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Community Health Literacy to Enhance Community Empowerment

in People with Tuberculosis



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Community Health Literacy to Enhance Community Empowerment in People with Tuberculosis

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Acronyms and Abbreviations

ACSM	Advocacy, Communication, and Social Mobilization
CEPAT	Community Empowerment of People Against Tuberculosis
COD	Community organizational development
CoP	Chief of Party
HIV	Human Immunodeficiency Virus
JKM	Jaringan Kesejahteraan/Kesehatan Masyarakat - Networking for Community Health/Welfare
TB	Tuberculosis
M&E	Monitoring and Evaluation
MDR	Multi-Drug Resistant
MoU	Memorandum of Understanding
NGO	Non-Governmental Organization
NTP	National Tuberculosis Program
ToT	Training of Trainers
UI	University of Indonesia
USAID	United States Agency for International Development
UNAND	University of Andalas
USU	University of Sumatera Utara

Foreword

This book presents the role that community health literacy an important part in increasing the number of tuberculosis (TB) case findings, case holdings, and success rate by supervising and mentoring the cadres and community leaders. It shows how TB case detection rate improved through an understanding of the community literacy of health and the engage of community empowerment.

This book is primarily addressed to health programmer, TB programmer, public health researchers, stake holders, who play a very important role in the control of TB or other diseases in the community. There are best practices how to expand community-based models to achieve universal access to TB testing and treatment. An understanding of community health literacy, as one of the basic factors that influence mobilizing and empowering the community to prevent, detect, and treat TB, MDR-TB, and TB-HIV.

Grateful acknowledgment is here made to USAID, Westat, National TB Program, Provincial Health office, District health office, Cadres, and those who helped this researcher gather data for this book. This work would not have reached its present form without their invaluable help.

16 January 2018,

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She is a full Professor in the Department of Public Health and Community Medicine, Faculty of Medicine, Andalas University and is Dean, Faculty of Nursing Andalas University. She has lead and/or supported research through funding from WHO, Global Fund, USAID and other agencies. She has substantial experience with community engagement and outreach to marginalized populations, particularly through many years of community-based work in tuberculosis with CEPAT (Community Empowerment People against Tuberculosis) project. The work has involved community driven interventions to reduce discrimination and stigma among remote and poor communities. She has experience in community organizational development and with working in partnership across local governments. And she has been regularly involved in the Regional Planning Board Office of West Sumatra, Indonesia as consultant undertakes monitoring and evaluation especially for health policy for more than 15 years. She has managed health program work to improve human resources capacity as well through education, training, information dissemination, and providing opportunities to develop the potential of individuals and the community. She has provided advice to WHO on the practical application of health literacy in ethically and culturally diverse communities in Indonesia.



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Dr. Delyuzar is a pathologist who received his medical degree from the University of Sumatera Utara (USU), and a specialty in pathology from USU. He has been a Lecturer in the Faculty of Medicine, USU, Medan. He also has experience working with partnerships, local governments at the community level and/or with NGOs. He has substantial experience with community engagement and outreach to marginalized populations through his many years of HIV/AIDS work, and counseling about discrimination due to stigma. He has encouraged community health education by cooperation with newspaper media as well as various radio stations. It was the way to make an understanding of the community literacy of health and the engage of community empowerment to achieve universal access to TB testing and treatment. Dr. Delyuzar has also been heavily engaged in tuberculosis control. He is head of the TB-HIV task force, which is a collaboration with North Sumatera, Aceh, West Sumatera and also Riau Association of Patients and Community in TB concerns. He has mobilized the TB community for case finding and Treatment programs in 8 districts in North Sumatera province, also cooperating with partners such as the FIDELIS-UNION organization, Empowerment of Community, Aisyah organization and Global Fund. For TB CEPAT He brought in 20 years of experience and responsible for project deployment, strategic planning, external and internal inputs and coordination with project counterparts, such as USAID, GOI contacts, and other donors.



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He was the dean of the Faculty of Medicine, Andalas University (UNAND) when TB CEPAT project was implemented in Indonesia. He is a senior lecturer at the Department of Nursing, Faculty of Medicine. He received MD from UNAND and MSc in Epidemiology, Prince of Songkla University (PSU), Thailand and got Doctor degree in Medical Science in Airlangga University Indonesia. What he had done for TB CEPAT, as Dean in that period, he used UNAND's link to local government as well as our alumni association in West Sumatera to engage the provincial and district level health leaders. The provincial and district governments should aware of the issues around TB and the importance of consistent and quality program support. Thus, it was importance an understanding of community health literacy, as one of the basic factors that influence mobilizing and empowering, for stake holders and policy makers. In a number of selected areas, local governments had decreased their funding of TB programs. He advocated local governments to set aside resources (financial and human) to develop sustainable approaches for future support of the TB program. Another strategy to make funding available is making some link with migrant associations to provide more support for donation programs for TB.



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Her career in the field of Public Health is supported by her current qualifications and skills in improving the health status of personal, communities, and general population, through health promotion, prevention and curative of diseases and health problems. She graduated from the University of Adelaide, Australia as Master of Public Health in 2011. She is also a Medical Doctor studied at University of Sumatera Utara - USU, Indonesia from 2001 to 2007. Her career as a researcher started from doing a qualitative research at the University of Adelaide and published it on Human Vaccines & Immunotherapeutic entitled Increased awareness and health care provider endorsement is required to encourage pregnant women to be vaccinated. Currently she works at the Hospital of Sumatera Utara University, and also as a lecturer at Department of Public Health/Family Medicine/Preventive Medicine of Medical Faculty of Medicine. Her position as the Community Organizational Development (COD) of a project funded by USAID on Community Empowerment of People Against Tuberculosis (CEPAT) also influenced her interest on Tuberculosis control in community.



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Mekkla Thompson is a project manager with 22 years of experience as a public health professional conducting qualitative and quantitative investigations for clinical and epidemiologic research, including studies in community-based settings in Thailand, Cambodia, Laos PDR, Indonesia, the Philippines, Myanmar, and Vietnam. She has worked for many U.S. Government agencies. She provides overall project management and is responsible for client reporting, subcontractor agreements, ethical review, budget and timeline monitoring, on-time submission of deliverables, and oversight of Westat IT and data management staff. Ms. Thompson is grant manager/project director for the Global Infectious Disease Research Training Program, funded by NIH's Fogarty International Center, to train tuberculosis researchers in Myanmar, China, Indonesia, and Thailand. She was the project director and a co-investigator for Westat's work on a NIAID project to test a simple MAS-PCR rapid screening test for MDR TB technique in resource-limited countries. For the TB CEPAT, Indonesia program. Ms. Thompson oversees overall project management and provides local organizations with technical advice on grant and project management. She also oversees the technical support Westat provides on program monitoring and evaluation and also Epi Info database development, data entry training, data collection, and data quality and data analysis. In addition, she advises and works with a team in preparing quarterly and annual reports to USAID.

Abstract

The weakness of community level tuberculosis (TB) services is a major concern for TB health promotion in Indonesia. These weaknesses are associated with a low level of awareness and knowledge and a high level of TB stigma in the community subsequently causing a low TB case detection rate (CDR).

Indonesia as the country with large archipelago had a thousand of language in Community. People in Indonesia consist so many tribe and have culturally rooted health beliefs and practices. The community context is important to health in many ways. It needs unique and specific way to make the community got the TB literacy that will impact to their knowledge and detection rete on TB.

We developed community level health literacy through multiple health communication existing channels in community to train community volunteers for advocacy and social mobilization and to mobilize and empower the community to prevent, detect, and treat TB, MDR-TB, and TB-HIV in three provinces of Indonesia.

The activities with emphasis of community health literacy had improved the awareness of symptoms and reduced stigma and access to TB testing and treatment in community- dwelling in Indonesia.

Introduction

TB is a leading public health concern in Indonesia which ranks second on the list of high burden TB countries(Health, 2015; Organization, 2015). The number of TB cases detected in Indonesia is still below the national target(Health, 2015). This is because the cases exist in vulnerable populations: people who are poor, live in remote areas, slum areas, and post-disaster areas. We assume that nearly 30 percent of TB suspects are undetected, diagnosed late, or receive incomplete treatment because of low level awareness and knowledge in our project areas: North Sumatera, West Sumatera, and DKI Jakarta. It means that they may struggle to understand basic health information of TB or TB literacy. Knowledge of health, health services, and resources will depend on levels of health literacy.

Many study reported that a large increase in health literacy across enough individual members of a community could provide community-wide health benefits(de Wit et al., 2017; Elsworth, Beauchamp, & Osborne, 2016). Those who live in communities where many people report low health literacy have, on average, worse health than people who live in communities where few residents report low health literacy(Das, Mia, Hanifi, Hoque, & Bhuiya, 2017).

Understanding health-related information requires not only knowledge, experience, and skills, but also accessibility of health information. This means that information needs to be available, readable and comprehensible(Batterham et al., 2014). It became harder in delivering the TB message due to more than one langue in the area. It is a challenge in health communication for the health providers.

Besides of that, we know in Indonesia that the community context is important to health in many ways. The religious and cultural background influence health decision-making which is often a communal rather than an individual process(Rikard, Thompson, Head, McNeil, & White, 2012).

With all the challenges, it is thought that community level health literacy approaches may have greater impact and warranted on TB control. We would

say that the program need to be implemented in districts where TB case detection rates were the lowest. We need to focus on community level in health literacy potential enhance community empowerment in people with tuberculosis. It is wondering how to develop community level health literacy through multiple health communication existing channels in community.

Purpose of the document

The purpose of this document is to highlight cases in which community level health literacy through advocacy, communication and social mobilization interventions with multiple health communication existing channels in community. We want to share our best practices to increase detection rate on TB with the burden of different region with different culture, different language and hard to reach population. That would be contributed to a positive outcome of tuberculosis (TB) control activities directed to a range of audiences and settings.

It is intended for on-the-ground stakeholders who are interested in successfully integrating community health literacy strategies and activities into TB control programming, as well as for decision-makers who can provide greater political and financial support for community health literacy activities at the national, sub-national and international level.

The cases in this document illustrate some of the innovative ways in which projects have incorporated advocacy, communication and social mobilization strategies in their TB prevention and treatment efforts. The program has been customized. For example, one cannot simply translate materials from one language to another and expect the program to be equally effective in the other language. It used multiple health communication existing channels in emphasis understand well basic health information of TB.

Although the nature of the activities they have employed varies, each of the case is an example of how to put the component of TB control strategy to empowering people with TB and communities in practice.

Community level in health literacy affected by TB is at the core of each project. It is a critical matter for augmenting the efficacy of the overall TB control activities, especially about such vital goals as: improving the rate of early case detection and treatment adherence, combating stigma and discrimination against TB patients, creating an enabling environment to empower people affected by the disease, and mobilizing political commitment and resources to address TB.

Community health literacy

Health literacy is an increasingly important public health concern and the concept of health literacy is evolving. Since 1998, WHO had defined health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”(Moore, Smith, & Reilly, 2013). The conceptualization of health literacy from merely the ability to apply functional literacy skills in a health-care context to a wider ability to exert control over the determinants of health. Many study reported that health literacy is an important factor at both the individual and community level(Das et al., 2017; Elsworth et al., 2016).

Community health literacy were engaged in critical reflection to gain a better understanding of how health is conceptualized within their socio-economic and political environment and its implications for practice, power relations and subjective experiences (Schlichting et al., 2007). Some research indicates that people who have limited literacy skills are in triple jeopardy because they have limited access to care, are less likely to participate in screening and disease prevention activities, and are less likely to manage a chronic disease(Das et al., 2017; Han, Boyle, James, Yu, & Bennett, 2015). Consequently, they are seven to eight times more likely to die unnecessarily of a chronic disease(Wu et al., 2017).

There is variability of beliefs across people and cultures and how this influence decision-making about health(Abebe et al., 2010). We must take consideration on it, that it links between social context of health and related decision making(Egbert, Mickley, & Coeling, 2004). Decisions about health are often made by families and communities, and this is particularly so in communal cultures. So individual, family and cultural beliefs influence decisions made about health(Houston, Harada, & Makinodan, 2002).

Community health literacy on tuberculosis suggested language and usage for tuberculosis care, communications and publications. It needs change communication promotes tailored messages, personal risk assessment, greater dialogue(Moore et al., 2013). Change communication is developed through an interactive process, with its messages and approaches using a mix of communication channels to encourage and sustain positive, healthy behaviors. It may also involve encouraging healthcare providers to perform certain actions, such as TB screening(Schlichting et al., 2007).

Another consideration in community health literacy that health is often in competition with other personal, family, community and national issues where trade-offs need to be made between caring for health and attending to other concerns. If health is viewed as separate from these other concerns then it can be neglected by individuals, by communities and by governments. However, if health is seen as being connected to community and development activities then opportunities to support and promote health will frequently emerge(Harris et al., 2015).

Project of CEPAT Community Empowerment People Against Tuberculosis

Community health literacy to enhance community empowerment in people with tuberculosis study is part of a larger study, the community empowerment against tuberculosis (CEPAT) project, which was funded by USAID and lead

by Jaringan Kesehatan/Kesejahteraan Masyarakat (JKM) or Networking For Community Welfare & Health in West Sumatera.

CEPAT is a TB collaboration project between Jaringan Kesejahteraan/Kesehatan Masyarakat (JKM), with three Indonesian universities, University of Indonesia (UI), University of North Sumatera (USU), and Andalas University (UNAND); a U.S.-based capacity-building partner, Westat; and TB experts from two universities in Thailand, Prince of Songkla and Mahidol. JK M, the primary institution for the grant, is headquartered in Medan and has conducted several community health projects in North Sumatera, DKI Jakarta, West Sumatera, Aceh, and Riau.

This project has continued for five years in three provinces with significant tuberculosis (TB) problems: DKI Jakarta – four districts: South Jakarta, West Jakarta, North Jakarta, and East Jakarta; North Sumatera – four districts: Serdang Bedagai, Deli Serdang, Tanjung Balai, and Medan; and West Sumatera – six districts in post-disaster areas: Solok, Kota Padang, Tanah Datar, Pasaman, Padang Pariaman, and the Mentawai Islands.



Figure 1. Map of CEPAT Project Area in Indonesia

The main goal is to decrease burden of TB disease in vulnerable populations, especially people living in urban slums, remote islands, post-disaster areas,

poor and malnourished people, contacts of TB and MDR-TB patients, and people living with HIV/AIDS.

The strategic objective of this project is to improve community empowerment against tuberculosis in these three provinces. JKM has built networks with stakeholders which associate with TB control program, such as Province and District Health Office, Local Parliament, Women Community Board (PKK), primary and secondary health services (puskesmas and hospitals), local government, and community groups.

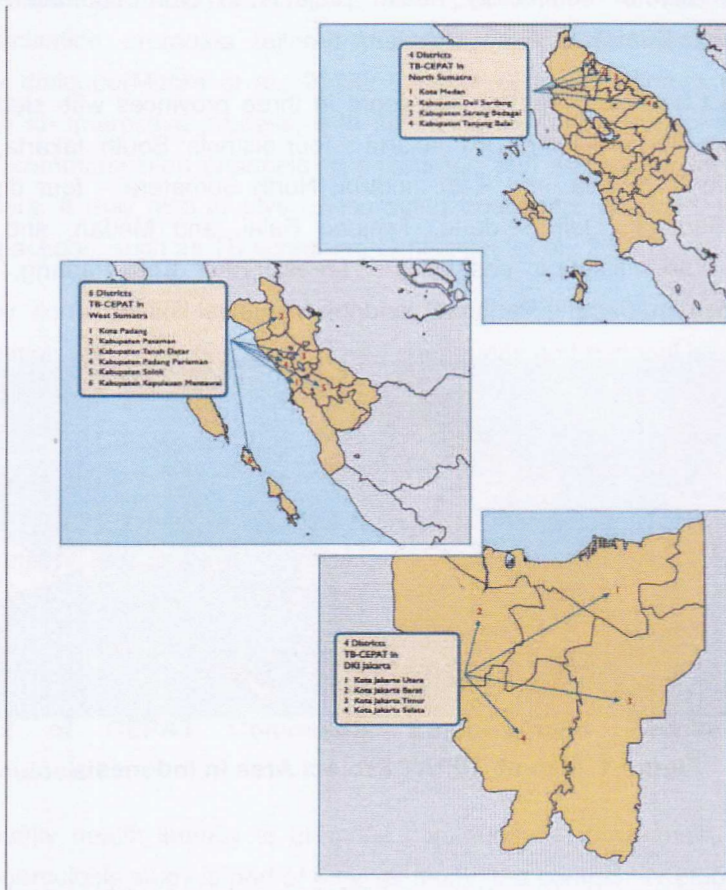


Figure 2. TB CEPAT Project coverage areas by district in three provinces: North Sumatra, West Sumatra and DKI Jakarta, Indonesia

CEPAT program of JKM is expected to raise public knowledge, awareness and participation in eradication of TB so they can protect themselves, their family and their environment from TB. This program is also expected to screen at least 70% of TB case and achieve healing rate of 85%. JKM approach through Mobilization of Advocacy, Communication and Social to get support for TB patients and to commit with the Government to explore local potency to improve TB service.

Community Health Literacy related to Community Empowerment in People with Tuberculosis

In order to decrease of TB mortality, morbidity and infection rate, we had to develop and expand community-based models to achieve universal access to TB testing and treatment. CEPAT project train community volunteers for advocacy and social mobilization and We build upon our team's experience and modify and utilize the tools that JKM has already developed for community mobilization, TB patient support, and community health worker outreach.

Regarding to information needs to be available, readable and comprehensible, figure 1 will describe logic frame the necessity of community health literacy in step of activity of community empowerment people against tuberculosis.

The blue boxes are the important and critical area, that we had to put community health literacy concern in our intervention activity project. These activities target improving TB care access and services to the most vulnerable groups, including people living in urban slums, remote islands, post-disaster areas, the poor, malnourished, and contacts of TB patients and people living with HIV/AIDS, MDR-TB people. These steps need understanding about community health literacy. Due to more than one langue in the area in our project area. We have to consider as well, the beliefs across people and cultures and how this influence decision-making about health.

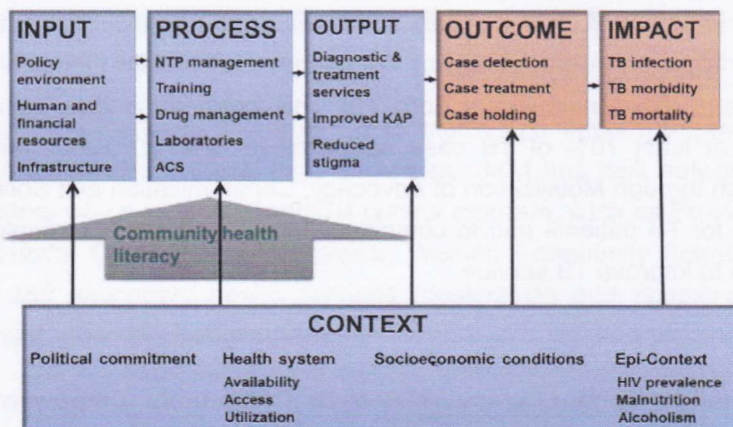


Figure 3. Logical Framework and community health literacy in community empowerment people against tuberculosis

The activities rise the ability to apply functional literacy skills in a health-care context to a wider ability to exert control over the determinants of health. Furthermore, it mobilizes and empower the community to prevent, detect, and treat TB, MDR-TB, and TB-HIV in three provinces.

The existing community networks are the potential media to mobilize for referral systems, knowledge of local settings and resources to develop and expand community-based access to TB treatment, particularly among the most vulnerable populations. We use advocacy, communication, and social mobilization training curriculum for community mobilization, TB patient support, community health worker outreach and local government advocacy.

We advocate the local government to change the regulations that are not consistent with the NTP guidance, increase funding and provide better quality TB services. The activities for advocacy, such as workshops for health providers, regular meetings with local government and parliament, to increase district budgets. These stakeholders play important role in community level health literacy on TB, that have huge impact to increase TB resources and improve TB services.

Case Studies of Good Practices

Overcoming stigma regarding TB by engaging traditional community leaders

Community Health Literacy Challenge

TB control problems are associated with a low level of awareness and knowledge of TB, mainly due to the high level of TB stigma in the community. Stigma of TB in Indonesia is mainly related to the belief that TB as a hereditary disease, TB as a magic-related disease or TB as the disease of the indigent people, and it is shameful to have a family member with TB. Stigma of infectious diseases, including stigma of TB, is usually observed among isolated communities, population with low education and low socio-economic status, many of whom are not reached by the health care system. Other hard to reached population include those living in urban slums, post-disaster area, remote areas, the poor, contacts of TB patients, people living with HIV/AIDS, and malnourished people, among whom TB is usually under-detected.

We conducted this study in the West Sumatera Province, more specifically in District of Solok, Padang and Padang Pariaman. These areas are in the western part of the Sumatera Island, which are quite remote in the earthquake-prone area which was hit by multiple earthquakes in the last decades. However, those districts have lower Human Development Index compared to other regions in the West Sumatera province. The TB coverage detection rates are also the lowest than compared to that in the other districts.

Rationale

Researches in another setting have shown the need to address cultural health beliefs about the locus of control in the design of developing programs TB care and treatment (Houston et al., 2002). The results of that study revealed that foreign-born Vietnamese clients tended to operate with an internal locus of control in health beliefs that attributed the resolution of health

problems such as tuberculosis to chance rather than something that could be controlled by others.

People in West Sumatera are mostly Minang tribe, they hold culturally rooted health beliefs and practices. There is a folk tradition of the Minangkabau ethnic group which incorporates music, singing, story-telling called Saluang, Indang, Rabab. It is very popular and usually performed for traditional ceremonies and festivals. Stories are delivered by both the acting and the singing and are mostly based upon Minangkabau legends and folktales. Many research reports that cultural approach can be potential channel to deliver the edutainment of TB disease (Paul, Näsström, Klingberg-Allvin, Kiggundu, & Larsson, 2016).

Community Health Literacy Intervention

The conduct the project that focus and figure out the best channel that specific for West Sumatera characteristic, on identifying possible TB cases in vulnerable populations to find them, especially people living in urban slums, post-disaster areas, the poor and contacts of TB patients and people living with HIV/AIDS, MDR-TB and malnourished people. We develop and expand community-based models to achieve universal access to TB testing and treatment.

Initial engagement was tailored which is appropriate for community outreach based on FGD and in-depth interview in first step. This supported community engagement, seeking to achieve effective health communication where the community moving to run the TB program. The community empowerment activities should be done independently and without any coercion from outsiders - spirit of local community as a bottom up process.



Figure 4. Focus Group Discussion – Initial engagement

We conducted qualitative study by FGD and depth interviews in Solok, Padang and Padang Pariaman Districts among 25 of TB officers, informal leaders, and traditional artist. There are six in-depth interviews with TB Officers, traditional artists, and four FGDs with informal leaders, and cadres per each district.

We asked open-ended questions about their perceptions on determining which methods were best used to increase knowledge and awareness of community to support the TB programs, finding solutions to solve the TB problem together (how to increase awareness, knowledge and thus case finding rate). The interviews were recorded and transcribed verbatim. The transcripts were thematically analyzed. The analysts coded the transcripts and reviewed, discussed, and refined the coding schemes until consensus was reached. Emerging concepts were assessed using the constant comparative method from grounded theory. The venue being held in the center of the village, led and supported by the head of the village, in community in Solok, Padang and Padang Pariaman district. We developed and expand community-based models to achieve universal access to TB testing and treatment.

Result from the qualitative studies show that theme of stigma in TB Program showed there were specific health communication channels which was appropriate for community outreach assisted in increase TB knowledge and Awareness for TB Program. Our findings had suggested areas of intersection

between a patient's health care and their cultural beliefs that need unique health communication channel in population to reduce stigma.

We conducted cultural approach: performed a story-telling and singing of Saluang, Indang and Rabab about TB, identify famous singer to sing about TB, where traditional music included 2 edutainment sessions with free traditional music and ethnic theatricals by the singer. We delivered through free traditional music and ethnic theatricals Saluang, Rabab and Indang.



Figure 5. Saluang, Rabab and Indang performance for TB socialization in Solok, Padang and Padang Pariaman District

In the implementation process for traditional music, we approached the community formal and informal leader for permission to conduct the Saluang, Rabab, and Indang in their community in Solok, Padang and Padang

Pariaman District. We identified the famous singer or traditional musicians in the village through informal leader. We provided the information about TB to the singer. The singer composed the song to include TB information at which they will talk about TB to improve awareness of signs and symptoms of TB and knowledge about TB available services and to encourage health-seeking behavior.

The cultural contexts also played role in health communication. Establishing local culture such as Saluang, Indang or Rabab with communities raising TB awareness amongst the general population. The traditional musicians talked about TB to improve awareness of signs and symptoms of TB and knowledge about TB available services and to encourage health-seeking behavior. It could be both interesting community because of events that were served were entertaining while still providing the benefits of TB knowledge to society.

Related study on role of cultural content in health communication was from Houston HR, et al. He found that development of a culturally sensitive educational intervention program could reduce the high incidence of tuberculosis among foreign-born Vietnamese(Houston et al., 2002). Furthermore, such efforts could play an important role in reducing the stigma associated with the disease.

Traditional music from Minang tribe, Saluang, Rabab and Indang were effective channel to increase knowledge and awareness to in the TB program and reduced stigma. It improved awareness of symptoms and reduces stigma and access to TB testing and treatment. We increased the case detection rate from 47% to 85%.

It is thought that community health through cultural approaches may have greater impact on TB control. Given that health decision-making is often a communal rather than an individual process in many most low-income countries, including Indonesia, community health channel through cultural approaches seem warranted.

Reaching hard to reach population in TB Program through religious leader

Community Health Literacy Challenge

As the largest archipelago country in the world, Indonesia's area consists of 80% of water, and only 20% of land covering an area of 2 million km². The majority of the 235 million Indonesian population are spread over in five main islands, namely Sumatra, Java, Kalimantan, Sulawesi, and Irian Jaya, and the remaining live in about 13,000 smaller islands, mainly of which are isolated.



Figure 6. Landslides, Remote Islands, there is no road access in Mentawai District

The Mentawai district consists of a cluster of islands large and small, amounting to 99 islands surrounded by the Indian Ocean. The most of resident lived in 4 main islands such as Siberut, Sipora, North Pagai and South Pagai. All the transportation between islands used boat.

The district had a lot of people living in urban slums, remote islands, post-disaster areas, the poor, malnourished, and contacts of TB patients. It is challenge for TB officer, that there's geographic burden in their area: they had wide and remote area to reach TB patient. Sometimes there were landslide and storm and made the area isolated.

In West Sumatra 47% of TB cases are undetected, diagnosed late, or receive incomplete treatment because of low level awareness and knowledge especially among the hardest to reach populations (e.g. urban slums, post disaster area, remote areas).

Understanding health-related information requires not only knowledge, experience, and skills, but also accessibility of health information(Abebe et al., 2010). The information needs to be available, readable and comprehensible. Mentawai district has different langue from other districts. It became harder in delivering the TB message due to more than one langue in the area. It is a challenge in health communication for the health providers.

Intensified efforts are required to reduce TB transmission and accelerate reductions in TB incidence, particularly in those difficult terrains or hard to reach populations.

Rationale

In order to effectively reach target populations, public health promotion efforts have tried to engage faith-based organizations over the past few years. The involvement of religious leaders in health-related interventions has generally been found to improve the participation of their congregations in these interventions and thus promote positive health outcomes.

Religious and spiritual leaders are some of the most credible people who influence the thoughts, emotions, and actions of a person of faith(DeHaven, Hunter, Wilder, Walton, & Berry, 2004). People of faith often make a conscious decision to behave in a manner that is consistent with the expectations of their religious or spiritual messages(Green, 2001; Pirkani et al., 2009).

All people in West Sumatra are religious community. In Mantawai, the majority are Christian, and they always come to church every week. Religious and spiritual leaders can deliver with local language to make it understandable for local people.

Community Health Literacy Intervention

Firstly, we are mapping the best channel for hard to reach group by focus group discussion and depth interviews, brainstorming with the community about their problems. In our project area, Mentawai, there are three in-depth interviews with TB officers and religious leaders, and two FGDs with informal leaders, and cadres.

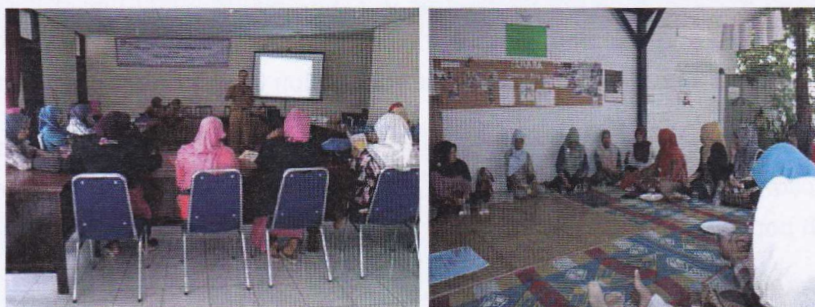


Figure 7. FGD Reaching hard to reach population in TB Program

Our findings had suggested areas of intersection between a patient's health care and their religious beliefs that need unique health communication channel in hard to reach population. The theme of reaching hard to reach population in TB Program showed there were specific health communication

channels which was appropriate for community outreach assisted in increase TB knowledge and Awareness for TB Program especially those who lived in the remote areas. This theme reflected there were problem in TB control program and the need of channel for hard to reach population through religious leader.

Secondly, we set the solution to solve the problem together, made plan of action and implementation of the TB program. People in West Sumatera are religious people, especially in Mentawai district, the majority are Cristian, and they always come to the church every week. We conduct the meeting with all 5 religious leader Protestant pastors who were selected via purposeful sampling. Semi-structured interviews were conducted with Protestant pastors.

The pastors from various Protestant denominations were approached by the researchers and invited to participate in this research. One of the researchers contacted them to explain the procedures and answer any questions. Agreement to an appointment for an interview was considered informed consent. The participants were invited to venue which are provided by District Health Office of Mentawai, we interviewed them with regard to numerous TB topics. The interviews lasted 60 minutes on average.



Figure 8. Training for religious leader

Moreover, interview questions were added or adapted based on the analysis of previous interviews in order to understand and test emerging concepts.

Inclusion and thus the interviewing of participants was continued until no new information was gleaned.

We had trained the 5 religious leaders include simulated questions that might be asked by the people in their communities, and provided them all TB materials. We had trained community volunteers and leaders using the ACSM Training Curriculum, we utilized the tools as in our previous projects. The All religious leaders of Mentawai fully accepted and willingness to be apart in support for TB control program in their region.



Figure 9. The religious leaders conducted speech to increase community awareness and knowledge about TB, and improve community health-seeking behavior during them preach.

The religious leader, when they give speech in religious activity, weekly or monthly religious meeting in society, they bring Information, Education, Communication TB materials such as brochures and leaflets for community group, which is hard to reach population. As religious community the people of West Sumatera province are respect for their religious and informal leader.

Based on our study, the role of religious leader had proven leverage impact on other disease besides TB. The same study approach such as in Uganda, that called faith-based initiatives in which involvement of religious leaders and organizations in HIV/AIDS prevention has had major impact(Green, 2001). Minetti A, et al found that addressing spiritual issues can make such a

difference in an individual's experience of illness — and often in health outcomes as well. This study was talking about reaching hard-to-reach individuals in response vaccination for measles (Minetti, Hurtado, Grais, & Ferrari, 2014). Another study related to the role of religious contents in health communication was Toni-Uebari et al. His study on haemoglobinopathies found weaving spirituality into medical education has become a priority among integrative medicine leaders. It made sense that attention to spirituality is also important for health care providers themselves (Toni-Uebari & Inusa, 2009).

We suggested areas of intersection between a patient's health care and their cultural-religious beliefs that need community level health literacy approach to assist in increase TB knowledge and Awareness for TB Program.

The understanding of community health literacy is important and needed by health care providers. They should tailor health communication to enhance message relevance and should have the skills to identify health communication situations. Health care providers may sometimes be uncomfortable talking about cultural-religious health beliefs and behaviors with patients and families. It can say as a community health literacy problem, this condition become a challenge for TB officer in delivery TB promotion.

The need for adequate language interpreters in health care settings is uniformly addressed, but it is also imperative for people to be able to communicate with leaders of their faith community. These influential figures can help interpret what is happening on a spiritual level during a health crisis for patients and their families. Religious leaders can clarify which tenets cut across the branches of their faith in matters TB disease.

Involving School Children and Women empowerment in Wide Sector Approach as Strategies to Reduce the Stigma of TB in Indonesia

Community Health Literacy Challenge

The stigma of TB is the biggest obstacle to TB control in Indonesia (Health, 2015). Several programs were designed and implemented to decrease TB prevalence and increase the success rate of TB treatment, even though it does not have a substantial leverage to reduce stigma.

According to TB Knowledge-Attitude- Practice survey, only 21 percent of Indonesians are aware of the risks for TB or how to properly treat it. The community's knowledge on TB points out that they still hold stigma of TB. Kind of stigma evolves in community is that; TB is a hereditary disease, it's shameful to have a family member with TB, TB is a disease of indigent people, TB is a magic-related disease. It impacted on the estimated TB cases were still not being detected and many patients are diagnosed late

The approaches taken so far have weaknesses as they target to educate only adults, not yet involving school children as promoter TB Control.

TB control program have not set the implementation of TB program with wide sector approach through high-level people. They are important people as role model against TB. To make the TB program successful and sustainable, the TB programmer must engage them.

Rationale

The children are the future generation, they do not have any stigma, we put the right information about TB Message. They are potential promoter at least, they can deliver right TB message promotion to their parents. Involving school children as TB promoter is one of choices to reduce stigma

Health promotion for combatting TB goes beyond health care to reduce stigma with wide scope range and make it sustain in the community, we need the conducive environment, that need to set from the top system first. So, it

could not directly through community to reduce stigma (Sachdeva, Kumar, Dewan, Kumar, & Satyanarayana, 2012).

We engage government, wife of governor, provincial health office by system. We advocate them to put health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health, especially for TB program. The result of this advocacy is support for this program, increased awareness of TB problems, and establishment of the committee to support the TB program at the provincial and district level.

Community Health Literacy Intervention

There were two (2) step; Firstly, preparing the conducive environment, improve local legal and regulatory environment for TB to make it sustainable in TB control program. Secondly, we educated the 1st-3rd elementary school children to the media with fun and attractive. We were using storytelling and with cartoon that they should coloring in the TB coloring book. With fun, attractive and proper information of TB, the stigma reduces from the children. They would be an agent of change against TB.

The stage in the first step, as follows; We set the environment by advocated local governments to change regulations that are not consistent with the NTP guidance, increase funding, and ensure better quality TB services. We set up a steering committee that includes the governor, high-level district officials, and representatives from the government health sector, parliament, and the media.

The roles of government and high-level stakeholders are crucial in supporting the actions to combat TB problems in Indonesia. Advocacy is a strategy to involve them taking responsibility in TB control.

We involved them from the start of the project and informed them concerning the project progress quarterly. We state their commitment with a letter that the governor and mayors are signing in it. Engaging with the high-level

people with authority through a wide sector approach to make it sustainable with conducive environment for TB control program.

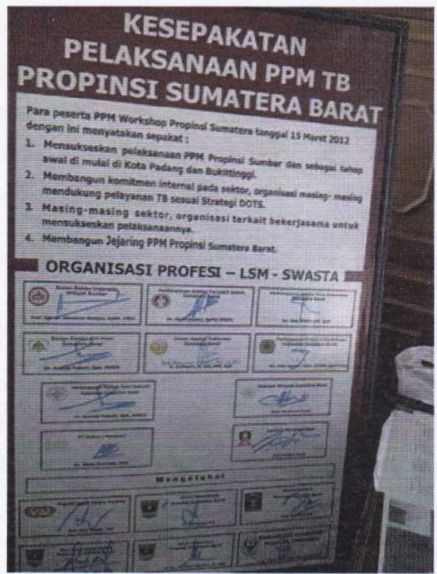


Figure 10. The governor, high-level district officials, and representatives from the government health sector, parliament signing the commitment to support TB Program

In the second step, we involved wife of the governor. As the wife of the governor, she has a civic official organization of West Sumatra called

Pembinaan Kesejahteraan Keluarga (PKK- women association for family's welfare). This organization is engaged in women's empowerment. She took a part as a leader in conducting a coloring books and knowledge competitions about TB in their region. Furthermore, these activities will be conducted in all districts of West Sumatra during the multi-year project.

We involved the teachers as well. We trained 10 teachers and gave the TB coloring book to them, to be continued the program to their children in the school. They teach the student TB promotion to improve knowledge and awareness and to encourage health-seeking behavior of TB and increase the TB detection.



soal dan jawaban
answer and question

- 1. Bisakah TB diturunkan? Can TB be inherited?**
Tb tidak diturunkan tetapi ditularkan dengan penyebaran virus serta menggunakan alat yang telah dan jajan oleh Dokter
Tb can't be inherited but is transmitted by using virus treatment and having medication as instructed by the doctor
- 2. Alas Pengekotan? (ruband cover)?**
Pengekotan Tb harus dibersihkan secara teratur selama minimal 4 kali
TB prevention must be clean regularly for at least 4 weeks
- 3. Bagaimana mendeteksi TB? How to detect TB?**
TB dapat dengan mudah dideteksi dengan pemeriksaan dahak, rontgen dada di awal sesitan atau rontgen dada
TB can be easily diagnosed with a sputum examination on a chest X-ray at a health clinic or hospital
- 4. Dapatkah TB diobati? Can TB be prevented?**
Risiko TB dapat dikurangi dengan meminum obat TB hasil obat serawi hasil meminum dan saat dengan obat, vaksinasi BCG saat lahir mengurangi risiko TB pada anak
The risk of TB can be reduced by taking a healthy lifestyle such as a not smoking and a health diet. BCG vaccination at birth reduces the risk of TB children
- 5. Apakah semua rumah TB perlu dirawat di rumah sakit?**
Tidak, ada rumah TB yang dapat diobati secara rawat jalan dan hanya perlu dirawat jika ada komplikasi medis
Not every TB patient can be treated on hospital ward, visit and rest only be necessary if there are medical complication
- 6. Dapatkah TB ditularkan melalui perabotan rumah atau benda dengan pasien TB?**
Tidak, penularan TB pada penghunian yang efektif tidak memutar dan tidak ada penularan tersebut melalui media
No, TB patients or objects treatment are not infectious and there are no restriction on being staying outside of housing

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lekat di bawah dengan
Tim perencana PKK PROVINSI SUMATERA BARAT

Figure 11. The TB Coloring book, adapted with local cultural background

At the event of TB coloring competition, the children were coloring the cartoon in The TB coloring book, which was adapted with cultural background of West Sumatera Province. There were TB story in 11 pages, which the dialog including the against TB message (Houston et al., 2002). There were questions and answers about fake or fact about TB they should know.

The winner of TB coloring book competition was given in the same time in the big event where the Governor and the mayor signed their commitment for TB control program.

We were very honored that the big event, which was ceremonial of signing the commitment of TB and awarding prizes to the winners of TB coloring book competition, were attended by the governor, all the mayor and the secretary general of ministry of health (100%). The respond rate from the high-level people are very good.

All the activities were under coordination with Provincial health office (PHO) which was JKM as a partner. The PHO set all the material of the TB coloring books. The JKM set the logistic of the event funded by Westat.



Figure 12. The first TB coloring book competition was conducted in a provincial region among 600 children aged 6-9 years at grades 1 to 3 in elementary school.

The first TB coloring book competition was conducted in a provincial region among 600 children aged 6-9 years attending grades 1 to 3 in elementary school. They were all very excited. After competition, we took some samples to tested them. The average scores of correct answers were 80%.

The children were coming to the event accompany by their parents and their teacher. More than 1000 people attended.



Figure 13. The Ministry of Health represented by the secretary general gave of TB promotion book to the PKK- women empowering organization led by the wife of governor



Figure 14. The winners of TB coloring book competition with Governor of West Sumatera, USAID, Ministry of Health, PKK, Provincial Health Office

Involving children in a wide sector approach with high-level people against TB would reduce the stigma efficient and effectively.

Civil society mobilization to improve TB case detection and treatment outcomes among vulnerable populations

Community Health Literacy Challenge

The system on TB control in community has not been built optimally. The informal leader and the cadres raised perceived there was no comprehensive and coordinated approach to engaging the community in supporting TB services, including helping patients stay on treatment, proactively identifying possible TB cases, and advocating for better quality TB services. So on, TB officers realized that community systems had limited capacity to increase public knowledge of TB, support improved TB diagnosis and treatment.

Rationale

We had our existing community networks that can be used for referral systems, knowledge of local settings, and resources to develop and expand community-based TB activities. We need to train community volunteers and leaders for community mobilization, patient support, and community health worker outreach.

Community Health Literacy Intervention

We train the cadres to improve their Advocacy, Communication, and Social Mobilization (ACSM) skills, perform TB surveillance and reporting, TB contact tracing, and TB specimen collection. An essential focus of this activity is to build strong linkages between the newly trained cadres and the existing health facilities. We facilitate and ensure these strong linkages established.



Figure 15. Cadre Training in Deli Serdang, attended by Chief of PKK (the wife of Mayor Deli Serdang), Head of Sub-district Government, Head of Puskesmas and representative of USAID

All the cadres activity are followed up by their Community organizational development (COD). This activity is conducted during the regular meeting with cadres at sub district. Existing cadres have their activity supervised by the COD. New cadres who were recently trained with case finding are mentored by the COD to assist their work.

Following the training, the community cadres are supervised and monitored by the COD and sub district facilitator. They will also have mentoring activity in regular meeting at the sub district. After the training, they do home visit to case finding and case holding.

Below illustrates the approach of using cadres in increasing TB case detection.

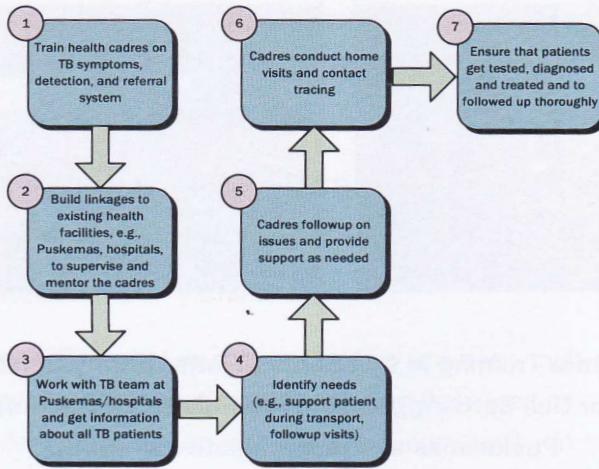


Figure 16. The approach of using cadres in increasing TB case detection

We conduct regular supervision and monitoring in the fields. Our sub grant: Westat, USU, UI, and UNAND are involved directly when conducting field activity. This aims to monitor TB CEPAT program implementation in each province and district. The result of this activity is reported and evaluated to arrange intervention/ innovation to achieve the program main goal.

Increase Advocacy to Strengthen the TB Program

Community Health Literacy Challenge

The sustainability of cadre activities in eradicating TB in West Sumatera, especially in areas where CEPAT program is implemented for 5 years are uncertain due to the budget allocation. The weaknesses are associated with a low level of awareness and knowledge in the policy maker subsequently causing a low TB budget.

Rationale

For the sustainability of the activities of the cadres, cooperation from the Mayors of District, District Health Office and the Local Legislative of District where the program is conducted to engage the NTP, Province and District-Level Health Leaders. We need to increase allocated resources and improved local legal and regulatory environment for the TB program as well.

An understanding of community health literacy for policy maker, as one of the basic factors that influence mobilizing and empowering the community to prevent, detect, and treat TB, MDR-TB, and TB-HIV through availability budget for the TB program(Paul et al., 2016).

Community Health Literacy Intervention

This activity aimed to advocate the district leaders to increase their local budget allocation in health, especially TB program. The new leaders support and afford all active community cadres through universal health access by covering their insurance payment through APBD (local budget revenue and expenditure). Second, we also advocated the leaders to provide good access and facility for the continuity of TB patients' treatment.

In advocacy aspect, we have succeeded to support integrated action for the preparation of Local Policy/Regulation for TB control environment. This program has increased local government's awareness about CEPAT cadres utilization as invested resources for TB control in the community.

Initiating the advocacy, Program Director of CEPAT dr. Delyuzar, M. Ked (PA), Sp. PA (K) with WESTAT Consultant, Mekkla Thompson, Advisor Program of CEPAT DR. dr. Masrul, MSc, Sp.GK, COD of West Sumatera DR. dr. Rizanda Machmud, Mkes, accompanied by West Sumatera Provincial Health Office, representatives of Pulmonary Division of M. Djamil Hospital of Padang and CEPAT team met the Governor of West Sumatra, Irwan Prayitno.

At this meeting we presented what has been done of CEPAT program in West Sumatra, especially in 6 districts where the program is implemented. We also presented the amount of funds needed to continue the activities of TB cadres in the region.



Figure 17. Advocacy process at West Sumatra Governor Office

The governor instructed the West Sumatra Provincial Health Office to make an official letter to the district government to include the budget of TB cadre activities into the 2018 Budget Plan so that the cadre activity could continue under the supervision of the district government.



Figure 18. Advocacy process at the West Sumatra Provincial Health Office



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Padang, 2 Maret 2017.

Nomor : 443.3/015/P2P/LLI/2017
Lampiran :
Perihal : **Pesanggaran Pengendalian Penyakit Tuberkulosis Paru.**

Kepada Yth :
Sdr. Bupati/Walikota se Sumatera Barat
di :

Tanah

Dengan hormat,

Dalam rangka mendukung Pelaksanaan Program Pengendalian Penyakit Tuberkulosis di Kabupaten/Kota Provinsi Sumatera Barat, bersama ini disampaikan kepada Saudara hal sebagai berikut :

1. Penyakit Tuberkulosis merupakan salah satu penyakit menular yang sebagian besar menyerang penderita pada usia produktif serta berdampak pada ketidupan baik sosial maupun ekonomi, karena kurangnya produktifitas dari penderita tersebut.
2. Dalam pengendalian Tuberkulosis, selanjut ini dibantu melalui dana hibah dari United States Agency International Development (USAID) dan hibah ini telah berakhir pada Tahun 2016.
3. Sehubungan dengan hal diatas, untuk kelangsungan pengendalian penyakit Tuberkulosis diwujudkan, diminta kepada Saudara untuk dapat mengalokasikan kegiatannya ini pada APBD Tahun 2018 di masing-masing Kabupaten/Kota.

Demikian disampaikan, atas perhatiannya diucapkan terima kasih.

GUBERNUR SUMATERA BARAT



Figure 19. The internal memo about budget allocation for TB control in 2018

An internal memo was released by the governor of West Sumatera regarding budget allocation for TB control to be provided in APBD of 2018 after JKM team had discussion at Governor's house

Bringing this letter, we visited the District Government where the program was conducted to advocate for further program sustainability. We went to the Mayor and Local legislative accompanied by the District Health Office.



Figure 20. Advocacy to the Mayor and the Local Legislative of Solok District

We conducted an advocacy meeting with Local legislative and Head of District. This aimed to pass the information of CEPAT exit strategies in West Sumatera before the program ended.

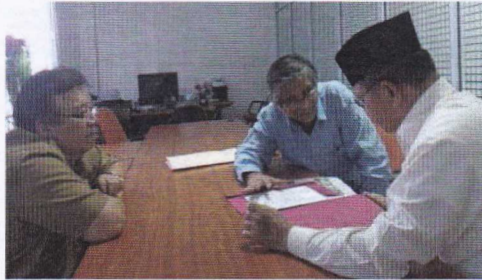


Figure 21. Advocacy to the Mayor of Padang Pariaman District

In response to West Sumatera Governor's internal memo, Tanah Datar Health District initiated to expand TB cadres involvement in 5 more subdistricts (total 12 sub district) by training the new cadres since CEPAT has contributed to increase CDR in Tanah Datar. They will have allocated operational budget for 350 TB cadres. In Padang Pariaman and Solok, the Head of District stated that his governance commits to continue supporting of TB program.



Figure 22. Advocacy to the Mayor District and Local Legislative of Tanah Datar

We conducted advocacy as well to the wife of Padang Major (Harneli Bahar) to socialize about CEPAT sustainability issue and the Governor's internal memo regarding TB resource allocation, especially to support TB cadre activity. As the wife of the mayor, she has a civic official organization of Padang District called *Pembinaan Kesejahteraan Keluarga* (PKK- women association for family's welfare). This organization is engaged in women's empowerment. It was pointed that the Major wife as CEPAT cadres governing board which aims as the facilitator for CEPAT cadres to conduct TB control activity in Padang.

We conduct hearing with Legislators About TB Regulatory Environment for cadres and the poor. During the district meeting, advocacy to support TB health regulatory for cadres and the poor will be approached to the district leader and participated by Local legislative, District Health Officer, Primary Health Care Officers, Policy maker, TB CSOs and stakeholders. This activity

will facilitate the preparation of district regulations (PERDA, Peraturan Daerah) for supporting the TB program, especially for cadres and poor people to access free public health service, local health coverage.

We presented that CEPAT program has a lot of investment in TB control for the selected area in West Sumatera province. We have built the combat TB program and the system and monitoring evaluation of TB control as well for 5 years.

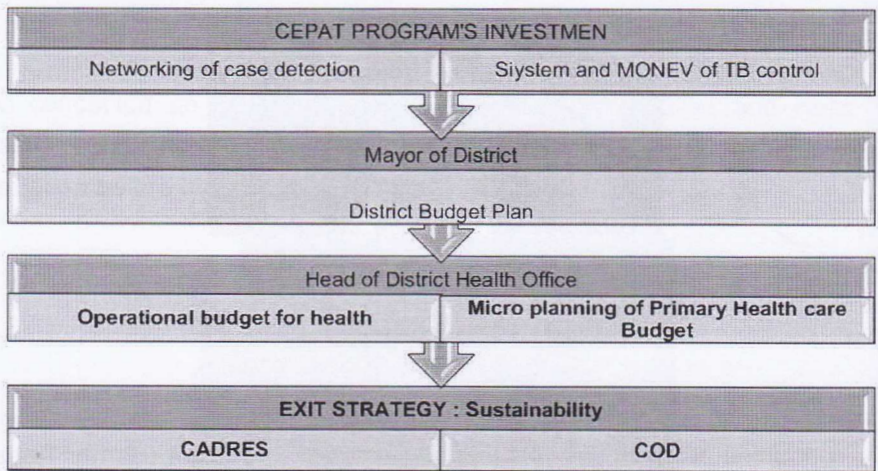


Figure 23. Scheme of Sustainability that is presented in advocacy meeting

We made the exit strategy of the CEPAT Program that governance commits to continue supporting of TB program. They should include the budget of TB cadre activities into the 2018 Budget Plan, in district budget plan. And for district health planning budget they will put allocation budget for TB control in operational budget for health and micro planning of primary health care budget section.

The meeting will also inform the Primary Health Care (*Puskesmas*) regarding the optimization of Operational budget for health *BOK* (*Bantuan Operasional*

Kesehatan) provided by Indonesian Ministry of Health for Primary Health Care. According to the technical guidance for BOK utilization, the allocated budget in BOK can be used to support cadre transport while providing health service process at the community or accommodation/ per diem payment for cadre activity located in remote areas.

We had a positive respond from the district health office of Padang, a letter for Puskesmas An internal memo was released by the them regarding budget allocation in microplanning Puskesmas for TB control

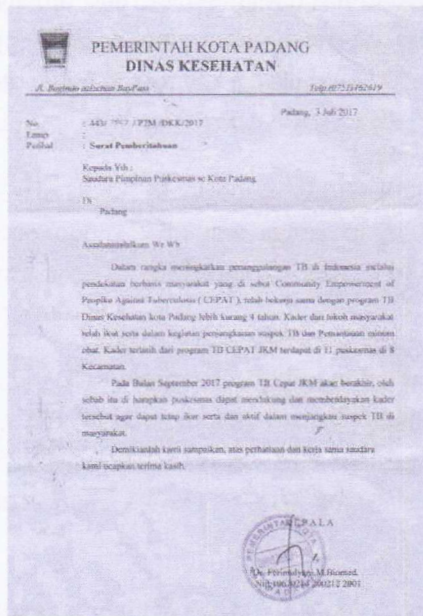


Figure 24. The letter of Padang Health Office to Puskesmas to continue supporting cadres activity for TB control in 2018

Discovering the broader context of a patient’s life was critical to providing responsive care and assuring good in TB health outcomes. It could be increasing awareness, knowledge, case finding rate, access to TB treatment,

adherence and successful treatment. Community health literacy promotes to combat TB not only for individual but also for stake holder as policy maker.

Our approach in line with the recent Rio political declaration as result of World Conference Social Determinant of Health announces that countries agreed to achieve social and health equity through action on social determinants of health and well-being by a comprehensive inter-sectoral approach. It might be solved through three main actions (3): a) Involvement of organized communities and all levels of government – local, provincial and national. b) Solutions often lie beyond the health sector, and require the engagement of many different sectors of government and society. c) Local leaders and governments could and should play a key role in TB control in Indonesia

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The weakness of community level tuberculosis (TB) services is a major concern for TB health promotion in Indonesia. These weaknesses are associated with a low level of awareness and knowledge and a high level of TB stigma in the community subsequently causing a low TB case detection rate (CDR). This book presents the role that community health literacy an important part in increasing the number of tuberculosis (TB) case findings, case holdings, and success rate by supervising and mentoring the cadres and community leaders. It shows how TB case detection rate improved through an understanding of the community literacy of health and the engage of community empowerment. This book is primarily addressed to health programmer, TB programmer, public health researchers, stake holders, who play a very important role in the control of TB or other diseases in the community. There are best practices how to expand community-based models to achieve universal access to TB testing and treatment. An understanding of community health literacy, as one of the basic factors that influence mobilizing and empowering the community to prevent, detect, and treat TB, MDR-TB, and TB-HIV.

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