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Esty Febriani Lembaga Kesehatan Nahdlatul Ulama (LKNU), STIKES Kuningan Jawa Barat, esty6602@gmail.com

Adik Wibowo Health Policy and Administration Department Faculty of Public Health, Universitas Indonesia, adikwibowo@gmail.com

Neeraj Kak University Research Co., LLC, Chevy Chase, MD, USA, nkak@urc-chs.com

Hala Jassim Al Mossawi

University Research Co., LLC, Chevy Chase, MD, USA, hjassim@outlook.com

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# **Empowering Health Cadres to Support Drug-Resistant Tuberculosis (DR-TB) Patient to Enroll in Treatment**

Esty Febriani<sup>1,2\*</sup>, Adik Wibowo<sup>3</sup>, Neeraj Kak<sup>4</sup>, Hala J Al-Mossawi<sup>4</sup>

<sup>1</sup>Technical Tuberculosis Advisor at Lembaga Kesehatan Nahdlathul Ulama (LKNU), Indonesia

<sup>2</sup>Lecturer of Public Health Master Degree Program STIKES Kuningan, Kuningan, West Java, Indonesia

<sup>3</sup>Department of Health Policy and Administration, Faculty of Public Health, Universitas Indonesia, Depok, Indonesia

<sup>4</sup>University Research Co., LLC, Chevy Chase, MD, USA

#### Abstract

Tuberculosis (TB) remains a big challenge globally, while the involvement of health cadres' constitutes one of the key strategies for the TB program in Indonesia. These roles were further expanded to providing support to DR-TB patients. This study was a qualitative study, conducted in 2015 to explore the various factors which influence the performance of health cadres' in supporting DR-TB patients to enroll in treatment. A total of 39 informants consisting of 24 health cadres, three nurses, four DR-TB patients, and three family members, two peer support, a head of primary health care, and two TB staffs from the District Health Office were recruited for this study. Meanwhile, a refresher training for health cadres was conducted regarding knowledge on TB, community support, effective communication, as well as patient tracing. There was no significant difference in the pre and post-test results; however the health cadres showed great capability in communicating and assessing the condition of patients. In addition, the health cadres assisted in carrying out patient tracing process, an important initial step to better understand patients's overall condition and identify problems faced while seeking treatment. Health cadres need to work with various parties such as family members, close relative to the patient, peer support groups, and nurses to encourage patients to enroll in treatment.

Keywords: default patient, drug resistant-tuberculosis, health cadres, patient tracing

#### Introduction

Tuberculosis (TB) remains a big challenge globally, the World Health Organization (WHO) reported the estimated TB incidence rate to be 9.6 million and 13% coinfected with HIV, 1.5 million died of TB where 1.1 was HIV negative and 400,000 positive. Besides, there was also a challenge where 480,000 Drug-Resistant Tuberculosis (DR-TB) occurred in 2014, but only 123,000 cases were detected and reported.<sup>1</sup> Untreated TB cases continued to transmit disease rapidly; hence it was important that all case needed to be placed under evidence-based treatment and to ensure that each patient complete the treatment successfully. Moreover, when patients failed in DR-TB treatment, it potentially results in Extensively Drug-Resistant (XDR-TB). The average proportion of DR-TB cases that became XDR-TB was 9%.1 In 2018, WHO reported that the estimated number of DR-TB in Indonesia was 2.4% new cases, 13% and previously treated cases, 24,000.<sup>2</sup>

In 2013, the Minister of Health of the Republic of Indonesia No. 13 of 2013 was launched. It explained that

**Correspondence\*:** Esty Febriani, Public Health Master Degree Program, STIKES Kuningan, Lingkar Bayuning Street No.2, Kadugede, Kuningan District, West Jawa 45561, Indonesia, E-mail: esty6602@gmail.com, Phone: +62 81314388171 DR-TB is a man-made phenomenon, while the three main components that contributed towards the occurrence of DR-TB include health workers, patients, and the TB control program. The main factor causing resistance towards TB drugs was the human factor which failed to carry out TB treatment management properly. This factor is concerned with health workers' skills and performance, nonadherent patients, and a weak TB control program.<sup>3-5</sup> Based on previous studies, the determinants of DR-TB include side effect during first-line treatment, negligence by health care worker, interruption of treatment, previous default, and duration of treatment between 2-6 months.<sup>6-8</sup>

Matebesi and Timmerman,<sup>9</sup> concluded that lack of knowledge about TB, unsustainable TB education, side effects of drugs, hunger, lack of family support, stigma, and various factors were all related to health services. Similar situation was also reported in Persahabatan Hospital, Jakarta, Indonesia. Based on data collected from 2009 to 2013, of 595 confirmed cases for DR-TB,

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only 402 (67%) enrolled in the treatment. The most stated reason for the failure in follow-up was transportation cost and living expenses (57%), followed by side effects (22%), psychosocial problems (6%), work reasons (6%), while 5% were unknown, and 4% were due to other reasons.<sup>10</sup>

Overall, the DR-TB enrollment rate was not improved and even worse. Based on the global TB report and the results of the joint evaluation monitoring mission,<sup>11</sup> the situation has not changed. The treatment outcome of DR-TB patients in Indonesia has not changed and even tends to decline at 50%.<sup>2,11</sup>

According to the National Tuberculosis Control Guidelines, the Direct Observer Treatment (DOT) officer is responsible for tracking default TB patients. Whereas, based on the Technical Guidelines for Integrated Program Management of Drug-Resistant Tuberculosis Control (PMDT), health workers in hospitals or Primary Health Care are responsible for preventing and minimizing loss to follow-up cases including tracking default patients. However, this procedure has not always been carried out in reality. Limitations in time among health workers as well as incomplete patient information failed to track patients that did not enrol for treatment.<sup>4,12</sup>

As an effort to control various public health problem, community involvement has been applied in providing support to TB patients. Involvement of health cadres in improving case tracking and supporting drug-sensitive TB patients has long been applied in Indonesia, although this role is yet fully implemented. In other countries, the community-based approach tends to improve the cure rates for DR-TB patients. A psycho-social support group (PSSG) consisting of psychologists, social workers, and TB nurses jointly improved treatment adherence from 47% to 97% in Kazakhstan.<sup>13</sup> In Bangladesh, the involvement of community health worker (CHW) in supporting DR-TB treatment reduced follow-up loss from 27% in 2008 to 14% in 2011.<sup>14</sup>

Since June 2014, there were 30-72 health cadres in North Jakarta and Central Jakarta. This community intervention was to increase the enrollment rate of DR-TB patients. Based on the pre-study, the health cadres successfully encouraged five out of 21 DR-TB patients that delayed treatment, three out of the default patients continued the treatment. Hence, it was concluded that the role of health cadres in encouraging patients to increase the enrollment rate of TB patients is not yet effective. This was an exploratory study conducted to evaluate the main roles of cadres and the various factors influencing the performance in supporting DR-TB patients' enrollment for treatment.

The logic model developed by Naimoli, *et al.*,<sup>15</sup> and was used to explore various factors influencing the per-

formance of health cadres in supporting DR-TB patient. It is a pathway or theoretical flow about the causal performance of CHW as well as mapping the relationship between program planning and goals to be achieved. Using this model, it was concluded that when various activities at the program and system-level are well performed, there is improvement in CHW performance and the program goals are achieved.<sup>15</sup>

#### Method

The explanatory study conducted using qualitative methods from April to July 2015. It aimed to explore the main roles of health cadres in encouraging patients to enrolled for treatment and explore various factors influencing the health cadres' performance. The study results were expected to provide basis for the development of more appropriate strategies to increase the enrollment rate of DR-TB patients.

Data collection was carried out with focused group discussion, in-depth interview with key informants, communication skill observation, and review of routine data monitoring. There were two Focus Group Discussions (FGDs) with health cadres from Central and North Jakarta. In-depth interview conducted with six health cadres, three nurses, two DR-TB patients that complied with treatment, one defaulter patient, a DR-TB patient with experience as a defaulter and three family members, two TB staffs at North and Central Jakarta Regional Health Office staff, and the head of primary health care. A self-administered questionnaire was used to describe the characteristic of the 24 health cadres, including variables, such as socio-demographic data, history TB experience, motivation and perspective about the training material, non-material incentive, and work satisfaction.

Data were analyzed through several stages namely codification based on interview transcript and FGD, grouping theme, data validation using the triangulation method and conclusions. The result was used to identify the key topics that expected to be covered in the refresher training. In September 2015, a three-day refresher training was conducted to improve the capacity of 24 health cadres. The topics covered in training include TB knowledge, improving effective communication and conducting patient assessment skill, collaborating with former patient groups, and carrying out report recording.

A pretest was performed to measure the knowledge of respondents while the posttest was done three months after the training. In addition, communication skills observations were conducted to observe the capability of the health cadres while conducting home visits. The routine monitoring data were reviewed to analyze the progress of health cadres in providing support to DR-TB patients in three months.

The study fulfilled the standards set by Komisi Ahli

*Riset dan Etik Riset*—Research Committee and Research Ethics—Faculty of Public Health, Universitas Indonesia, for explanatory study using qualitative methods under 195/H2.F10/PPM.00.02/2015.

### Results

Table 1 shows the characteristic of health cadres. This was needed to explore more appropriate criteria for cadre selection. Forty-two (42%) of the health cadres were aged between 40-45 years, 54% have 0-5 years experience while 25% had more than 10 years of experience. Furthermore, 87.5% completed Senior High School education. In comparison, 50% were also active as cadres for other health programs such as Community Based Vehicle to Improve Child Survival and Development—Pos Pelavanan Terpadu (Posyandu), community support for dengue-Juru Pemantau Jentik (Jumantik), Family Welfare Program—Pembinaan Kesejahteraan Keluarga (PKK), people with HIV/AIDS (PLWHA), data collection in children with disabilities by the Social Service and Family Planning Assistance-Penyuluh Keluarga Berencana (PPKB) of the division of regions in Indonesia under the Neighborhood Council. Two respondents worked as a kindergarten teacher; one was a security guard and another is even currently active as Neighborhood Ward in the resident area. The analysis was carried out to determine the relationship between cadre characteristics and the motivation to be active as cadres, based on FGD and interview results. The cadres with TB experience or had infected family members showed high motivation to support to the patient.

"If you see this one, it feels like you want to help even though we don't know it, but surely it feels like to help." KP-3 (56 years)

"I am not a rich person. I can't give money. I can only

Table 1. Characteristic of Health Cadres, September 2015

| Characteristic       | Category                          | n = 24 | %    |
|----------------------|-----------------------------------|--------|------|
| Age                  | <40 years                         | 3      | 13   |
|                      | 40–45 year                        | 10     | 42   |
|                      | >45–50 years                      | 6      | 25   |
|                      | >50–55 years                      | 2      | 8    |
|                      | >55-60 years                      | 3      | 13   |
| Gender               | Male                              | 1      | 4    |
|                      | Female                            | 23     | 96   |
| Marital status       | Married                           | 22     | 92   |
|                      | Divorce                           | 2      | 8    |
| Education            | Junior high school                | 3      | 12.5 |
|                      | Senior high school                | 21     | 87.5 |
| Work status          | Health community cadres           | 17     | 71   |
|                      | Work (e.g., kindergarten teacher) | 7      | 29   |
| Experience as cadres | 0–5 years                         | 13     | 54   |
|                      | >5–10 years                       | 2      | 8    |
|                      | >10-15 years                      | 6      | 25   |
|                      | >15 years                         | 3      | 13   |
| Experience on TB     | No experience                     | 17     | 71   |
|                      | Has family member infected by TB  | 6      | 25   |
|                      | As TB patient                     | 1      | 4    |

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#### help him if he can recover." KP-1 (43 years)

The main roles of health cadres in supporting DR-TB patient was identified based on FGD and in-depth interviews with health cadres. Based on the results, the roles include accompanying patients to the health facility for diagnosis and treatment, educate and motivate the patient and family, and be the first person to be contacted by the health provider when the patient fails to visit the health facility to get regular medication, in turn, the health cadres is to conduct patient's tracing.

"... then she/he also helped me often to contact with family as well..when the patient did not come to Puskesmas, then I call health cadres. I had no time.. huh..to do a home visit. She/he could do it three times a week ... I just could not do it (home visit)...maybe.. sometimes could be once in a month", the Nurse (52 years) explained the roles of the cadre in tracing patient.

The health cadres also play important role in carrying out patient tracing. This role is to monitor the patient's condition by conducting a home assessment. Certain steps are to be followed during the home assessment, namely, inquire whether the patient and family are available for the meeting, or the patients often feel reluctant to be open at the beginning. When this happens, the arrangement is to be made for another visit. When possible, health cadres are expected to conduct the assessment to identify the actual condition, support the patient, and



Figure 1. The Flow of Patient's Tracing for Home Assessment

#### Table 2. The Result for Pre-test and Post-tests

| Tonic                         | Pre-test $(n = 17)$ |    | Post-test (n = 20) |    | Domente  |  |
|-------------------------------|---------------------|----|--------------------|----|--|--|
|                               | n                   | %  | n                  | %  | Kemarks  |  |
| About DR-TB                   | 13                  | 76 | 5                  | 25 | The pre and post-test were not the same.       |  |
| Treatment duration            | 11                  | 65 | 18                 | 90 | In post-test, one topic consisted of more than |  |
| The causes of default patient | 5                   | 29 | 1                  | 5  | one question and there were some questions     |  |
| Patient' tracing              | 10                  | 59 | 9                  | 45 | with multi answers.                            |  |
| TB Prevention                 | 16                  | 94 | 12                 | 60 |  |  |

**Note:** DR-TB = Drug-Resistant Tuberculosis

#### Table 3. The Communication Skills of Health Cadres\*

| Health Cadre | Communication Skill (Observed by the Researchers)  | Self-Assessment (by Health Cadres)  |
|--------------|--|---|
| 1            | Health cadres have done well in; showing empathy, understand-<br>ing patient's explanation, did not urge the patient to answer,<br>appreciating the patient at the end of the assessment.<br>Health cadres need to improve communication skills especially<br>in terms of making sure the patient understand the posed quest-<br>ion, making eye contact, providing opportunity for questions. | Health cadres were able to provide a clear explanation to the patient, did not<br>urge the patients to answer, appreciate the patients at the end of the asess-<br>ment.<br>Health cadres need to improve the process of exploring the patient's experi-<br>ence.                                 |
| 2            | Health cadres have done well in; greetings, using simple language<br>that the patient understands making eye contact, showing empathy,<br>listening to explanations, did not urge the patient, asked aout<br>patient's plans for treatment, appreciating the patient at the end<br>of the assessment.  | Health cadres were able to use simple language that the patient understand,<br>made eye contact, showed empathy, listened to the patient's explanation, did<br>not urge the patient to answer, asked about patient's plans for treatment,<br>appreciate the patient at the end of the assessment. |
|              | Health cadres need to improve communication skills, especially in terms of providing an opportunity for questions.   | Health cadres need to improve in providing complete explanations on drug-<br>resistant TB, showing empathy, thinking about other things and sometimes<br>interrupting when patients were explaining.  |
| 3            | Health cadres have done well in; showing empathy, listening to patient's explanation, appreciating patient at the end of the assessment.   | Health cadres were able to communicate without stigma, listened to the patient's explanation, appreciate the patient at the end of the assessment.  |
|              | Health cadres need to improve communication skills, especially in<br>terms of ensuring that patient understand the question posed, pro-<br>viding opportunity for questions.   | Health cadres need to improve showing empathy when listening to patient<br>explanations, thinking about other things and sometimes interrupting while<br>the patient was explaining.  |

Note: \*The communication skills observation just carried out only with limited number of interaction between health cadres and DR-TB patients since only most of patients did not allow the researcher to conduct the observation.

identify the barriers to accessing the treatment. The flow of patient tracing is shown in Figure 1.

Patient tracing activities are conducted not only for DR-TB patients that have not enrolled for treatment or default patients but also for new patients that are yet to begin the treatment. There was no significant difference in encouraging default patients or new patients to enroll for treatment. Instead, the challenge in making default patients return for treatment was greater compared to new patients. This step is important since the loss of follow-up on DR-TB patients was one of the main challenge es in the DR-TB program.

Based on the in-depth interviews with four DR-TB patients, several factors were found concerning to patients that enroll and complete the treatment. These factors include personal motivation, family support, side-effect management, knowledge of patient and family, health workers' empathy, peer support, health cadres, and friends support.

The information collected from all informants was

used to develop the refresher training modules. Furthermore, the pretest was carried out to determine the topic that needs to be emphasized during the training, whereas the post-test was carried out three months after the training. The results are presented in Table 2.

Aside from the pre-test, the authors observed the capacity of some health cadres to communicate with patients and family during patient tracing. Although the health cadres showed the capability to communicate effectively, however, certain skills still needs to be improved, like ensuring the patient understands the question, exploring the patients' experience conrening to DR-TB, eye contacting, and showing empathy (Table 3).

The authors also reviewed the process by which patient's tracing was performed. Three months after the training, 36 patients have been traced by the health cadres. The result of the patient's tracing from September to December 2019 is presented in Table 4. In total, 36 patients were traced, while eight had already moved to another place and refused to meet the health cadres.

Table 4. The Result of the Patient's Tracing by Health Cadres

| Region        | Category                               | n  | %  |
|---------------|--|----|----|
| Jakarta Pusat |  | 20 | 56 |
|               | Patient's defaulter                    | 3  | 15 |
|               | Have not started treatment             | 0  | 0  |
|               | On treatment                           | 8  | 40 |
|               | Died                                   | 4  | 20 |
|               | Move to other places or could not meet | 5  | 25 |
| Jakarta Utara | -                                      | 16 | 44 |
|               | Patient's defaulter                    | 5  | 38 |
|               | Have not started treatment             | 3  | 19 |
|               | On treatment                           | 3  | 19 |
|               | Died                                   | 2  | 13 |
|               | Move to other places or could not meet | 3  | 19 |

Table 4 shows the result of patient tracing activities by health cadres. It was extracted from routine data monitoring. Based on the results, the information obtained by cadres was not accurate. Four of the patients visited in Central Jakarta had died; meanwhile, based on data from the hospital, these individuals were lost in the follow-up process. The major difficulties faced while conducting patient tracing was incomplete or inaccurate address information.

"...I got the name of the patient, but...when I traced the address..it was fake..then I searched with Pak RT, RW data," health cadres (46 years).

Besides, some patients have moved to another place and did not know the new address; also, the status of some default patient was not right for instance, the patients that have died, non DR-TB patient, or the patient was still enrolling for the treatment. The role of health cadres in tracing patients was noticed and assisted by the nurses in health facility to understand the updated situation of the patients.

"... Anyway, it really helped to keep update the condition of the patient in the reports ... like xx (mentioned the patient's name), he didn't want to meet me, because he didn't take medicine anymore. So..the health cadre came to visit the patient and assessed the lastest condition of the patient... ", Nurse (52 years).

#### Discussion

The health cadres' retention or activeness percentage after 1.5 years was 63% or declined at + 37%. This percentage was based on the number of health cadres that actively provided support to DR-TB patients compared to the newly recruited. Similar results were obtained for community health workers in several countries, where the decline rate of total cadres varied each year between 3.2% to 77% per year.<sup>16</sup>

The DR-TB is predominately a disease of socially vulnerable groups, making long-term adherence to treatment a major challenges. The lost to follow-up constitute one of the major programmatic challenge for many countries.<sup>2,5,7</sup> The role of health cadres as part of the community was expanded also to support DR-TB patients. There is no ideal prescription for CHW. Certain criteria are needed to identify and select candidates. The personal characteristics of CHWs play an important role in the relationship with the community and motivation.<sup>17</sup> In this study, it was discovered that health cadres with experience in relation to TB tend to show high motivation to support the patient.

The expanding role of health cadres in providing support to DR-TB patients is a relatively new approach. In addition, the knowledge about TB obtained from continuous training is also required. During patient's tracing, the health cadres show effective communication skills in showing empathy, active listening, motivating and encouraging patients to be open.

Haaq and Hafeez,<sup>18</sup> reported that CHWs might seem elementary in high-resource settings; however, these individuals play a valuable in developing countries. Some basic steps were required to facilitate efficacy and effectiveness. A continued process is needed in the primary health care programs where opportunities are provided to community health workers to update knowledge, sharpen communication skills and gain credibility as personal health educators. The USAID reported that additional tasks were assigned to CHWs after the initial training coupled with corresponding training. In addition, training is expected to go beyond technical skills, that include "soft" skills, such as time management, problem-solving, and communication.<sup>19</sup>

The complexity of the guidelines, including inappropriate training, weak supervision, lack of support, and weak relations with the community, were some of the factors that culminated in the low performance of cadres. Other alternative methods may be applied like providing information with simpler methods such as pictures or giving quizzes at meetings. The regular monthly meeting is an avenue to increase understanding of topics that need to be mastered.

Naimoli, *et al.*,<sup>15</sup> emphasized that CHW needs to be integrated with the health system for health workforce development both in training and supervision. Supervision by nurses through direct skill observation can improve performance. The supporting role played by health cadres have no significant influence on the enrollment of DR-TB patients. Low enrollment rate remained one of the major challenge in the DR-TB program at North and Central Jakarta. These patients are also well know to usually drop out of treatment.

Maeve, *et al.*,<sup>6</sup> reported that most DR-TB patients usually fail to enroll for TB treatment. The patients that failed the treatment have a higher risk of further treatment failure; thereby leading to death. The process of bringing back default patients to return for treatment was



Figure 2. The Initial Steps in Supporting the DR-TB Patient

a major challenge. There were several factors that influence treatment adherence (1) health-services related such as unavailability of drugs, knowledge of staff about TB, limited access to health services, and waiting for long duration to get services; (2) socioeconomic factors; (3) patient knowledge about TB, as well as related factors such as family history, age, and gender; (4) patient's condition such as alcohol consumption, HIV, and history of treatment failure; (5) treatment-related factors including side effects and improvement, and; (6) lack of support.<sup>8</sup>

The role of health cadres has no direct influence on treatment adherence of DR-TB patients. Besides, the key role of health cadres is patient assessment, which is an essential step to identify the barriers in accessing treatment and solutions to overcome the problem. The health cadres also play a role in tracking the lost to follow-up patients.<sup>20</sup> These two roles are performed using a similar mechanism (see Figure 2). Accurate information concerning patient's condition and complete data regarding the patient's address are needed to trace patient easily.

#### Conclusion

This study was conducted to explore the main roles of health cadres in providing support to DR-TB patients. It was beneficial to determine the challenges of patients in enrolling for treatment and solution, factors that influence health cadres' performance, programs to supports the health cadres such as training, supportive supervision, and rewards for motivation. This study also described a clear flow patient's assessment and the needed information to be prepared for this activity and how to synergize with other parties including peer support group or nurses in primary health care.

The limitation of this study is related to the limited number of health cadres involved. This affected the study as it failed to apply the methodology by which the results is statistically analyzed. Moreover, the authors were involved in developing procedures and training material for health cadres. Several study assistants were recruited to carried out data collection and avoided possible bias.

#### Recommendation

Technical Guidelines for Integrated Management of Drug Resistance Tuberculosis Control (PMDT) stated that health workers are responsible for carrying out patient tracing; however, this was not applied in the reality. Therefore, there is a need for revision to accommodate the clear roles of health cadres. The selection of health cadre's needs to be in line with several criteria, namely 56 years as the maximum age limit, high school education, minimal workload. Also, selected cadres are expected to work well with other health parties and not give up easily. The training is highly expected to improve the knowledge and skill of health cadres. Capacity building through continuous training is needed with appropriate methods which focus on a specific topic such as patient' tracing and communication.

The roles of health cadres failed to increase the enrollment rate of DR-TB patients. Collaboration with various parties is needed by developing a comprehensive community-based approach. Specific support such as psycho-emotional patient assistance by psychologists is needed for some patients. Optimizing patient decentralization to primary health care needs to be intensified to reduce hospital burden. There is a need to develop a community database for monitoring patients to provide community support and a strong link system to provide complete and accurate patient information for easy and immediate follow-up.

The National TB program is recommended to refine the policy and regulation to clarify the community, especially health cadres under a legal framework. Further, comprehensive studies are needed to understand the effectiveness of health cadres in patient tracing as well as the role of various community components in reducing the number of default patients to increase the enrollment rate of DR-TB patients.

### Abbreviations

TB: Tuberculosis; WHO: World Health Organization; XDR-TB: Extensively Drug-Resistant; DR-TB: Drug-Resistant Tuberculosis; DOT: Direct Observer Treatment; CHW: Community Health Worker; FGD: Focus Group Discussion; Jumantik: *Juru Pemantau Jentik*; PKK: *Pembinaan Kesejahteraan Keluarga*; PLWHA: People Living with HIV/AIDs; PPKB: *Penyuluh Keluarga Berencana*; PMDT: Program Management of Drug-Resistant Tuberculosis; USAID: US Agency for International Development.

#### Ethics Approval and Consent to Participate

The study fulfilled the standards set by *Komisi Ahli Riset dan Etik Riset*—Research Committee and Research Ethics—Faculty of Public Health, Universitas Indonesia, for explanatory study using qualitative methods under 195/H2.F10/PPM.00.02/2015.

#### **Competing Interest**

The authors declare that there are no significant competing financial, professional, or personal interests that might have affected the performance.

#### Availability of Data and Materials

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#### Authors' Contribution

EF conceived and designed the study while EF, KA, OD, and AR performed the study. EF and OD analyzed the data, while EF conceived and wrote the manuscript.

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