# **Problems of Treatment and Management of Tuberculosis**

By: Neti Juniarti, S.Kp., M.Kes., MNurs

Faculty of Nursing
Universitas Padjadjaran
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By: Neti Juniarti, S.Kp., M.Kes., MNurs

Lecturer of Community Health Nursing Department

Faculty of Nursing Universitas Padjadjaran

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Acknowledge by:		
Dean,		

Hj. Helwiyah Ropi, S. Kp., MCPN. NIP. 140067327

## **Problems of Treatment and Management of Tuberculosis**

TB becomes a major problem in the world because it can affect physical, economic, social, and mental health condition of the patient. According to WHO (2002), poverty, a lack of basic health services, poor nutrition, and inadequate living conditions all contribute to the spread of TB. In turn, TB can create and worsen poverty in many countries because the average TB patient loses three to four months of work time with total lost of earning up to 30% of annual household income. Some families lose 100% of their income because of death or permanent defect as result of TB. TB is estimated can reduce the incomes of the world's poorest communities by a total of US\$12 billion per year (The Global Fund, 2005).

TB also has impact on women and children. TB is a leading cause of death among women of reproductive age because woman is less likely to be tested and treated for TB than man (The Global Fund, 2005). More women tend to default from medication, and men tend to have high cure rate rather than women. One of reason for this because fewer women come to clinic and they use most of their time to take care of family rather than to take care their self. TB also can give more emotional and social burdens to women and children (Weiss, et al. 2006). Over 250,000 children die every year of TB because children are vulnerable to TB infection as result from frequent household contact. Children also suffer when their parents are infected. Every year in India alone, more than 300,000 children leave school because of their parents' TB (The Global Fund, 2005).

'TB is responsible for considerable direct and indirect costs to individuals and society' since TB affected the most productive and economically active segments in community (WHO, 2002). Direct costs include paying for visits to clinics, test, and drugs. Indirect costs including additional nourishing foods, absent from work, and transport to and from clinics, lost household income and production, adverse impact on health and education. This indirect cost can become major problem for poor households (The Global Fund, 2005). With a good management program to control TB, it can give financial benefits

which can reduce direct and indirect cost, reduce poverty and promote development of society because productivity is increased (WHO, 2002).

#### Side effect of anti-TB medication

Side effect of anti Tb medication are rare, if there is side effect it is usually mild and patients should not stop the treatment. Some mild side effect of anti-Tb medication is skin rash, flu syndrome, and stomach ache syndrome such as nausea, vomit, sometimes diarrhoea; mild pain in joints; myalgia; and tinnitus (WHO, 2003).

#### **Treatment problem**

Tuberculosis difficult to control because the amount of medication and long treatment at least 6 months so that sometimes after two or three months of treatment patients stop the treatment because that felt better already. Other factors that caused patients stop the treatment before the time frame are financial factor, personal problem, loss of job, afraid of isolation from family, friends or neighbours. These problems are difficult for patients, however it is important to find some ways to increase patient's adherence to complete the treatment (Crofton et al.1992).

DOTS strategy with community based and patient oriented are the right way to address Tuberculosis issues (Thomas, 2002). In order to do community based and patient oriented strategy, it is important to recognize cultural differences in community (Sarwono, 2001) including stigma and cultural beliefs related to TB treatment and family support to TB patients (Helman, 2000). Cultural factors could become causal factor, contributing factor or protective factor when related to disease including economical status, family structure, gender, age, educational level, employment status, and culturogenic stress (and nocebo effect) (Helman, 2000). Culturogenic stress is beliefs, values, hopes, and practice of certain culture that have tendency to increase amount of stressor. Nocebo effect is negative effect from belief and assumption toward health (Helman, 2000).

According to Helman (2000), there are two major obstacles to the success of Tuberculosis control which are delay to seek treatment and ignore/leave the treatment before it really effective. Cultural beliefs about the importance of early symptoms of tuberculosis play an important to this treatment. For example, a study in migrant worker in California found that there were significant delay (approximately 8.5 months) between onset of symptoms and decision to consult with doctor. Most of them misinterpreted early symptoms such as cough, fatigue, weight lost, back pain, or common cold as evidence from less serious

condition. Most of them related the fatigue and weight lost as result of working too hard and not enough sleep, and when early symptoms present they do self-treatment by reducing cigarettes and alcohol consumptions, sleep early, using medication, and do what they think as healthy life style (Helman, 2000).

Further reason for delay in seeking TB treatment (include ignore treatment) is stigma that related to this disease. A study in Mexico reveals that 52% TB patients after discharge from hospital were not allowed to come home by their family because they did not like the disease; another study shows that many patients ignore their medication because of family disintegration, fear of rejected by family (25% defaulted patients did not tell their family about their diagnosis). Since the success of treatment completions have strong relationship with social support from family, stigma that related to tuberculosis has become one of reason for the failure of tuberculosis control.

Another reason for the failure of tuberculosis control program related to health service system itself and the way of management of tuberculosis clinic. For example inappropriate time of appointment, repeated registration every time patient visit the clinic, waiting room that full of patient with less ventilation, rigid way in locking TB patients (and ignore unusual condition), and doctor using technical jargon when talk to patient. These conditions can contribute to patients reluctant to come to the clinic for treatment or follow-up (Helman, 2000). Edginton, et al. (2002) suggests that health professionals should identify and learn local beliefs that can influence patient's compliance to complete tuberculosis medication.

# Stigma related to tuberculosis

Nowadays, there were increased of interest from health professionals and public health practitioners about the concept of stigma because it contributes to the burden of illness and it influences the effectiveness of case finding and treatment as major interests of disease control. Stigma also becomes an important aspect of many chronic diseases and health problems throughout the world which more vulnerable for marginalized people because they are stigmatized for other reason that may contribute to social disadvantage or discrimination, for example: poverty, ethnicity, and sexual preferences. (Weiss, Ramakrishna, and Somma, 2006).

## Definition of stigma

It is difficult to make a clear definition of stigma because it is an abstract concept. The following are some definitions of stigma:

- 'Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was
  cut or burned into the skin of criminals, slaves, or traitors in order to visibly
  identify them as blemished or morally polluted persons. These individuals were to
  be avoided or shunned, particularly in public places. The word was later applied to
  other personal attributes that are considered shameful or discrediting.' (Healthline
  Network Inc., 2007)
- 2. Stigma is defined by Goffman (1963) as the phenomenon whereby an individual with an attribute, which is deeply discredited by his/her society, is rejected as a result of the attribute' and that reduces the bearer from 'a whole and usual person to a tainted, discounted one'. Stigma commonly results from a transformation of the body, blemish of the individual character, or membership of a despised group.
- 3. Stigma is the attachment of negative stereotypes to, and production of accompanying negative feelings about a person or issue, usually associated with certain health problems (Ganfyd, 2007).
- 4. 'A social process to be understood in relation to the concepts of power, domination, and difference. It is a proces worsening already existing inequalities and exclusion' (Parker & Agleton, cited in Macq, Solis, & Martinez, 2006).
- 5. 'Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social about a person or group'. This judgment is based on a health problem or health related condition, and sometimes medically unwarranted. The discriminatory social judgement may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgements about enduring features of identity apart from health-related condition (e.g., race, ethnicity, sexual preferences), may also affect health'. (Weiss, Ramakrishna, and Somma, 2006).

In short definition, stigma is a social process which gives mark, sign, or attribute to individuals which characterize by deeply discredit, negative stereotype, exclusion,

rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social about a person or group.

Since the stigma has various range of definition, indicators is needed to determine wether a person or a group of person suffering from stigma. There are ten things that indicate a person or a group of person received or experience the stigma regarding to TB which are:

- 1. Hide disease and Reluctant to disclose the problem (Atre et al. 2004; Weiss, Ramakrishna, and Somma, 2006)
- 2. Think less of self and diminished selfesteem (Atre et al. 2004 Weiss, Ramakrishna, and Somma, 2006)
- 3. Community think less of patients, and other local disease- and setting-specific indicators of the denial of full social acceptance (Atre et al. 2004; Weiss, Ramakrishna, and Somma, 2006)
- 4. Community think less of family and social impact on family (Atre et al. 2004; Weiss, Ramakrishna, and Somma, 2006)
- 5. Hurting behaviour (Atre et al. 2004)
- 6. Problems in arranging marriage, problems in current marriage, problems in family to marry (Atre et al. 2004; Weiss, Ramakrishna, and Somma, 2006)
- 7. Exclusion or rejection from school, work, social groups and activities (Weiss, Ramakrishna, and Somma, 2006)
- 8. Blame and devaluation (Weiss, Ramakrishna, and Somma, 2006)
- 9. Spouse support (Atre et al. 2004)
- 10. Economic impact (Weiss, Ramakrishna, and Somma, 2006)

## Type of stigma

The term of stigma has a doubt perspective which is problems with discredited behaviour—the person assume other people is already known about his disease, and discreditable perspectives where the person assume no one know about his disease. In general, there are three different types of stigma. First, here are various physical deformities that dislike by other people. Next there are mark of individual character

perceived as weak will, unnatural passions, rigid beliefs, and dishonesty which is being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, and radical political behaviour. Finally, the tribal stigma of race, nation, and religion which can be transmitted through lineages and equally contaminate all members of a family. In all of these various instances of stigma, an individual might have been received easily a trait that can stick out itself upon attention and turn other people away from him (Goffman, 1963). Another type of stigma is based on social discrimination and on fears arising from self-perceived stigma (Weiss, Ramakrishna, and Somma, 2006). Stigma may refer to enacted, perceived or anticipated social judgement because of disqualification of individual from full social acceptance (Goffman, 1963; Weiss, Ramakrishna, and Somma, 2006).

Even though Goffman's theory about stigma is widely used, according to Weiss, Ramakrishna, and Somma (2006), at least three substantial limitation the utility of Goffman's formulation of stigma for applications to health esearch and policy, and especially to health problems in low-income countries. This limitation including (a) the language and taxonomy of abominations, blemishes and tribal identities is out-of-date, (b) the range of phenomena is so vast that the concept fails to adequately address health-related interests of social and health policy, (c) the conceptual framework based on normalcy and deviance is both inadequate and inappropriate for cross-cultural research and policymaking, and implications to recognition and appreciation of multicultural societies and multiculturalism (Weiss, Ramakrishna, and Somma, 2006).

# Impact of tuberculosis stigma

Stigma of infectious diseases such as TB has common and typical features which could lead to considerable impact on the understanding of illness, care-seeking and treatment adherence for TB. The impact of TB stigma has also been reported in low- and middle-income countries including West and East Africa (Weiss, Ramakrishna, and Somma, 2006).

Stigma is an important consideration for social and health policy and for clinical practice because the emotional impact of social disqualification and the impact of the meaning of the disease may be as great or a greater source of suffering than symptoms of the disease, for example: stigma may delay appropriate help-seeking or terminate treatment for treatable health problems, and hearing diagnosis of tuberculosis is likely to be far more

troubling than the symptoms of TB. Stigma of TB may also be enhanced by association with AIDS, which could contribute to treatment delay for TB in an HIV high-prevalence area (Weiss, Ramakrishna, and Somma, 2006).

TB control is also important to prevent resistance to anti-tuberculosis medication. Stigma and concerns about not being identified as a patient with TB were responsible for 28% of patients not being observed in a DOTS program, take longer time to seek help for TB, and hide their diagnosis of TB. These conditions happen particularly for women who were widows or married and living in joint families (Weiss, Ramakrishna, and Somma, 2006).

Study of stigma should consider psychological processes of individuals, social dynamics of institutions, and various social and economic processes that influence policy. Study about stigma have to consider all sake holder including people with a stigmatized health problem which could provides an account of self-perceived stigma; people without that problem in the community which could clarifies social contexts of stigmatization; families, friends, loved ones, health care providers, volunteers who work with affected individuals, and key persons or groups within a community such aas political leaders, policy makers, and teachers. Their attitudes are likely to influence the social production of stigma or desirable alternatives (Weiss, Ramakrishna, and Somma, 2006).

According to qualitative systematic review from Noyes and Popay (2007) about facilitators and barriers to accessing and complying with Tb treatment, there are five themes emerged from the 1990 - 2002 synthesis:

• Socio-economic circumstances, material resources and individual agency.

The major theme emerge is dominance of poverty and disadvantage group (for example refugees, migrant worker and asylum seekers) as a risk factor of TB and barrier to early diagnosis and effective treatment. There are some reasons for these conditions, including inability to give up work or risk the loss of earnings in order to participate in treatment; the cost of transport to health care centre, inability to pay for drugs or extra food.

• Explanatory models and knowledge systems in relation to TB and its treatment.

Misconception about cause of TB or effect of anti TB medicine could be considered problematic or incorrect. For example: perception that TB as punishment from God,

TB is a dirty disease, and for drug user they afraid that they have to give up their drug addiction.

• The experience of stigma and public discourses around TB.

Stigma associated with TB is wide spread across most cultures and social groups which make people reluctant to seek a diagnosis or treatment or kept secret about the diagnosis.

• Sanction, incentives and support, and

Sanction associated with TB treatment may be an important barrier to uptake in rich and poor countries, particularly among immigrant worker and drug users. Financial support from family or friends also important in determine successful of treatment.

• The social organization and social relationship of care.

TB treatment services which did not suit the users need and availability also make patients difficult to complete treatment. High direct and indirect cost also mentioned as factors affecting treatment completion. Negative attitude and social relationship of care between providers of service and people with TB could lead to authoritarian services, lack of respect for, and empathy with TB patients.

#### Conclusion

In conclusion, Tuberculosis control is very important because the potential of resistance with anti-TB medication. Stigma associated with TB could cause delay in help seeking, reduce adherence, and decrease quality of services. There fore, qualitative review about stigma is important in order to make an appropriate health education and intervention to reduce stigma of TB in community; and increase help seeking behavior and adherence to TB treatment.

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