



#### **Conference Paper**

# Community Perception of Tuberculosis Management Program in Suburban Surabaya: A Qualitative Study

Mundakir1, Asri<sup>1</sup>, Septian G. Winata<sup>2</sup>, Pipit F. Wiliyanarti<sup>1</sup>, and Ratna P. Priyanti<sup>3</sup>

<sup>1</sup>Vocational Education Program, Department of Community Mental Health Nursing, Faculty of Health Sciences, University of Muhammadiyah Surabaya, Indonesia

<sup>2</sup>Vocational Education Program, Department of Adult Nursing, Faculty of Health Sciences, University of Muhammadiyah Surabaya, Indonesia

<sup>3</sup>Vocational Education Program, Department of Emergency Nursing, STIKES PEMKAB Jombang, Indonesia

#### **ORCID:**

Asri: https://orcid.org/0000-0001-7448-8414

#### **Abstract**

Tuberculosis (TB) is still one of the main infectious diseases in Indonesia. The national program, Directly Observed Treatment short course (DOTS), that began in 2014 is unable to deal with TB cases comprehensively. The community has an important role in TB management because they directly intersect with patients and public health. The aim of this study is to explore the condition of the TB management program. A descriptive qualitative study was conducted in three sub-districts with high cases of TB. A semi-structured interview was conducted with 25 participants drawn from the suburban TB task force, community health volunteer groups, Community health Nurses, and subdistrict officers. Results reveal four themes which affect the implementation of TB management programmes: volunteer shortage, do for humanitarian intention, the myth and stigma, providing social and economic support. In conclusion, community-based TB management needs to be improve in the availability of budget, staff, training and resources while maintaining the ongoing work of the TB task force team.

**Keywords:** Community-based management, Community Health Volunteer, Descriptive Qualitative, Humanitarian Intention, Social support, TB.

# Corresponding Author: Asri asri.ners@fik.um-surabaya.ac.id

Published: 15 March 2021

# Publishing services provided by Knowledge E

© Mundakir et al. This article is distributed under the terms of the Creative Commons

Attribution License, which permits unrestricted use and redistribution provided that the original author and source are credited.

Selection and Peer-review under the responsibility of the IVCN Conference Committee.

# 1. Introduction

World Health Organization (WHO) states that Tuberculosis (TB) is a global emergency problem for humanity and an important problem in various countries around the world. In Indonesia, although the Directly Observed Treatment Short course (DOTS) strategy has proven to be very effective for TB control, the burden of TB in the community is still high. This is because the implementation of the DOTS strategy and programs for handling TB in its application still have challenges and problems in the community. The

**□** OPEN ACCESS

main obstacle is the failure to mobilize all community capacities, involving community members to participate, and unclear forms of contributions and who should be involved in TB Handling Program activities that affect the sustainability and effectiveness of the program [1].

East Java Province is one of the provinces in Indonesia which still has problems in tackling tuberculosis with a prevalence of 110 per 100,000 population. In Surabaya 16,616 people were suspected of TB and 2,330 people were TB positive. Based on data from the Surabaya Health Office 2015, the highest prevalence of TB was in Tandes Subdistrict with 551 people suspected TB and 114 people found with TB positive[2]. In 2016 there were 109 new TB, with a total number of 170 TB patients and a Success Rate of 88.64 [3]

Modern society is more likely to solve problems independently through various technological advancements that exist. Individual attitudes and feeling capable of solving problems independently can have an effect on the awareness to live in society as a result is the value in society to help each other, mutual cooperation, and others diminish, depicted by various individual actions that do not lead to a collective goal but lead to a destination according to the individual's wishes. Coleman explained in his ideas about individual actions influenced by the value of an event, that individuals will act based on the interests and benefits obtained from each individual [4]. If this condition is associated with handling TB cases, it can slow down the handling of cases. If the ability of social management is understood as a social ability in forming a nursing care by optimizing the health service system based on the culture of individuals, groups, families and communities, investment in community-based management is a useful strategy for increasing community nursing care to treat TB[5].

Community-based TB management is believed to be able to increase the capacity of the community to work together in solving health problems because the basis of management can be characterized in the form of individual willingness to prioritize community decisions in resolving health problems. Citizens who are in a community with good community management will form a cohectivity which is interpreted by the existence of horizontal cooperation and norms of reciprocity because they will also have high confidence, to collaborate or cooperate and help each other[6].

Numerous programs are related to TB but have not yet provided comprehensive solution. The parties related to TB control will operate with their respective own programs. In addition to those programs, the prevalence of TB cases is still increasing. Many people also still think that TB is not a serious disease, just an ordinary cough so the risk of



transmission is very high. This study aims to reveal how the community is making efforts to manage tuberculosis with all their ability and resources in their place.

#### 2. Methods

## 2.1. Design

A qualitative descriptive studywas conducted in Tandes, the sub-district with the highest incidence of TB in Surabaya.

### 2.2. Participants

The participants of this study were selected using purposive sampling method including; 1 official heads of villages, 4 director of the community welfare and safety sub-district office, 3 community nurses who worked at the local public health center, and 18 community health volunteers and Local Health officer.

Inclusion exclusion criteria?

#### 2.3. Data collection

Data were collected from January to May 2019 in Tandes,. A total of 104 cases of TB were reported in 2017. The semi-structured interview questions focused on the influence of Community Perception on TB prevention, control and related experiences. The interviews focused on the participants existence?, role, experience, and connection to the community within TB prevention and control activities. the interview lasts 45 - 60 minutes for one-time data retrieval.

Interview guideline (brief but detail)

The community health workers were interviewed in their homes, and the sub-district officer and the community nurses were interviewed in their workplace to provide them with comfort and convenience. All interviews were recorded and transcribed for data analysis.

### 2.4. Data analysis

Interview data were analyzed using Uwe Flick[6]. The practical steps of analyzing and representing interview data were performed. Data analysis began with [1] reducing data

to locate and examine phenomena of interest. In this phase, the interviews were transcribed, and then the data were read and reread. The next phase was [2] reorganizing, classifying, and categorizing data, in which the researchers generated assertions about topics by reassembling and reorganizing the data, codes, categories, and stories. The last phase was [3] interpreting and writing up findings. In this phase, the researcher considered assertions and propositions in light of prior research and theory to develop arguments. Re- searchers developed stories that conveyed the main idea developed in the data analysis and presented data excerpts or stories to support assertions.

The stories were sorted to examine the existence of community based management on TB prevention and control.

#### 2.5. Ethical considerations

Ethical approval to conduct this study was granted by the Institutional Review Board Ethical Committee of Airlangga University No. 630-KEPK, the Regional Department of Health (Surabaya, Indonesia), and the Regional Department of National Unity, Politics, and Public Protection (Surabaya, Indonesia). All participants were provided with a participant information sheet written in Bahasa Indonesia, and they signed the consent form prior to participating in the study.

#### 3. Results

Below is the themes found from data analysis.

#### 3.1. Do for humanitarian intention

One of the forms of Community based management, which plays an important role in the efforts to eradicate TB, is Volounteer. In the Tandes sub-district, six volounteers worked in the two primary health centers (PHCs). The volounteers were responsible for the entire TB prevention and control program in the region and implemented it in their own PHCs. In overcoming health problems, especially TB, at the government level, there is an institution called the TB Task Force and for non-government TB elimination programs carried out by the Aisyiyah Organization. Both work together with puskesmas in conducting TB elimination programs. Social awareness is their basic foundation in working to reduce TB problems.

They said, "we want life to be beneficial for others. The rest is so important that sincerity and maintaining sincerity are difficult.(P1)

We are also happy if we come to the patient then the patient according to that, the patient is happy, we are also happy. also the name of humans must be beneficial to others too. (P2)

When I saw the patient not recovering and then broke up the medication, I felt unsuccessful in carrying out my duties, I felt sorry for why I could not make the person recover (P3).

Yes because of humanity, another is the intention to seek (religious) reward (P5)

I also do not know maybe it has been my destiny from time to time, I have always loved it. Although you never got anything, you can imagine making a posyandu serving green beans, its CHWs contributions, doing door to door was ridiculed by the person, then the door was closed, especially the some ethnic group. (P7)

# 3.2. Volunteer shortage

The problem of TB requires complex management involving all elements of the community and requires evaluation of successful treatment for quite a long time. Treatment is complete for 6 months and the ease of transmission of the disease, requires TB observers to carry out monitoring, mentoring and reporting that are really serious. The large number of TB Elimination programs is not balanced with the needs of existing labor or human resources.

... yes until now, even now the active CHWs are old. I remember there was a very old CHWs from an area, the oldest CHWs here was someone who was 65 years old and his condition was very healthy (P1)

at most because of laziness, fear... Most are afraid. for example.....among 10 people who are active only me. there are often people who say Ouch I can't eat two days if there is phlegm it's make me feels nausea... even though (phlegm) it's already closed, yes but I imagine it's still there... I can't be a CHWs (P2)



# 3.3. Covering the myth and stigma

The wrong prejudice about TB is still a probelm that is very difficult to dispel. some people still believe that people with TB must be excluded, or should be ostracized, because they know that it's an infectious disease that's hard to cure. the role of health volunteer is very important, one of which is to cover up this stigma not to spread misinformation to the wider community.

it is just counselling, so every opportunity is made to do counselling especially if there is a tuberculosis patient in that area, but we cannot open that such person is a TB patient, so usually if there is a neighbour asking that patient, no, we just do this counselling so that it is no health problem. (P9)

... this is just for neighbourhood, For example, I want to go to A, I don't go directly to A, but to the neighbour first, there are many people who think negatively, so I go to the neighbours first.... People were afraid, especially if there is someone from the puskesmas or from health officer, so they immediately close the door. (P14)

know but don't want to say that he was (TB patient)... "what have you been sick of even though the puskesmas had told me the disease... I continued to visit in two weeks. "How's the medication, is it already done? Is that fine?" It is okay. "That means I don't know about the disease so much" when in the beginning I knew. Pretend that i don't know. It will Keeping him (TB patient) shy. In fact, it will be nice if he shares it later. (P15).

# 3.4. Providing social and economic support

The Surabaya Health Office has provided free medical assistance to TB patients. In addition to the assistance of giving drugs without paying expenses, TB patients also get free nutritional intake in the form of formula milk given when patients take drugs at the Puskesmas. Other parties who also provided material assistance for underprivileged TB patients were Aisyiyah, in the form of 30,000 in cash. But in reality the support is still considered lacking.

The Voulunteers said, "There are those whose economic conditions are very difficult, the puskesmas also needs to ride a pedicab, but there is also funds from the SSR during treatment, only once," P1 (cadre).

Sometimes if you see something like that, the cadres' own initiative is mas, so we give you something, bro. The point is trying to be concerned, there is a distribution of our basic necessities for the sick patient with P1 TB (cadre).

"Once, when I was OK, then I gave 25,000 people money, and I didn't feel very happy. (P2)"

The Nurse Said, "Yes, we are still on a social mission, which we complain about is usually we have a visit while we have not been able to give transport money so we also usually hesitate if we have to ask" why haven't you visited this?" (P4)

In Tandes Subdistrict there is still no specific counseling program about TB. This is because TB is still not a priority in community problems. The main TB program is the door knock and cakning program where this program is a program with a ball picking approach or visiting the community one by one to be given counseling and looking for TB suspects. But with the constraints that not all communities receive TB health programs, not all levels of society get counseling about TB disease. So an effective way to provide counseling with the participation of many people is through community social groups.

The Voulunteers said, "in the recitation, PKK meetings and also at the puskesmas when there is counseling for us to give brochures about TB, so later if they go back to the RW they can transmit the knowledge they get through the brochure.'(P3).

Actually, if you look at the condition of TB patients it seems that what they really need is a decent life because all this time we know, even though there are some patients who are already living well, most of them do not live properly from the side of their residence, because they become patients and after they recover it should be given a job, meaning that given the work that does not require or spend a lot of energy. while there are still children who still need their living expenses, which means economic problems, yes, most of them are in economic problems. (P1)

"If there is an automatic posyandu, if there is a posyandu, even though they are not active in community activities, the posyandi is definitely going to participate, yes, the opportunity for us to provide information is also helped by the RT" (P11)

Those who are still on treatment, we still see the main help, how come oh, this mother still needs assistance, if there is no family as Drug swallowing supervisor PMO, I will assist to take medicine and deliver the medicine to patients the house (P12)

#### 4. Discussion

Evidence from this study proves that community-based approved programs are also acceptable. WHO has issued community-based DOTs to complement health-based DOTs in the high burden of TB, resource-limited countries [7]. Until the patient and community attitudes and perceptions of the community and health facility-based DOT discussed and calculated with this assistance will not be carried out with success.

The findings make the drug cadres and supervisors almost unforeseen women and family members. The responsibility of sick family members in most areas of Surabaya is defined as the role of women [8, 9]. The idea because families cannot participate because of DOT is because culture, family or family relationships are not proven in our study. Even though, that is support patients satisfied with them as supporters of care. Studies conducted elsewhere indicate family members are DOT that effectively supports treatment [10, 11]. A study conducted in Indonesia, however Australia, did not show benefit in using family members supporting DOT treatment [12].

The context in Australia may be different from Surabaya where large family members are an important part of social networks. In Surabaya and Indonesia at the time of the care of family members taken as family members who were moved inside local culture and values [13]. Members of the caregiver family for chronic diseases such as HIV / AIDS and there is no reason not to believe this phenomenon will be different in TB cases [14]. Future studies should consider the impact of care on TB treatment and how it affects family relationships.

It is very supportive for research in our study that supports motivation to support care by carers and former TB patients for reasons of altruism. The majority of patients can also support other TB patients after completing treatment. This The findings are important for two main reasons: first, it shows the potential for using former TB patients in TB control activities. In one study, former TB patients found to be an important source of information for TB Patients [15]Former TB patients can also help TB patients and the TB community can indeed be cured. This is very important in Tanzania where many people do not have enough knowledge of TB and delay in seeking treatment [16] the national TB program needs to address this problem based on available local resources.



#### 5. Conclusion

Our findings provide a valuable agreement for the effective implementation of relevant, sensitive and acceptable TB control interventions for the needs of patients and society in general. Community-based TB Program is a viable option and can be built based on health facilities in DOTS, especially in developing countries such as Indonesia where the health system is overwhelmed by increasing the number of TB and HIV / AIDS patients. The community-based TB Management must be seen as a complement? and perhaps a substitute for a national TB activity program.

# **Funding**

The author(s) received financial support for the research from the Ministry of Research, Technology, and Higher Education, Directorate General of Resources for Research, Technology and Higher Education of Indonesia as at the expense of PDUPT

# **Acknowledgments**

The author(s) would like to thank the grant is provided by the Ministry of Research, Technology, and Higher Education, Directorate General of Resources for Research, Technology and Higher Education of Indonesia for providing this research, Faculty of health Sciences, University of Muhammadiyah Surabaya, and Research Center Department of University of Muhammadiyah Surabaya

#### **Conflict of Interest**

The authors have no conflict of interest to declare.

#### References

- [1] Depkes. (2016). *Pedoman Nasional Penanggulangan Tuberkulosis*. TB -PERSI Indonesia.
- [2] Kesehatan PKS. (2016). *Profilkesehatantahun 2016*. Surabaya: Dinas Kesehatan Kota, pp. 31–40.
- [3] (2018). *Profil Kesehatan Kota Surabaya Tahun 2017*. Surabaya: Dinas Kesehatan Kota Surabaya.

- [4] Field, J. (2008). Social Capital. Routledge, p. 193.
- [5] Kawachi, I., Subramanian, S. V. and Kim, D. (2008). Social Capital and Health. In *Social Capital and Health*. New York: Springer New York, p. 1–26.
- [6] Flick, U. (2014). The SAGE Handbook of Qualitative Data Analysis.
- [7] Dheda, K., Barry, C. E. and Maartens, G. (2016). Tuberculosis. The Lancet. New York
- [8] Escott, S. and Walley, J. (2005). Listening to those on the Frontline: Lessons for Community-Based Tuberculosis Programmes from a Qualitative Study in Swaziland. Soc Sci Med., vol. 61, issue 8, pp. 1701–10.
- [9] Kusimo, O., et al. (2015). Perceptions of Community Members on Tuberculosis and its Effect on Health-Seeking Behavior in Nigeria. Int J Mycobacteriology, issue 4, p. 61.
- [10] Massey, P. D., et al. (2012). TB Questions, East Kwaio Answers: Community-Based Participatory Research in a Remote Area of Solomon Islands. *Rural Remote Health*, issue 12, p. 2139.
- [11] de Vries, S. G., et al. (2017). Barriers and Facilitators to the Uptake of Tuberculosis Diagnostic and Treatment Services by Hard-To-Reach Populations in Countries of Low and Medium Tuberculosis Incidence: A Systematic Review of Qualitative Literature. *Lancet Infect Dis.*, vol. 17, issue 5, pp. 128–43.
- [12] Main, S., et al. (2019). Training for Tuberculosis Elimination in Indonesia: Achievements, Reflections, and Potential for Impact. *Trop Med Infect Dis.*, vol. 4, issue 3, p. 107.
- [13] Craig, G. M. (2015). The Social Context of Tuberculosis Treatment in Urban Risk Groups in the United Kingdom: A Qualitative Interview Study. *Int J Infect Dis.*, issue 32, pp. 105–10.
- [14] Sissolak, D., Marais, F. and Mehtar, S. (2011). TB Infection Prevention and Control Experiences of South African Nurses A Phenomenological Study. *BMC Public Health.*, vol. 11, issue 1, p. 262.
- [15] Okeyo, I. and Dowse, R. (2016). Community Care Worker Perceptions of their Roles in Tuberculosis Care and their Information Needs. *Heal SA Gesondheid.*, issue 21, pp. 245–52.
- [16] Wandwalo, E. R. and Mørkve, O. (2000). Delay in Tuberculosis Case-Finding and Treatment in Mwanza, Tanzania. *Int J Tuberc Lung Dis.*, vol. 4, issue 2, pp. 133–8.