	1,143	113	10	72	7	990	87
2015	1,155	1,220	131	9,70	94	7.70	1,026	84

Source: National Data

South Sulawesi is one of high endemic province for leprosy which has not reached elimination at provincial level (with the prevalence rate more than 1 case per 10,000 populations). In 2015 the prevalence rate is 1.36. In National Road Map, this province was targeted to achieve elimination in 2017. There were 16 districts/ city in South Sulawesi Province among 24 which haven't achieved elimination in 2012.

There are 278 health centers with leprosy patient and 157 health centers without leprosy patient across South Sulawesi Province in 2013. Dr. Tadjuddin Chalid Leprosy Hospital in Makassar is the referral hospital for Eastern part of Indonesia. They have a quite percentage of high trained doctors and leprosy technical officers since until a few years ago, National Leprosy Training Center was located there for many years. Leprosy control program in this province were fund through local budget, central budget and NGO.

South Sulawesi Province is one among few provinces in Indonesia which have started to empower People Affected by Leprosy since many years ago. In South Sulawesi also developed many Self-Care Group of People Affected by Leprosy. The biggest association for People Affected by

Leprosy in Indonesia is *PerMaTa (Perhimpunan Mandiri Kusta*). It is only exist in three provinces in Indonesia: South Sulawesi, East Java and East Nusa Tenggara. In South Sulawesi, they have branches in many district/ city. They were quite active in delivering information on leprosy, advocacy to the local stake holder. Makassar Branch started to involve in case detection activities together with leprosy team of Makassar since 4-5 years ago. Now they have started to facilitate short training for People Affected by Leprosy from districts/ city in South Sulawesi which is funded by local NGO (38,39,40).

1.5 The Project

MoH collaborates with NTD Unit of WHO country office, PHO of South Sulawesi and DHO of Bulukumba to conduct a project in 2013. The project named "Community participation in early leprosy case detection activities in high endemic district". Kajang Sub-district, Bulukumba District was chosen as the implementation area for this project.

The general objective of this project is to enhance reduction of NTD burden by implementing best practices, disease control activities based on recent proved studies. Specific objectives of this project are to strengthen capacity and participation community and Person Affected by Leprosy in supporting the program to reduce burdens of leprosy and to support health workers in promoting early case finding and self-reporting; and facilitating default case for regular treatment.

The detail information of the project implementation as written bellow:

Preparation

- Socialization
  Meeting has been conducted in South Sulawesi Provincial Health Office and districts. Related stakeholders involved are South Sulawesi Provincial Health Office, BTKL PP Kls I Makassar (Bureau for Environmental Health Technique) Makassar, *PerMaTa*/ *Perhimpunan Mandiri Kusta* (People Affected by Leprosy Association South Sulawesi).
- Training for People Affected by Leprosy and village health volunteers and Launching of the activity
  The training was conducted for four days and facilitated by *BTKL PP Kls I Makassar* and *PerMaTa* of South Sulawesi. This activity was attended by 42 participants who consist of: 1 District Technical Officer for Leprosy and Yaws, 9 People Affected by Leprosy and 32 village health volunteers from 16 villages. This activity has been launched officially by Local Administrative of Bulukumba District.

Implementation

- Routine visit
  The team consists of local People Affected by Leprosy and village health volunteers identified regular meetings or activities in village level (official village meeting, village health volunteers meeting,

religious meeting and others) and developed a plan for visiting them. The team in collaboration with health workers participated on that meetings and requested time for providing health promotions/ educations on leprosy. Some suspect signs of leprosy identified by person affected by leprosy and cadres referred to the health centers for further confirmation and treatment.

- Defaulter case management
  People Affected by Leprosy and village health volunteers, in collaboration with health center identified and visited leprosy patients who default from the treatment. Supports including motivation were provided to those patients in order to complete the treatment and prevent disability.
- Advocacy
  Some important issues regarding to leprosy have been addressed to the village leaders.
- Group meeting
  Planning and monitoring were discussed in regular group meeting which conducted on the fourth week in every month.
- *Monitoring and evaluation*
  This activity conducted and facilitated by Sub directorate of Leprosy and Yaws, Ministry of Health, WHO Indonesia and Provincial Health Office of South Sulawesi

  The same activity also been in Wajo District in 2014. Pitumpanua Sub-district, Wajo District was chosen as the implementation area for this project. The training was attended by 33 participants those include: 1 Officer of Pitumpanua Sub district Office, 2 health workers of Pitumpanua Health Center (Leprosy and Health Promotion workers), 4 People Affected by Leprosy and 26 village health volunteers . This activity was launched officially by Local Administrative of Wajo District.

CHAPTER TWO
PROBLEM STATEMENT, JUSTIFICATION, OBJECTIVES AND METHODOLOGY

2.1 Problem Statement

Indonesia has the world's third-highest number of leprosy cases, after India and Brazil with 17,025 new cases in 2014. Elimination at national level was reached in the year 2000, but the number of new cases detected has been stable for the past 15 years with around 17,000-20,000 cases per year. This shows that there are still challenges in achieving the goal of the leprosy control program based on the National Road Map (36,38,39).

Among the 17,489 new cases in 2015, the proportion of child cases was 11%, MB proportion and the G2D proportion among new cases were 84 % and 9.7% respectively. The high disability proportion shows that there is a delay in case detection and continued transmission of leprosy. As of 2014, out of 34 provinces, 16 are classified as a high burden area which is defined as a province with more than 1000 new cases per year or with a New Case Detection Rate (NCDR) of more than 10/10,000 population. Leprosy is an prominent cause of preventable disability (38,39).

The above epidemiological situation has pushed the National Leprosy Control Program – Ministry of Health (NLCP-MOH) in Indonesia to come up with innovative activities that would significantly contribute to detect the new cases in communities as early as possible and to reduce the disease burden in the country. Increasing community awareness regarding leprosy plays an important role in achieving national set targets as well as early detection of (suspected) cases, management of default cases and soft-advocacy to stakeholders regarding leprosy issues and health promotion/ education activities. This is in line with the Road Map of the Leprosy Control Program in Indonesia: Towards Elimination at Provincial Level 2015-2019, the general objective of this Roadmap is to reduce the burden of leprosy towards elimination on the provincial level. Specific objectives to be developed are: to strengthen policies and regulations that support leprosy service at all levels, to strengthen comprehensive and affordable services and promote its integration into general health services and to enhance self-reliance of the community including person affected by leprosy in community based activities of promotion, prevention and rehabilitation (38).

Strategies of the NLCP in the Road Map by 2014-2019 are early case finding and prompt treatment, integration of qualified leprosy services in to general health services, strengthening the capacity building of health workers and sustainability of government and local government's commitment (38).

The role of People Affected by Leprosy, in sustainable leprosy services, was one of the issues discussed in the WHO-Technical Advisory Group (WHO-TAG) on Leprosy Control in Congo in 2014. There are some good examples of participation by persons affected from a few countries like Brazil, China, Ethiopia, India and Mozambique but there was not much progress reported. The persons affected face barriers that include the mind-set of professionals towards inclusive strategies and lack of opportunities to develop their capacity (35).

In 2013 and 2014, NLCP-MoH conducted a program on community participation in early case detection in two high endemic districts: Bulukumba and Wajo in South Sulawesi Province. Kajang and Pitumpanua sub districts were selected as the implementation areas, based on the case detection rate. A 4 days training prepared village health volunteers and People Affected by Leprosy to work in their respective villages. In the training they learned to carry out routine health promotion/ education activities, to identify people with signs and symptoms suspect for leprosy and to manage default cases. They also learned to use soft-advocating techniques aimed at involving related stakeholders in leprosy related issues such as posyandu (Integrated Health Post), religious village meetings, formal village meetings, informal village meetings, women village meetings, home visits and family gatherings.

The local government strongly supported this program aimed at community involvement, as it is in line with the local program objectives and it will contribute directly to achieving some of the set programmatic objectives. NLCP-MOH has not conducted a review of this project. The results of the program have not been reported specifically, but it was integrated into the health center's routine report.

Therefore, it is important to explore whether involving People Affected by Leprosy in case detection activities can be one possibility option.

2.2 Justification

Impairments caused by leprosy may give rise to disabilities, such as limitations of activities involving the use of hands, feet and eyes, and restrictions in social participation. However, leprosy is still often diagnosed too late, when permanent impairment has already occurred. Early case detection is very important in leprosy. Delay in case detection is shown by the proportion of G2D among new cases. People affected by leprosy with G2D are likely to suffer from social stigma and discrimination leading to economic loss.

2.3 Objectives

2.3.1 General Objective

To explore the involvement of People Affected by Leprosy in case detection activities in order to increase early case finding and provide

evidence-based recommendations to National Leprosy Control Program – Ministry of Health

2.3.2 Specific Objectives

1. To analyze whether over time the involvement of People Affected by Leprosy has made any difference in the program achievement
2. To explore supporting factors and obstacles of the involvement of People Affected by Leprosy in case detection activities
3. To review experiences and identify good practices from similar programs described in international literature
4. To provide recommendations to the leprosy control program in order to make the involvement of People Affected by Leprosy in case findings more effective

2.4 Methodology

2.4.1 Study Type

This study consists of two components: secondary data and literature review. The analysis of secondary data designed to meet specific objectives 1 and 2 through annual/ quarterly data, project data/reports. The literature review designed to meet objective 3. Objective 4 will be met by the final analysis of all evidence collected for objectives 1-3.

2.4.1.1 Secondary Data

2.4.1.1.1 Data Collection

The analyzed data comes from annual, quarterly and project data or reports. If it is not enough, the gap will be filled by interviews with the key informants. The key informants are the national manager of leprosy control, the leprosy technical officer of DHO and people affected by leprosy.

There are two high endemic districts involved in this study which are Bulukumba and Wajo in South Sulawesi Province. From each district, there will be one sub-district. The data collected consists of a number of new cases, G2D and Release From Treatment rate.

Bulukumba District:

1. Kajang sub-district
2. Data will be provided started from 2010 up to 2015

Wajo District:

1. Pitumpanua sub-district
2. Data will be provided started from 2011 up to 2015

2.4.1.1.2 Data Analysis

Collected data from annual, quarterly and project data or reports will be analyzed data will be analyzed for changes and differences in trends.

2.4.1.2 Qualitative Study

2.4.1.2.1 Data Collection

Data collection for qualitative study will be done by conducting literature review. Where existing literature was not sufficient, gaps of knowledge will be filled by information from key informant's experience.

2.4.1.2.2 Search Strategy

Data was collected by searching the electronic database through VU, PubMed, and The Cochrane library with Google Scholar as search engine. Information was also gathered through institutional websites of WHO, SEARO, MoH of Indonesia, BPS-Statistics Indonesia. This thesis also used data reports, policy papers, articles related and authors personal experiences during working in MoH. In order to gain information about evidence based practices, the author searched for articles and case studies in the area of empowerment on people affected by leprosy and other diseases. The selected literature is between the year 1995 and 2016 except for the law and regulation, in order to prevent outdated information. The searching process was limited to English and Bahasa Indonesia because the author is conversant in those languages.

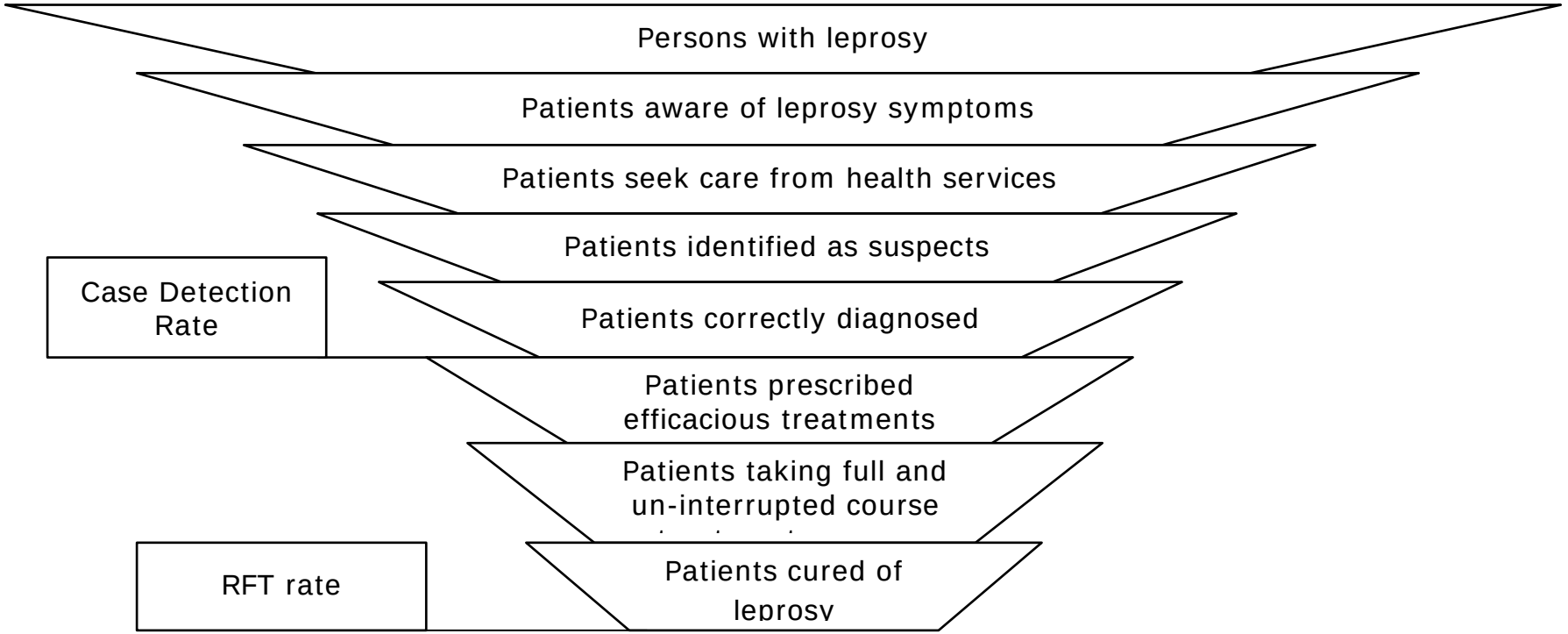
2.4.1.2.3 Search Words

In order to explore the information, related to involvement of people affected by leprosy in case detection activities, the search words are: health system, leprosy, people affected by leprosy, empowerment, community participation, case detection activities, stigma, self-stigma, social stigma, communicable diseases, neglected tropical disease, infectious diseases, PLHIV, tuberculosis.

2.4.2 Framework for analysis

The framework for data analysis to be used is an adaptation of Piot's (1967) model for case management of tuberculosis, as it highlights the steps required for case detection and treatment (41).

Figure 2 Piot's Model



2.5 Study Limitations

The study limitations may occur related to the methodology which is secondary data. Since implementation of the project, there was no clear reporting, monitoring and evaluation system for the project. In addition to this limitation is poor quality of the data. Based on the author's experience on working in MoH, recording, reporting and data storage has been a big challenge faced by the central level.

In addition, there may be a possibility of bias from the author. The author was involved in both projects during 2013-2014. Furthermore, the experience of the author working in the program itself may have influenced the interpretation and analysis of the data.

CHAPTER THREE
RESULTS, FINDINGS AND ANALYSIS

This chapter will present information which has been collected from the project, literatures, project report and information from key informants. The information will be presented and analyzed based on Piot's Model as the framework for analysis for this thesis

3.1 Persons with leprosy

In Piot's Model, a person with leprosy is the first starting point which is the burden of disease. The real burden of the disease means the estimation of prevalence in the area.

Study related to estimation of prevalence was very limited. On the global level, the author found one paper published in the Bulletin of WHO in 1992 by SK Noordeen et al. This paper presented an estimation of prevalence in 25 countries with the highest number of leprosy cases which was done in 1991 (42).

Another study was conducted during November 2002 to February 20013 by Fake J. Moet et al in Bangladesh. Random sampling was done to4 million people living in two districts in Northwest Bangladesh about the prevalence of previously undiagnosed leprosy in the general population. The results showed that the prevalence of previously undiagnosed leprosy was six times higher than compared to the registered prevalence. In high endemic areas, full village surveys were recommended to be done and compared to contact surveys (43).

There is no data related to the number of persons with leprosy from this project. This is not surprising since the estimation of the prevalence is also not available on the national level. It is not so easy to develop an estimation of e prevalence of leprosy. Several barriers to develop an estimation of the leprosy prevalence are a small number of cases found the distribution of cases and funding.

3.2 Persons aware of leprosy symptoms

Patients aware of leprosy symptoms are the next step of Piot's Model. Before seeking treatment, patients will be aware of the leprosy symptoms. The patient's awareness which is mentioned above, in a larger scope it is community awareness. Community awareness on leprosy is related to their knowledge on leprosy including signs, symptoms and transmission of the disease.

In this project, data for community awareness in this area is not available. Several studies were done in Indonesia in a small scope to measure community awareness. In a study by Mujib Hannan et all which studied about the description of knowledge on leprosy transmission among contacts of leprosy patients in Pragaan Health Center, Sumenep

District. The study showed that only 10% of the respondents were categorized as good, 33.3% categorized as sufficient and 56.7% were categorized as low in knowledge on leprosy transmission (44).

Another study was conducted by Pramila Barkataki et al during December 2003 to February in Uttar Pradesh on knowledge and attitude on leprosy. This study involved 130 leprosy patients/ People Affected by Leprosy, 120 non-leprosy patients and 150 community members from the surrounding of the hospital. Statistical analyses show that almost everyone in those three groups knows about leprosy. 60% of the leprosy patients group mentioned, while 20% or less from the other group. Less than 10% of the illiterates and 40% of the literates mentioned that leprosy is caused by infection. According to Pramila Barkataki et al, the results of this study are quite disappointing since there had been a massive health education and Information Education and Communication (IEC) campaign (45).

Another study has been conducted in Sunsari District, Nepal by Agrawal S et al. 1647 questionnaires from DHO were analyzed using EPI Info software version 5. Half of the respondents (53%) knew that leprosy was caused by “germs”. 60% could mention leprosy symptoms and 81.8% of the respondents knew that leprosy is curable. The number of respondents that knew that leprosy drugs are available for free was 75% (46).

According to project data of Kajang Sub-district in 2013 the health information on leprosy had been delivered to 556 villagers through village meetings, religious meetings, women village meetings, home visit, family gathering and integrated health post. While according to project data of Pitumpanua Sub-district in 2014, health education on leprosy had been delivered to 315 villagers through village meetings, religious meetings, women village meetings, home visit, family gathering and integrated health post.

Recently in Indonesia there are several IEC materials used to deliver information on leprosy. Public service advertisement is shown several times a day on national television and radio. This advertisement focused on the increased awareness on skin patches which is known as leprosy jingle. Another IEC material used for activities is a plastic hand fan. On one side of the plastic hand fan there are several pictures of skin patches of leprosy cases. On the other side are some messages including where to refer if there is someone with skin patches as shown in the pictures on the plastic hand fan. Generally, both of those new IEC materials give a positive impact, even though study on the effectiveness has not been done until now.

According to the leprosy technical officer in Bulukumba and Wajo district, the People Affected by Leprosy’s role in increasing community awareness can be identified as a supporting factor. But at the same time can become an obstacle for them to play role in this activity. In general they don’t

have the confidence and an adequate ability to deliver information on leprosy.

3.3 Patients seeks care from health services

In this level, People Affected by Leprosy and village health volunteers delivers information related to leprosy to the community. Suspected cases will be referred to health workers. So the numbers of patients who seek care from health services and are identified as suspects can be defined as the same. In Kajang Sub-district, 656 suspect cases were referred to the health center since 2013. Since 2014, 23 suspect cases in Pitumpanua Sub district were referred to the health center.

Cacilda da Silva Souza et al published a study in 2003 on delayed diagnosis of leprosy and the potential role of educational activities in Brazil. This study involved 40 leprosy patients. 32.5% were misdiagnosed as experiencing diseases other than leprosy and 55% of the respondents were diagnosed 1 year after the awareness of signs/ symptoms. 23% of them had no disabilities. This study concluded that the main factor that leads to delayed diagnosis were misdiagnoses and unawareness (47).

A study on health seeking behavior and delay in diagnosis of leprosy in a low endemic area of China was done by Furen Zhang et al. This study involved 88 newly diagnosed leprosy patients. The main reason for delay concluded from the study is because most of the patients are ignoring the illness (48).

Another study by PG Nicholls et al have conducted a literature review on promoting early detection in leprosy addressing the patients related delay on 19 publications. Only 10 of those publications addressed the patient related delay. They concluded that there were a very limited number of interventions which targeted women, people affected by leprosy and community leaders (49).

3.4 Patients identified as suspects

Patients identified as suspects are the next step of Piot's Model. According to the leprosy technical officer in Bulukumba and Wajo district, this step is where People Affected by Leprosy can play an optimal role. Their experience as someone who has experienced leprosy can convince suspect patients on their condition. In this project, village health volunteers or People Affected by Leprosy or collaboration on both of them will refer the patient to the health worker in the health center.

In Kajang Sub-district, 656 suspect cases were referred to the health center since 2013. Since 2014, 23 suspect cases in Pitumpanua Sub district were referred to the health center. Due to the limitation, in this project there is no exact number available on how many patients were referred by village health volunteers or People Affected by Leprosy. Both leprosy technical officers of DHO mentioned that in general the village

health volunteers of the intervention sub-district referred much more suspect patients than People Affected by Leprosy.

3.5 Patients correctly diagnosed

Patients correctly diagnosed are the next step of Piot's Model. In this project there was a difference between patients identified as suspects. This could happen because the knowledge given to the People Affected by Leprosy and village health volunteers was to identify suspect cases. They were not given knowledge and skills to diagnose patients.

Based on the project report, among 656 suspect cases in Kajang Sub-district that had been referred to the health centers, had 47 of them confirmed as leprosy. While in Pitumpanua Sub-district among 23 suspect cases referred to the health center, 3 were confirmed as leprosy.

Community empowerment leprosy control activities have been conducted in some districts those are coordinated with related parties in the field. In 2012 throughout the year, 14 villages in several districts of Central Java Province a 1,055 leprosy suspected cases were referred by village health volunteers to health centers and 46 of them were new positive leprosy cases confirmed by health workers in health centers.

3.6 Patients prescribed efficacious treatment

The next step is patients taking a full and un-interrupted treatment course. In the step of the prescribed efficacious treatment, health workers in the health centers play the role to prescribed patient with the right drug based on type of leprosy and in this project all of the patients diagnosed were prescribed the treatment according to the national guidelines on leprosy treatment.

In the project, People Affected by Leprosy and village health volunteers plays an important role to persuade patients to take full treatment. The existences of People Affected by Leprosy with no disability or with disabilities were able to convince the patient to continue the treatment. This project shows that there are numbers of patients who continue their treatment after been given health promotion by People Affected by Leprosy. In this project all the patient confirmed were prescribed efficacious treatment.

3.7 Patients taking full and un-interrupted treatment course

In this project it was found that not all the patients who had been confirmed positive took a full and un-interrupted treatment course. According to the leprosy technical officer there are some reasons including that the patient moves to other district and they didn't follow up the patient's history treatment, refused to continue the treatment because of side effects of the treatment and they feel bored to follow a long treatment. According to the technical officer there are some reasons

including moving to other places, refused to continue treatment. In Pitumpanua Sub-district among 3 patients confirmed, only 1 patient took a full and un-interrupted treatment course or Release from Treatment. While in Kajang Sub-district, a technical problem occurred which made that the technical officer couldn't provide the number of patients who were able to take a full and un-interrupted treatment course.

In the project, People Affected by Leprosy and village health volunteers plays an important role to persuade the patient to take full treatment. According to the leprosy technical officer of Bulukumba and Wajo District, People Affected by Leprosy could play an important role in this level. The existences of People Affected by Leprosy with no disability or with disabilities were able to convince the patient to continue the treatment. This project shows that there are numbers of patients who continue their treatment after been given health promotion by People Affected by Leprosy. People Affected by Leprosy in Bulukumba and Wajo District feel that this role is one of the supporting factors for them in this project. They assumed that their experience to be in the leprosy treatment can motivate patients to continue their treatment. In Pitumpanua Sub-district among 3 patient confirmed, only 1 patient took a full and un-interrupted treatment course or Release from Treatment. While in Kajang Sub-district, a technical problem occurred so the technical officer couldn't provide the number of patients who were able to take a full and un-interrupted treatment course.

In a study conducted by Naeli RZ et al in Brebes district (2015), which explore factors related to the leprosy patient's adherence in taking their treatment. The results showed that the patient's adherence related to several factors including knowledge, attitude, perception, and support from family and health workers (50).

3.8 Patients cured of Leprosy

Patient cured of leprosy after taking full and un-interrupted treatment course. In this project, not all of the patients are cured from leprosy because not all patients took a full and un-interrupted treatment course.

In this project, not all of the patients are cured from leprosy. According to the technical officer there are some reasons including moving to other places and refuse to continue treatment.

The sustainability of this activity is also an issue raised by DHO. The sustainability of the project for the village health volunteers were much more clear, because the existence of village health workers as a formal group in the village.
The secondary data of this project were not analyzed statistically because it was not complete and poor quality. The outputs of the project haven't shows a big difference in the program achievement.

CHAPTER FOUR
GOOD PRACTICES FROM OTHER DISEASES

This chapter will explore some good practices in other diseases which could be adapted as a lesson learned in developing the leprosy program.

a. HIV Program

People Living with HIV (PLHIV) were considered as an important factor in the HIV program. Activism is one of the various ways where communities can participate in the HIV program. HIV activists are community members who may or may not be infected with HIV and who promote equal rights and opportunities for PLHIV. Activists play an important role in changing legislation and policy that work to the disadvantage of PLHIV and vulnerable populations. Through activism and workshops with the medical community, they are able to negotiate for better and specially tailored services. They also contribute to the mitigation of stigma and discrimination by educating journalists to use more appropriate terminology when reporting on HIV-related issues. In many countries, stigma and discrimination against PLHIV are the key reasons that people give for refusing testing, medication and other HIV services. Activism may take the form of education, mass media campaigns, law suits and public demonstrations (51).

PLHIV itself could play an important role in encouraging testing and disclosure, reducing stigma, providing credible information and raising funds by openly disclosing their status. Depending on legislation, associations of PLHIV can be comprised entirely or partially of HIV-positive persons. Other groups that might participate can include people affected by HIV, such as those living with or related to someone who are HIV-positive. Associations of PLHIV give a face to the disease, while providing comfort and support to persons already living with the disease. These associations are also the ideal forum for PLHIV to focus on their rights and health and demand an adequate response from their governments (51).

Karina Kielmann et al studied the rise of the “expert patient” in an expanding paradigm of the HIV case. The rise of the expert patient in HIV care must be situated in relation to key phases in the public health epidemiology of HIV, and subsequent health systems responses. It is important to consider how roles and relationships of ‘expert’ PLHIV will evolve if they are progressively assimilated into mainstream care systems. In the context of rolling out an antiretroviral treatment program in resource-constrained settings, ‘‘expert patients’’ are hailed as an important step towards greater involvement of PLHIV in HIV care, and in addressing the human resources crisis. The rise of the ‘‘expert patient’’ in HIV care partly echoes the move towards greater patient agency and self-

management that informs health services delivery in industrialized countries (52).

A study was conducted in Uganda on how the role of PLHIV group networks is in increasing the effectiveness of HIV services (2012). In 2006 the Networks Project was launched which aimed to strengthen the capacity of PLHIV networks in Uganda and enhance community participation in HIV response. By the end of 2008, almost 40,000 PLHIV were already registered members of the connected groups. Several key messages from this study are; the important role of networks of PLHIV groups in sensitizing communities on HIV AIDS, improving access of communities to HIV prevention and to treatment and care for PLHIV and also support services. PLHIV groups also maximize and support disclosure, shared resources and capacity between PLHIV groups, which diversifies the range of services available for PLHIV. Networks provide platforms for community roles and action against HIV by PLHIV (53).

b. Tuberculosis (TB) Program

Information on empowerment of tuberculosis patients is not as much as with PLHIV. The author found a published paper from Africa related to TB clubs.

TB clubs are defined as a number of tuberculosis patients, usually 3 to 10 persons living in the same area, who attend out-patient appointments together in the same day. They elect one leader who is literate. The leader manages the members to come to the tuberculosis clinic on the appointed day and informs the clinic staff if a member is absent. This activity contributes to tuberculosis control activities (54).

They also have regular meetings, at least once a week in different places or social events. In this regular meeting they support each other in adhering to treatment, sharing information of the disease and help in identifying tuberculosis suspects' patients. In social events, they also deliver TB information and they were provided with IEC materials to deliver information on TB by MOH and the Regional Health Bureau. TB clubs were regularly supervised by local health workers and community health agents in the identification and referral of tuberculosis suspects patients. As soon as the members complete their treatment, they were encouraged to join "Anti-TB Associations". By joining this, they maintain close contact with the TB club by exchanging information and helping other healthy community volunteers to support and follow up tuberculosis patients (54).

A descriptive study was done in the rural district Estie in South Gonder, Ethiopia on formation of TB clubs and their contribution to case-finding and the treatment outcomes before and after formation of the TB clubs. TB clubs contribute in the district tuberculosis program by referring

tuberculosis suspect's patients, promoting the importance of adherence in treatment and tracing defaulters supported by community elders, community health agents and local health workers. The results show that TB clubs have referred 181 tuberculosis suspects in the community for investigation, of whom 65% subsequently had a diagnosis of tuberculosis. In the conclusion TB clubs contributed to the effective implementation of a district tuberculosis program (54).

CHAPTER FIVE
DISCUSSION, CONCLUSION AND RECOMMENDATION

Indonesia has achieved elimination of leprosy at national level in 2000. However, from 2001 until now, the leprosy situation in Indonesia has remained stable around 17,000-20,000 new cases. Indonesia has the world's third-highest number of leprosy cases after India and Brazil with 17,489 new cases in 2015, the proportion of child cases was 11%, Grade 1 Disability proportion and Grade 2 Disability proportion among new cases were 12% and 11% respectively. The high disability proportion shows that there is a delay in case detection and continued transmission of leprosy.

As of 2014, out of 34 provinces, 16 are classified as a high burden area which is defined as a province with more than 1000 new cases per year or with a New Case Detection Rate (NCDR) of more than 10/10,000 population. This shows that there are still challenges in achieving the goal of the leprosy control program based on the National Road Map.

Since 2015, the government has established the Road Map of the Leprosy Control Program in Indonesia: Towards Elimination at Provincial Level 2015-2019. Indonesia has targeted to achieve elimination of leprosy in sub-national level at 2019. One of the challenges identified in the road map is empowerment of the community and People Affected by Leprosy.

In order to increase efforts in promotion, prevention and rehabilitation of leprosy requires the participation of the community. Society is the leading guard who will first recognize disease occurrence and impact. Potential groups in society which have an important role are religious leaders, village health volunteers, People Affected by Leprosy and community leaders. Some studies show that routine passive services in the health center cannot describe the actual number of cases in the field. Usually there is a significant difference between the number of cases detected passively in the health center and the number of cases detected actively outside the building. This proves that there are a number of patients who do not or have not been detected by health workers in the field.

Defects in leprosy shows delayed discovery of cases which are associated with the lack of knowledge in health workers and low awareness of the community in recognizing early signs of leprosy. Stigma against leprosy in the community causes the patients to hide themselves and to not seek treatment. Information, Education and Communication (IEC) activities on leprosy in the community are required. Activities that positively impact, based on the evaluation of the program, include the dissemination of posters, leaflets in public places, the outreach to the community, socialization to religious leaders/ community and serving public service advertisements on television and radio. It is expected that through IEC,

community awareness and participation will increase and ultimately take part in to promote self-screening actively to healthcare facilities when they find early signs of leprosy.

In this thesis, the author used Piot's Model as the framework for analysis. This framework was developed as an epidemiological model which was used in estimating the effectiveness of measures in tuberculosis control. This framework helped the author to analyze the problems well, even though not in all steps. Data from this project was not available due to the limitation of the project.

Estimation of prevalence is very important because Indonesia's leprosy situation has been stable for around 15 years while almost all of the countries have reduced their number of leprosy cases detected. Estimation of prevalence will be important in order to develop a good quality of planning, strategies, logistics and innovative activities on all levels starting from national, provincial and the districts. In this decentralization era, districts have their own rights and responsibility to manage their local budget. The availability of estimation of prevalence data will reassure stakeholders in high burden districts, of the importance to a prioritized leprosy program in their policy and strategies including budgeting.

Community awareness on leprosy is related to their knowledge on leprosy including signs, symptoms and transmission of the disease. If people were aware on signs and symptoms of leprosy, they will seek for health care. Early detected means patient will be treated earlier too. This will also break the transmission. If they are not aware, what usually happen to leprosy case is delay treatment and end with disabilities.

In the findings shows that some of the results of this study are quite disappointing since there had been done a massive health education and Information Education and Communication (IEC) campaign. It is important to consider the IEC materials used, the technique and the audience. In this project, according to the leprosy technical officer in Bulukumba and Wajo district, actually the People Affected by Leprosy's role in increasing community awareness can be identified as a supporting factor. But at the same time can become an obstacle for them to play role in this activity. In general they don't have the confidence and an adequate ability to deliver information on leprosy.

Patients and community awareness related to the next step of Piot's Model, which is patients seek health care from health services. One of the leprosy program strategies is early case detection. Early case detection means that the case was diagnosed and treatment started before the onset of nerve impairment.

In general, studies mentioned above raised the issue of unawareness on sign and symptoms of leprosy. Unawareness can be the result of ignoring or less knowledge on leprosy. Usually, patients with skin patches won't go to seek for health care immediately.

Patients identified as suspects are the next step of Piot's Model. Obstacles identified are that People Affected by Leprosy in general doesn't have enough confidence and an adequate ability to deliver information on leprosy.

Patients correctly diagnosed are the next step of Piot's Model. In this project there was a difference between patients identified as suspects. This could happen because the knowledge given to the People Affected by Leprosy and village health volunteers was to identify suspect cases. They were not given knowledge and skills to diagnose patients.

There were limited international literature and publication on good practices in the other diseases. Empowerment of PLHIV in HIV Program has much more progress than TB patient in TB Program. International literature on TB patient's role also considered sustainability as one of their challenge.

The leprosy technical officers and national manager said that it is hard to measure the output due to short time since it started. They were sure this project will give a good outcome in few years ahead. In order to achieve it, several things have to be prepared. Preparation to be done starting from clear recording, reporting, monitoring and an evaluation system, guidelines, IEC materials and socializing this nationally through national guidelines.

5.2 Conclusion

The stagnant leprosy epidemiology situation in Indonesia during the last 15 years has pushed NLCP to conduct innovative programs and activities. The Road Map of the Leprosy Control Program in Indonesia: Towards Elimination at Provincial Level 2015-2019, has targeted to achieve elimination of leprosy at sub-national level in 2019. One of the challenges identified in the road map is empowerment of the community and People Affected by Leprosy.

Some studies show that routine passive services in the health center cannot describe the actual number of cases in the field. Usually there is a significant difference between the number of cases detected passively in the health center and the number of case detected actively outside the building. This proves that there are a number of patients who do not or have not been detected by health workers in the field. The community and People Affected by Leprosy were expected to be one of the potential groups which are identified to fill in this gap.

Supporting factors explored the involvement of People Affected by Leprosy in this project, in relation to their experience being affected by this illness. Findings from both national and international projects suggest that through their experience they can play roles in increasing the community awareness through delivering information on leprosy, identified leprosy suspect cases and refer/ report it to health workers to be examined. Furthermore they can also play an important role in motivating patients to finish their treatment completely. Nevertheless, this study was unable to conclude that the involvement of PAL has actually achieved this potential in the Indonesian context.

Obstacles identified are that People Affected by Leprosy in general doesn't have enough confidence and an adequate ability to deliver information on leprosy. Routine technical assistance, monitoring and evaluation from district, provincial and central can be considered as one of the solutions. The sustainability of this activity is also an issue raised by DHO. The sustainability of the project for the village health volunteers were much more clear, because the existence of village health workers as a formal group in the village.

Empowerment is a program that is prioritized by the Indonesian government nowadays. This is a good opportunity to strengthen the participation of the community and the People Affected by Leprosy in leprosy control programs. MoH has to be ready with a guideline on this so there is a clear role of each party related.

5.3 Recommendation

5.3.1 Ministry of Health

1. Develop, provide and socialize a clear recording, reporting, monitoring and an evaluation system. This can be used not only in Bulukumba and Wajo District, but also the districts which have trained potential groups in detecting leprosy suspect cases
2. Develop a clear national guideline pocket book in detection of leprosy suspect cases for non-health educational background. This guideline book can be used by People Affected by Leprosy, village health volunteers and all non-health educational background people/ groups
3. Develop a good quality of IEC materials prototype on detection of leprosy suspect cases for non-health educational background. These IEC materials have to be field tested before delivering it. It can be used by People Affected by Leprosy, village health volunteers and all non-health educational background people/ groups
4. Develop in the National Guidelines on Leprosy Control Program on empowerment of People Affected by Leprosy through routine case management by health center. This could be done by

delivering clear information about leprosy to potential patients in health center. Health workers can support them to deliver information on leprosy to their surroundings

5. Conduct qualitative research on People Affected by Leprosy participation in leprosy control program
6. Conduct prevalence survey to know the real burden of leprosy in Indonesia

5.3.2 Provincial Health Office

1. Identify districts which have started to involves non-health background groups in leprosy suspect case detection activities
2. Socialize a clear recording, reporting, monitoring and an evaluation system for the districts which have trained potential groups in leprosy suspect case detection activities
3. Provide technical assistance to DHO on these activities
4. Produce IEC materials in detection of leprosy suspect cases for non-health educational background. These IEC materials can be used by People Affected by Leprosy, village health volunteers and all non-health educational background people/ groups

5.3.3 District Health Office

1. Identify groups in the society to start the empowerment program and try to integrated leprosy and other diseases into it
2. Socialize a clear recording, reporting, monitoring and evaluation system for trained potential group in leprosy suspect case detection activities
3. Provide technical assistance to health centers on these activities
4. Implement the empowerment of People Affected by Leprosy through routine case management by health center. This could be done by delivering clear information about leprosy to potential patients in health center. Health workers can support them to deliver information on leprosy to their surroundings.

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ANNEXES

MINISTRY OF HEALTH
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July 2016

Number : TU.01.02/03/III.5/951/2016
Enclosed :
Subject : Request for permission to use data, information and interviews

Dear Alfinella Izhar Iswandi,

We have received your request for permission to use information in your thesis which topic is "An Exploration of Supporting Factors and Obstacles of The Involvement of People Affected by Leprosy in Case Detection Activities in South Sulawesi Province, Indonesia".

Regarding to those things mentioned above, I hereby allow you to use the information and interview key informants related to the activities.

Sincerely Yours,

Dr Wiendra Waworuntu, M.Kes
Director of Direct Transmitted Disease Prevention and Control

Cc:
1. Director General of Disease Prevention And Control, Ministry of Health
2. Head of Provincial Health Office of South Sulawesi
3. Head of District Health Office of Bulukumba
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