

The Development of Action Model that Integrate Tuberculosis Case Detection and Completeness of Treatment through Women Empowerment at District Level in Indonesia

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Abstract—*Mycobacterium tuberculosis* (Mtb) is the causative agent of human tuberculosis (TB) with an estimated 8.8 million new TB cases and 1.4 million deaths annually. According to MDG (Millennium Development Goals), Indonesia should be able to reduce half the number of patients with infectious diseases including tuberculosis by 2015. Based on Health Survey data in Indonesia, 2010, Lebak is a district in Banten Province with the highest TB prevalence rate of 1,282 per 100,000 population. In 2013, Lebak District Health Office stated that one of the main problems in treating tuberculosis patient was the patient's reluctance to go to a hospital or health center. Therefore, encouragement for the patients is very important to reduce this reluctance. On the other hand, women in Lebak are socially active, including in their religious group. This active social group in Lebak can be a good medium to encourage patients with tuberculosis to go to the hospital. Therefore, we develop an integrated system model for finding out new cases and completeness of TB treatment through women empowerment in the family and community.

Keywords- *Action model; Tuberculosis; Case detection; Completeness of treatment; Women empowerment*

I. INTRODUCTION

Mycobacterium tuberculosis (Mtb) is the causative agent of human tuberculosis (TB) [1] with an estimated 8.8 million new TB cases and 1.4 million deaths per annum [1]. According to MDG, by 2015, Indonesia will have to decrease by half the number of the patients with contagious diseases, including TB. Unfortunately, sustainable and accurate information on TBC epidemic does not exist [2]. This situation leads to the deployment of costly surveys and discontinuous information. TB case detection deserves to be better treated. According to WHO reports in 2012 [1], the increase of prevalence numbers obviously showed that TB in Indonesia has become a global health problem. This was measured from several indicators such as morbidity, prevalence, and incidence. Prevalence in Indonesia was 281 per 100,000 people, which was higher than China, India and Thailand (104, 249 and 161). On the other hand, the number of incidences in Indonesia was 187, which was also higher than China, India and Thailand (75, 181 and 124) [1].

Indonesia has implemented the DOTS strategy since 1995, but unfortunately the tuberculosis treatment problem cannot be handled only by concentrating on the medical treatment aspect, but also through discovering new patients. Therefore, estimated CDR (Case Detection Rate) of TB incidence is still low, and the proportion of TB which has not been handled is still fairly large [2][3].

Lebak is one of districts in Indonesia with a large population of poor people with TB. The percentage of TB patients in Lebak who took treatment for less than 6 months was 19.3 % and TB patients who did not take any medication was 4.5%. In 2013, The Lebak District Health Office (DHO) stated that one of the main obstacles in treating patients with tuberculosis was the patient's reluctance to go to a hospital or health center. Therefore, encouragement for patients is important to reduce this feeling of reluctance. On the other hand, the Lebak women are socially active, and social groups can be a good medium to encourage patients with tuberculosis to go to the hospital. One active group in particular is the women's religious group Fatayat NU. Therefore, there is a necessity to develop an integrated system model to identify new cases and maintain the completeness of TB treatment through women empowerment. This study offers a program to treat communicable diseases, especially TB in Lebak district. Through the implementation of this program, every component involved in the application of TB prevention program will benefit directly and indirectly [4].

This paper is structured as follows. In Section II, we present the research method. In Section III, the results are presented. Section IV presents a solution for increasing the community knowledge regarding the TB disease and developed system. In Section V, we discuss our findings. Section VI concludes the paper.

II. RESEARCH METHOD

This study has been ongoing for 17 months (began March 2013) and will conclude on October 2014. A variety of

methods were employed to develop the model in this study [5][6][7]:

1. Literature study of baseline data on case detection and number of drop-outs, and selected priority area had been conducted.
2. Knowledge and behavior of women in the communities to detect and treat TB cases have been assessed through quantitative and qualitative approaches.
3. Training on how to detect and treat TB cases in religious meetings for two months have been conducted.
4. Communication media to increase their knowledge of TB symptoms have been designed.
5. A short message application based on System Development Life Cycle (SDLC) and web design. Those methods were deployed to develop the information systems had been developed.
6. The integrated patients' database between the Health Center and community have been developed
7. A standard operating procedure (SOP) and knowledge suitable for other districts/counties to enable replication had been developed.

Three Primary Health Centers (PHC) were involved in this study, namely PHC Mandala, PHC Karanganyar and PHC Cibadak.

III. RESULTS

A. Problem Identification on Communities

150 women from 3 villages (50 women from each PHC) were interviewed, and results indicate that only 20% knew about the symptoms of TB, 50% had heard of TB, and only 1% knew about TB treatment. The result from problem identification indicated that the community tends to have poor knowledge and tends to be very passive toward TB treatment. Therefore, we developed an implementation strategy training to increase community awareness in detecting TB cases with an understanding of symptoms of TB diseases, such as:

1. Coughing for 2 weeks or longer
2. Sputum is mixed with blood
3. Cold sweats at night (while not conducting any activities)
4. Chest pains and shortness of breath
5. Decreased appetite and body weight
6. Fever in the evening for a month or longer

Each training took 3 days per season within two months. We held four trainings for the Lebak women. We also suggested the women who have received training to teach about TB symptoms to their social groups, such as their Quran recitar (*pengajian*) group and local women empowerment (PKK) (Fig. 1).



Figure 1. Training of women to detect and understand the symptoms of TB diseases

B. Media Communications Development

A communication media by creating leaflet and pocket book had been designed. This aims to provide information of TB, its signs and symptoms, and preventive measures. In this leaflet, there was also information of a Short Message System (SMS) gateway number that can be reached by the target group if TB symptoms are found in the family or surrounding community. On the other hand, the pocket book provides information on how to use the SMS application information system for health officers in PHC and mothers. Figure 2 illustrates the design process of leaflets, booklets about TB symptoms should be known and understood by mothers through several meetings.



Figure 2. Finished leaflet and process of designing leaflets

C. Problem Identification on System

Several problems were also identified in the assessment system conducted. Problems were divided into three components: input, process and output. From the input component, problems that occurred were [8][9]:

1. Recording and reporting process were still conducted manually and was potential to human error;
2. The software that can improve community-based

reporting and monitoring of TB patients' treatment completeness was not ready yet. The problem which occurred during the process is that the transformation process from data to information was still manually performed and, in turn, was not effective for creating routine reports. Because the manual process took some time, this in turn impacted on performing the output, such as the need for extra time for feedback to respond to cases and the difficulties for community to understand the sign and symptom of TB.

The constraint of the information systems development was that the system was not developed in an integrated manner. It should be developed by seeing the behavior of the unit of observation, ability of the operators, infrastructure constraints, standard operating procedures and decision makers' needs. Good information systems should be tiered, from the smallest unit to the decision-making units. The integrated information model unit that can perform well was the availability of trigger unit, which could enforce the observation unit to be very effective [10]. The TB patients, as the smallest observation unit, and women can be the trigger units which needs to be observed periodically. Therefore, in this proposal, empowerment of women in the family was chosen as the trigger unit in the integrated information system development.

Considering the aims of this study, we made problem solving *breakthroughs*, such as the use of SMS or text messaging to register suspected TB Patients into certain Primary Health Center [11]. Preliminary findings indicated by SMS had many advantages, such as: lower unit cost (no telephone calls or visits to PHC for reporting), no staff needed to administer (we designed the system to connect directly through SMS and PHC's system), and cost effective and efficient. In Lebak, most women have GSM mobile phones. Unfortunately, there are still fees for sending SMS or text messages.

IV. SOLUTIONS

There are a number of alternate solutions to overcome these problems [12][13]:

1. Share information on signs and symptoms of TB with the community;
2. Conduct trainings to increase health officers' capabilities so they can function as facilitators to increase community awareness;
3. Develop an information system to effectively assist communities to report cases to health officers.
4. Improve the integrated system process. A development that can reduce the delay in reporting process is required. Besides, this can improve access to the information, and information can be monitored and evaluated.

The expected output from this solution is the real time information which will improve case detection and reduce drop-outs [8][10]. Prior to these alternate solutions,

empowering community, especially women, to be able to perform active surveillance was a key element in the implementation of the information system. In order to reduce the difficulties experienced by that target user in using information system, in the early stages of implementation, health officers and community organizations will provide continuous assistance (Fig. 3) [14]. SMS or text messages are used to register suspect TB patients which are sent by trained women. If problems persist, health officers are to provide manual records to grant data transmission. These two activities will be conducted by considering the community's ability to adapt to the information system (technology acceptance).



Figure 3. Schematic of the SMS system report

A. The SMS for Life system

The system consists of two components [15][16]: an SMS management tool and a web-based reporting tool. The SMS management tool (Fig. 4) is an application stores with single registered mobile telephone number for each health care worker.

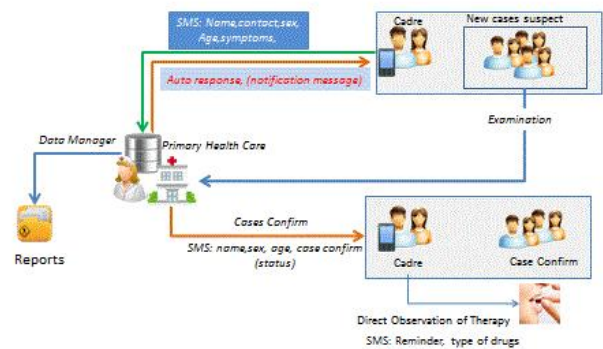


Figure 4. Scheme of the SMS system in the SMS for Life Pilot

B. Training and Socialization

Training and socialization participants include representatives of the Lebak District health office, data

management and information centers of Primary Health Centers, and 25 Fatayat NU cadres. These activities were held at the Fatayat NU Center over two days. The procedure of sending messages and patients data with symptoms as well as on leaflets and posters through sms is an important stage, given that this information system is built based on the patient data. Leaflets and posters were distributed over two weeks ago during a meeting with study groups in the organization Fatayat NU.

Participants were equipped with the knowledge to use the SMS tools, as well as the procedures for sending SMS module and assistance for patients to take medication. These activities were performed in conjunction with training in community health centers to receive cadre reports, as well as to send an automatic reply delivery cases and information on TB patients who had been positive TB diagnosed (Fig. 5). Health providers of Primary Health Centers has a number of responsibilities for the systems developed, such as monitoring TB patients to complete their treatments along with a Fatayat NU cadre, and compiling entire reports for Primary Health Center and Health District Office every three months.

The simulation to find cases done in these training was aimed to train participants to understand field situations and discuss potential scenarios. The training included question and answer session and an agreement to send SMS to primary health center if there is anyone suspected of having TB disease based on the symptoms explained in this training.



Figure 5. Training and socialization for Fatayat NU cadres and Primary Health Care providers

The trial specific procedures to recruit, enroll and follow-up participants were integrated within existing health care services pathways which were also discussed as well.

TABLE I. PATIENTS WITH SUSPECTED TB, POSITIVE TB DIAGNOSIS AND FOLLOWING TREATMENT

PHC Sub-districts	Years	Suspect			Diagnosed			Treatment			DO
		TW 2	TW 3	TW 4	TW 2	TW 3	TW 4	TW 2	TW 3	TW 4	
Kalangany	2013	5	24	25	3	10	5	3	7	5	3*
Mandala	2013	37	20	30	2	8	8	2	6	8	2*
Cibadak	2013	34	31	24	6	9	3	6	9	1	2*

Note: TW = quarter

Table I shows a tendency of TB suspect patients on the increase. This indicates that Fatayat NU cadres have actively approached and monitored the community in their area. Moreover, TB positive patients also increased in line with increased TB suspected patients. The numbers are quite similar to those of the Lebak District health office’s estimates on TB positive patients.

However, there are still patients who dropped out (DO) of their TB treatments. The main reasons of this are that the patients are unable to pay the cost of treatment and they felt healthier and, in turn, ended their treatments.

V. DISCUSSION

According to our findings, the women willing to enroll in this study such as cadres, were worried of contagious diseases and thought that the diseases will infect their families and friends. Ideally, women should be able to choose when and how frequently they would receive text messages, since a majority of women use their own mobile phones.

On the other hand, poor internet access via mobile phones and computer was one of the biggest obstacles for communicating with this community. However the strengths of this study included the representative sample of the general population. The unique personal identifiers made it possible to extract information through multiple record linkages on demographic and socioeconomic factors as well as previous hospitalization for all of the selected individuals.

The major weakness was the uncertain generalizability of our findings. However, there was still the benefit that can be obtained from the data that were linked with the registered based population, for instance the possibility to access the socio-demographic data. Coordination with partners (Department of Health and Fatayat NU) were carried out in order to perform a more precise analysis of the TB SMS trials system. In addition, this system showed that the majority of users were educated and younger individuals. The model was designed through media design communication and effective information system applications. The implementation of a system involving commitment between partners (Fatayat NU and Department of Health) as well as volunteers who were able to play an active role in carrying out these activities was necessary. Applications were developed by considering the efficiency and user friendliness which helped the system to be used optimally.

The benefit of an integrated information system is to increase the ability of community to recognize the signs and symptoms of TB disease. The increase of public awareness towards TB also affected the number of reports health workers received on presence of TB symptoms among communities [17]. The health workers will then proceed the reports by reminding the patients' families of the medical schedule that have been prescribed through Fatayat NU cadres.

As for the science development, this integrated information can be used as the reference for the further in-depth research on community empowerment through appropriate information technology. Moreover, this research can also be used to increase case detection and decrease drop-out rate from the TB medical treatment. Furthermore, this research can also be useful as reference in developing more user friendly information system for health workers and communities.

There are weaknesses in this system, such as dependency on computers, electricity, internet networks, and communication networks associated with mobile phone signals, as well as fees for sending SMS.

VI. CONCLUSION

This study shows that mobile phones are an acceptable approach for detecting new cases of TB and TB treatment completion and as a desirable and acceptable means of communication. However, we still need an effective communication media such as a leaflet that can be provided information of TB, its signs and symptoms, and preventive measures. Defining program success is not only determined by statistical significance, but also determined by the perception of users. In addition, monitoring and evaluation phase of designing a system is crucial to its success and needs to be enforced on a regular basis to maintain the true potential and continue to adapt with the needs of the patients.

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