

A QUALITATIVE STUDY ON INTERACTION BETWEEN PULMONARY TUBERCULOSIS PATIENTS AND THE ROLES OF TREATMENT OBSERVERS (PMO) IN MAJALENGKA DISTRICT

(Studi Kualitatif Deskripsi Interaksi antara Peran Pengawas Minum Obat dengan Pasien TB Paru di Kabupaten Majalengka)

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ABSTRAK

Latar Belakang: Lebih dari dua miliar penduduk (sekitar sepertiga penduduk dunia) diduga terinfeksi *Mycobacterium tuberculosis*. Salah satu penyebabnya adalah banyak pasien yang menerima self-administered pengobatan tidak patuh. World Health Organization (WHO) telah merekomendasikan strategi Directly Observed Treatment, Shortcourse chemotherapy (DOTS) untuk pengendalian TB dengan melibatkan "Pengawas Minum Obat" (PMO). Tujuan penelitian adalah untuk mengidentifikasi faktor-faktor yang mempengaruhi interaksi antara pasien dan PMO guna meningkatkan kualitas kepatuhan menurunkan angka TB. **Metode:** Desain penelitian adalah eksploratif dengan pendekatan kualitatif. Kabupaten Majalengka dipilih sebagai daerah penelitian karena memiliki persentase kedua tertinggi Baksil Tahan Asam (BTA) positif TB di Jawa Barat pada tahun 2000. Informasi diperoleh dari informan yang terdiri atas PMO, pasien TB, pelaksana program TB tingkat kecamatan Kadipaten, kepala Puskesmas Kadipaten, dan penanggung jawab program TB tingkat Kabupaten majalengka (Wasor). **Hasil:** Studi menunjukkan bahwa keberadaan PMO memiliki hubungan yang signifikan dengan hasil akhir pengobatan. Sebagian besar pasien mengakui bahwa keberadaan PMO sangat membantu untuk lebih "patuh" (compliant) dan mengurangi risiko kebosanan selama pengobatan. **Kesimpulan:** Kriteria terpenting dalam memilih PMO yang mempunyai hubungan dekat dengan pasien sebaiknya anggota keluarga atau kombinasi antara anggota keluarga dengan bukan anggota keluarga. Demikian juga, PMO yang berasal dari kader kesehatan atau petugas kesehatan menunjukkan pemahaman mengenai TB yang lebih baik daripada PMO yang berasal dari anggota keluarga. Penelitian memberikan saran bahwa promosi kesehatan harus menjadi program prioritas karena memberikan kontribusi terhadap penyebaran informasi tentang program dan pengobatan TB. Pembekalan pengetahuan TB harus diberikan kepada anggota keluarga terutama yang berperan sebagai PMO.

Kata kunci: Pengawas minum obat (PMO), tuberkulosis, studi kualitatif

ABSTRACT

Background: More than two billion people (about one-third of the world population) are estimated to be infected with *Mycobacterium tuberculosis*. One of the causes is the drop out from treatment because many patients do not adhere receiving self-administered treatment. World Health Organization (WHO) has recommended Directly Observed Treatment, Shortcourse chemotherapy (DOTS) strategy to control TB that involves "treatment observer" (PMO) to supervise patients in swallowing tablets. The purpose of the study is to identify factors influencing the interaction between patients and treatment observers for improving the quality of patient's compliance in reducing tuberculosis rate. **Methods:** Study design was exploratory with a qualitative approach. Majalengka district was chosen as a study area because it was ranked as an area where having the second highest percentage of smear-positive pulmonary TB in 2000. Information was obtained from treatment observers (PMOs), TB patients, coordinator of TB control program at Kadipaten Sub District, the head of Kadipaten Health Center, and coordinator of TB control program in Majalengka District called "wasor". **Results:** This study showed that the existence of PMO has significant relationships with the result of treatment. Most of patients admitted that having PMO's assisted them to be more compliant and reduced the risk of boredom likely to be encountered during treatment. **Conclusion:** The most

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criterion to choose PMO should be a close relationship with the patients whether they came from family member or non family member. The PMOs who came from voluntary health cadre or health provider showed a better understanding about TB disease and treatment than those are from family members. The study suggest that health promotion should become a high priority since it has contributed to the effectiveness of spreading the information of TB control program. Debriefing knowledge of TB should be given to family members particularly who becomes PMO.

Key words. *Treatment observer, tuberculosis, qualitative-study*

Naskah Masuk: 19 September 2012, Review 1: 21 September 2012, Review 2: 21 September 2012, Naskah layak terbit: 31 Oktober 2012.

INTRODUCTION

More than 2 billion people (about one-third of the world population) are estimated to be infected with *Mycobacterium tuberculosis* (Horsburgh). Tuberculosis (TB) is out of control in many parts of the world. In response to the World Health Organization (WHO) in 1993 declared a global emergency, pointing to the need to take prompt action to strengthen TB programs globally (Pinet, 2001). According to several researches conducting by several agencies and institutions, it was found that an estimated 8.4 million new tuberculosis cases occurred in 1999, up from 8.0 million in 1997. If this trends continue, 10.2 million new cases are expected in 2005 (WHO, 2001).

In South-East Asia Region, including Indonesia, about 38% of the world's eight million new cases of TB occur every year. TB causes death and prolonged suffering for millions of men, women and children. Seven-hundred thousand people in this region die every year because of TB (Rafei, 2001). The annual risk of TB infection in South-East Asia is 1 to 2.5 percent. This represents an upward trend. In Indonesia, there are at least half a million new cases of TB per year and 175,000 deaths (Jongh, 2001).

The government of Indonesia has several strategies to interrupt the chain of transmission of the disease. One of the biggest problems with tuberculosis control is the drop out from treatment regimes because many patients receiving self-administered treatment will not adhere to treatment. The strategy which was recommended by WHO (1995) to control TB is called Directly Observed Treatment Shortcourse (DOTS). This includes a system of regular supply of all essential anti-tuberculosis drugs. It also involves a supervisor watching the patient swallowing the tablets. The role of the supervisor, called "treatment observer" of "PMO" focusing to this study.

Indonesia has committed to undertake the DOTS strategy since 1995. The expansion of DOTS has

been successful after the government of Indonesia recommitted itself to TB control in 1999 under "GERDUNAS TB"- a nationwide effort to mobilize a diversity of forces against tuberculosis.

In West Java Province, the prevalence of pulmonary tuberculosis (PTB) was increasing every year. Based on health center report, the prevalence was 53,691 in 1995 and became 257,894 cases in 1999. Hospital record showed that the prevalence was 69,085 in 1995 and became 79,900 cases in 1999.

Majalengka District as a part of West Java Province was a second high rank in percentage of new sputum smear positive pulmonary TB patients in 2000. The incidence rate of TB in Majalengka District was 62/100,000 (year 2000), therefore Majalengka District has been chosen as an area for a TB intervention program under the Intensified Communicable Disease Control (ICDC) project and as study area for this research as well.

This study examined the relationship between PMO and patients of TB. There are several factors which influenced TB patients to comply the treatment. This study identifies this factors and relationship among factors in order to develop an effective program for reducing tuberculosis rate.

This study could be beneficial for policy makers in planning tuberculosis control programs, and in formulating a policy to improve the training, supervision and effectiveness of PMO.

METHODS

The study design was *cross sectional* with a qualitative approach. The type of data collected in the study area was mostly primary data collected directly in the field through in-depth interviews. Secondary data were collected from the health service office of Majalengka District and the health centre of sub district.

Population targeted were people involved in the DOTS program and health provider of the 7 villages in Majalengka District. Key informants for this qualitative study consisted of 3 groups of treatment observers with their patients i.e. first, a group of health cadre and their patients; then, a group of health providers and their patients; and lastly group of the family and their patients. For each group 3 treatment observers were selected, making a total of 18 people. Other contributing informants were the head of health centre or “Kepala Puskesmas” (1 person), the TB health provider at the health centre (1 person), and the TB health provider at district level or “Pengawas Supervisor (Wasor)” (1 person). All these key informants were indepth interviewed by researchers.

There are two groups which are interviewed for exploration: TB patients and PMO. Information collected from TB patients were: knowledge about medicine, perception of health provider, perception of drug taking observer (PMO), beliefs about health and illness, and health seeking behavior. Information collected from PMO were: knowledge about medicine and treatment, experience and workload and activities of the PMO. Those all factors were examined to identify the interaction between patients and PMO, then to determine what were their influence for complying with TB treatment.

RESULTS

Concerning the Availability of Tablets

Apart from confirming that the tablets for their medication were available at the health centres, all treated patients also realized the importance of taking those tablets regularly. This practice has been sustained successfully as a result of highly commitments of the patients, the PMOs and health providers in the study site.

In relation to picking up the tablets from the health centres, almost all patients interviewed said that their PMOs picked up the tablets for them. However, in a rare occasion where the PMOs had other more crucial activities or could not be present on time of medication, the patients themselves had to fetch the tablets from the nearby health centres.

Knowledge, Attitude and Practices of TB Patients

Most patients had sufficient knowledge about the treatment particularly the importance of having to stick with the treatment program for at least six consecutive months. Almost all patients regularly took all their tablets one or two hours after dinner. Some of them were fully aware of the health consequences if they broke the treatment cycle. They realized that if they ever break the cycle, the TB bacteria would become resistant.

Contrary to the initial positive attitude displayed prior to medication, most patients had negative feelings about the treatment they received which was largely due to the various side effects that occurred when they began taking the TB tablets. These effects include: headache, itch, breathing difficulty and change of urine colour. However, all patients persisted and forced themselves to continue the medication despite these reactions because they want to recover from TB disease.

The desire to get well was the main reason which motivate them to follow the treatment. However, many of them were not also intrinsically motivated and therefore, had to be encouraged by others such as nurse, GPs, health centre officers, neighbours and family.

Home visits by health provider as part of the DOTS strategy also boosted the patients' motivation to get through their medication. The patients who were visited expressed their gratitude since they were encouraged to get well. Unfortunately, not all patients had the good fortune to be visited by health providers. A patient stated that lack of reliable means of transport and shortage of time was possibly the primary reasons why health providers could not visit all patients.

During the visit by treatment observers, patients also received additional information concerning their health that was given by the health provider through health education on TB printed materials. These may include brief information about TB and how to prevent it.

All patients stated that they were feeling better after they were visited by their treatment observers. They felt that having PMO assigned to monitor the medications had a significant effect to their overall

motivation to get well. Most patients stated that they prefer to have family members as their PMO rather than health cadres or health providers. However, there are still a number of them who need the combination of both, the reason being that the PMO who are related to the patients often have insufficient knowledge about the wider aspect of the treatment and health in general. As explained by a patient who said:

"I think Mr. X is the proper PMO because he does not only understand TB disease, but also works as health provider at the health centre as well. In addition, he also has a close relationship with people here. I think he is better than those health cadres".

Although most patients have their close relatives as their PMOs, some of them show lack of respects when they are being counseled or given new information about their well-being.

Since lack of knowledge or information about TB, patients with TB symptoms such as regular cough or even coughing accompanying by blood, only used over the counter (OTC) medicines. Others choose to seek alternative medication by using herbal medicine. Most of them did not know the serious level of symptoms, nearly all patients admitted to feeling much better afterwards and therefore, stopped taking the medicine. The patients' health condition become so deteriorated because of that. If the case become so serious, i.e. often coughing accompanying by blood regularly, they start to realize that professional help is needed. Accordingly, several of them visit private doctors. It was quite expensive and sometimes they cannot afford it. They did not know about a free medication of TB in health centre, until doctors or other health officers inform them.

Knowledge, Attitude of PMOs

Regarding with the PMOs, if the patients cannot choose the observers themselves, the health providers choose the PMO for the patients. In other case, a PMO was selected prior to patients taking medication. Once selected, each PMO has the responsibility to see the patients through the entire treatment cycle. Following the selection process, all assigned observers were then trained by professional medical staff to ensure that the treatment will be done properly.

The main duty of PMO is to ensure the patient compliance by taking medicines proper and appropriate

use, by observing the patients taking the tablets and picking up the tablets at the health centre. PMO are also required to introduce additional information about leading a healthy life given by health providers. Unfortunately, PMO from family did not understand what they were supposed to do when they were asked to pass on these new pieces of information to the patients.

Being PMO is a voluntary job and they have showed to their commitment to carry out the responsibility in doing so for a number of reasons, for instance caring for their family member, or by the name of humanitarian reason.

When the tablets are run out, additional tablets are mostly picked up by PMO. However, if PMO occasionally has other engagements and cannot deliver the tablets, other ways are taken to ensure the patients to get their tablets. The patients will have to fetch the tablets themselves or the health provider will deliver the tablets to PMO's house if the PMO is too busy.

When PMOs go to health providers to pick up the tablets, they can use this opportunity to seek further advise from the health providers about solving various problems related to their duty and acquiring new information related to the cure and methods of preventing TB.

The most difficult problem faced by PMO is when they have to gently persuade the "uncooperative" patients to take the tablets. He (She) stated he (she) could not convince his (her) patient to take all of the medication fully, because he could not visit and observe his patient daily due to his other responsibilities.

In order to get close to the patients, PMO should observe without frighten the patients. A health provider stated:

"I think first of all do not frighten the patient, but approach them gently. If they distant themselves from us, they will not explain their problem to us, and they will hide everything. They will feel embarrassed and reluctant. So as health officer, I do not wear uniform, I just put on casual clothes. PMOs must be flexible and should not frighten the patients..."

Another one stated that PMOs must be patient and willing to pay attention to the patients.

Tuberculosis is already a common term among the people. Those people have also realized that this is

indeed a very dangerous disease. Information is very important in raising awareness of TB, and the desire of people to listen to the radio is still high. It is very effective to disseminate the information by radio.

The results shown that the existence of treatment observers has significant relationship with the end result of treatment. Patients admitted that having PMO assisted them to be more compliant and reduced the risk of boredom likely to be encountered during treatment.

The shortcomings of the relationship occurred in various forms such as lack of financial assistance from relevant institutions to cover the operational duties, lack of training for family PMO and time constraints of PMO to carry out their duties.

DISCUSSION

Tuberculosis is already a common term among the people in and around Majalengka District. They have also realized that this is indeed a very dangerous disease. Unfortunately, some did not realize that they got infected initially and were only aware of the situation when their health is getting worst.

Information is very important in raising awareness of TB, and the desire of people to listen the radio is still high, so dissemination of information by radio can be very effective.

Once treated, the patients knew the major details of the treatment. They realized that duration of the medication will take around a 6-month period and all of the medication had to be followed strictly. Although it is clear that the medication is designed to cure the patients, many of them still did not take it cooperatively because of the common side effects. Reider (1999) mentioned several side effects of intermittent therapy, which is a "flu" syndrome. However these conditions did not change the attitude of patients to continue taking the medication. This is because TB health workers at health centres had warned all patients, prior to taking the medication, that once a TB tablet was taken they had to complete the treatment cycle, otherwise they will have risk the development multi-drug resistant tuberculosis (MDR TB).

Although most patients are familiar with tuberculosis, many of them did not directly seek professional help, but rather found their own solution by using over the counter medicine or taking traditional herbal therapy in an effort to alleviate the symptoms.

This type of action was taken primarily because of limited financial resources and partly because of socio-cultural reasons. In addition, the lack of information about the availability of free medication at health centres was partly responsible in preventing TB patients from being treated sooner.

The relationship between treatment observer (PMOs) and TB patients, as can be seen as the mutual relationship. From PMOs perspectives, their main duty is to ensure the patients take medication properly and pass on extra information from health providers to patients and community in regards to healthy life. Since TB program was supported by head of Majalengka District, PMOs felt pride to involve in this TB control program. Their credibility will increase in the community as they were recognized as a pioneer and may improve their future job prospects. From patients perspectives, they feel more confident following the medication with the existence of PMOs because PMO can help them comply with the whole process of medication. They respect their PMOs because they realize that being a PMO means doing a totally voluntary job. PMO also helps to broaden patients' horizons and knowledge. Getting a free medication is the other benefit that TB patients can enjoy if they have PMOs.

Although the overall rate of dropping out patients is low, without a PMO the effect will be detrimental because the patients tend not to comply instruction to take medication regularly. This patient's disobedient might cause multi-drug resistance (MDR); the situation where mycobacterium tuberculosis resistant to become MDR. This study also found that there were 2 patients who had experienced drop out when they were prescribed medication by a private general practitioner. They complained the medication was very costly.

In terms of performance, although most of patients prefer to choose the PMOs who come from their family, in reality, the patients show more respect to the PMOs who come from cadres and health providers. However, it does not mean that the patients will not comply taking tablets, if their family is chosen as PMO. A possible explanation for this is patients feel that those PMOs who are not in one way or another related to them, tend to observe with more serious gestures and create a more serious atmosphere.

Sometimes the patients show uncooperative behavior when reminded to comply, especially

those patients whose PMOs came from the family. However, most PMOs agreed that whatever it takes, the importance of attitude of patients will at the end influence the sustainability of medication, as stated by Notoatmodjo (1993) that the attitude without knowledge and awareness will not be sustained longer.

The study showed that the existence of PMOs has a positive relationship with the rate of compliance. PMOs are not only providing positive motivation, but also assist them to be persistent in following the treatment despite having the comfortable side-effects at the beginning.

CONCLUSION AND SUGGESTION

Conclusion

For PMO selection, the most important criterion is to choose PMOs who have a close relationship with the patients. This can be patient's family member or a combination of a family member and a voluntary health cadre or health provider. PMOs who came from the family were highly motivated to make sure their patients get well and always available, whereas PMOs from health centre had better knowledge but were less available to the patient.

Factors that motivate to become PMO is enthusiasm to help TB patients and community standing in their environment as pioneer. While factors motivate the PMO to regularly pick up the tablets for the patients is a good assistance from health provider and having a close working relationship.

Patients' opinion about the work of PMO is positive. High dedication of PMOs and the proper implementation of their duty could influence the compliance of patients to follow the specified medication. The compliance of patients is primarily based on high motivation to be free from TB.

Suggestion

This study has several suggestions, *firstly*, a more effective means of telling people about free medication given at health centre is essential to reduce the number of TB patients; *secondly*, financial incentives are recommended for PMOs to recompense them for their time and costs and enable them carry out their duties better; *lastly*, training should be given directly to family members, and not limited to cadres and health workers only.

ACKNOWLEDGEMENT

I wish to thank many people who have supported throughout this process and the staffs health service of Majalengka District, especially Mr. Dede Supranoto for his accompanying in collecting data and processing this article.

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