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Family and Social Support in Treatment Adherence of MDR TB Patient in Nepal

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Abstract

Background: *Multidrug resistance is one of the emerging public health issue around the world as the treatment is challenging due to loss to follow up and side effects. Multiple factors are responsible for the adherence of treatment. Side effects of drugs, lengthy treatment duration, and complicated treatment procedures are major hindrances in treatment of MDR TB. Similarly, family and social support have prime role in maintaining the treatment adherence among the patients.*

Objective: *The objective of this study was to find out the role of family and social support in treatment adherence of MDR patients.*

Methods and material: *Focus Group Discussion and group discussion were conducted in 2 treatment centers NTC and GENETUP. The information collected through FGD and group discussion were translated, transcribed and then respective themes were constructed under which analysis was performed.*

Results: *Majority of the respondents had received family support for their treatment. Respondents reported that main reasons behind non-adherence of TB was due to side effects of the drugs. Almost 1/3rd of the respondents felt discrimination from the society while many of them are not engaged in any income generation due to weakness and physical symptoms. The disease status has been disclosed to only close ones in most of the cases rather than the neighbors. Social stigma and discrimination are the reasons behind not disclosing their status.*

Conclusion: *This study shows that family are the one who are close to the patient and their support plays a crucial role for treatment adherence. Societal support is also necessary but the various stigmas associated with the disease have resulted to hide the disease in community.*

Keywords: *Adherence, Family and social support, MDR TB, Resistance, Nepal.*

Introduction

With affecting approximately about one third of the world's population, TB is still one of the top 10 killer disease after HIV contributing to 45% of the global TB burden in South East Asia region (Global tuberculosis report., 2018). The number of people with multi-drug resistant tuberculosis (MDR-TB) is increasing with the majority in low and middle income countries(Khanal et al., 2017). The major challenge is that patient do not complete their treatment course, resulting emergency of resistant to the anti-tuberculosis drugs (Gube et al., 2018).

Although DOTS program have been implemented to manage the cases systematically but poor adherence has always acted as barrier resulting in treatment failure (Gebreweld et al., 2018). Nepal has also been implementing DOTS strategies since 1996 but a large gap could be observed in the annual case finding rates of MDR TB cases as the rates seems to be stagnant since many years (Nepal Tuberculosis Program Annual Report, 2018). A qualitative study done among 23 TB patients in Nepal shows that the majority of the respondent felt isolation (Lewis & Newell, 2009). Adherence to the treatment is important for any patient as they need to complete the full treatment course. Different factors associated with poverty, unemployment, and lack of access to healthcare prevent control of the disease(Paz-Soldán, Alban, Jones, & Oberhelman, 2013). The second line drugs are more expensive than first line drugs. Anti TB drugs have various side effects which varies according to the individual

patient whereas the treatment duration is also lengthy with complex treatment procedures are prime factors for non-adherence among the patients. The consequences of default from drug-resistant TB treatment may be particularly grave, because effective therapy for patients with drug-resistant TB relies on the remaining drugs to which the strain has in vitro susceptibility. Thus, treatment default may lead to the transmission of TB that is more difficult to cure with existing drugs(Franke et al., 2008).

Limited treatment options with long duration and associated toxicity adversely impact the physical and mental wellbeing of MDR-TB patients. Large number of research is conducted in the microbiological and clinical aspects of MDR-TB, but still lacks in the psychosocial context(Thomas et al., 2016). Hence, this study tends to find the role of family and social support in the treatment adherence of DR-TB patients.

Literature review

A qualitative study done in Nepal shows that that it was difficult to share their problems with family members, which they think is due lack of proper knowledge regarding the disease whereas stigma, discrimination and fear of loss of employment was highly faced by community. As a result most of them had not disclosed their TB status(Lewis & Newell, 2009).

A study on social support interventions among old age people in China showed that in comparison with the single health education, the interventions consisting of health education, psychotherapy and family & community support interventions, could effectively promote the social support for the elderly with TB in communities (Li et al., 2018).

A study done in India shows that self-motivation, awareness about the disease and treatment, counseling support, nutritional support, family and community support, and social support were the main factors for adherence to MDR TB treatment. Participants who were single, widowed or divorced, retired, and had fewer family members and lower family income were found to have lower social support scores. (Deshmukh et al., 2018).

A study in China regarding social support to MDR-TB patients showed that patients who were married and had larger families had higher social support, subjective and objective support scores than their counterparts. Studies have also shown that financial assistance is essential for TB patients to complete the treatment successfully. Participants who did not object to disclosing that they were MDR-TB patients tended to receive more social support (P=0.010)(Chen et al., 2016).

Methodology

Purposively two sites were selected for the study to represent varying respondents. NTC and GENETUP are two MDR-TB management centers from where the participants and health workers represented. Two FGDs and group discussions were conducted in NTC and GENETUP with 26 participants. Qualitative study was conducted in line with quantitative study to include the view of care takers as well as service providers. In FGD total 15 respondents (8 male and 7 female) and similarly in group discussion with health workers 11 respondents (4 male and 7 female). Family members of the patients have participated in FGD whereas group discussion was conducted with health workers of treatment center.

Similarly, FGD and discussion guidelines were developed as well in order to explore the in depth perception and attitude of patient's party and health workers. FGDs were conducted in the respective site in the presence of moderator and note taker whereas audio was also recorded. The audio-recorded FGDs and group discussions were transcribed into English and written in MS Word and themes were developed accordingly. Important theme from the data were extracted, analyzed and interpreted in the respective sections.

Ethics

Approval for the research was granted by Nepal Health Research Council (NHRC). Similarly, approval was also taken from NTC and GENETUP treatment. A written consent was obtained from all the participants for FGDs and group discussions.

Result

FGDs and group discussion were conducted with patient's party and health workers in order to gather information regarding the treatment adherence and family and social support to the patient. The overall findings were divided into four .themes which was Adherence in treatment, Family support, Social support and Availability of medicine and equipment.

Adherence in treatment

For maintaining the adherence, one should be aware about the treatment duration. All participants have good knowledge of treatment. During the discussion, patient's party described about their hardship they have to face to make their patient take the drug due to immediate side effects like vomiting, color change of skin and fever at the initial stage of the treatment. One of the participant explained her hardship as

"It was very hard to convince child for medicine at the initial phase. Now she is adjusted with medicines and remembers her medicines even if I am engaged in some works. She reminds me saying, Maamu, where is my medicine?" (Patient's party, 38, Female).

Meanwhile less motivation was experience by the patient's parties whose patient had previously diagnosed by TB.

"*At initial stage my husband didn't wanted to take the medicine. As the disease relapsed, he had less hope that it will be cured but we had to convince him though it was not easy. Now, I have been taking all the responsibilities of his treatment and diets." (Patient's party, 21, Female).*

All the participants during FGD agreed that knowledge regarding the treatment and side effects, have made them able to maintain adherence to the treatment. In spite of the sufficient knowledge, patient may feel panic and scared due to lengthy treatment regimen. Unbearable side effect was major reason for non-adherence among the patients. Similar incident happened other participant as well where he shared his bitter experience as

"My wife is a teacher by profession. Due to regular drugs, long treatment period and side effects, she felt depressed and had suicidal thoughts. She had loosed hope for the cure of the disease. Later on we made her believe that it is curable and if not we well then we will go to advance treatment. Then only she felt relaxed and better." (Patient's party, 40, Male).

A patient expressed his pain during interview

"Every day I have to take medicine. I try to cope with the medicines but each time I ingest it, nausea and vomiting occurs and it feels bad. I don't feel like having anything. I don't know how long my body will withstand the side effects. (TB patient, 55, Male).

Health workers during the group discussion also reported the importance of counseling during the treatment duration which in their view is very crucial in terms of treatment adherence. A service provider told her experience during the group discussion as

"Patient and their parties visit the treatment center with fear and anxiety at the initial phase. The situation is very stressful for both patient and their family members. After the proper counseling they feel more comfortable and happily start the course." (Health worker, 30, Female)

Family support

All the participants were very close to the patients who were well known about their treatment too. Participants agreed with the fact that family support is needed for every patient to recover soon. Participants told that emotional and psychological support were crucial during the treatment period.

Participants during the FGD said

"We never leave our patient alone as sometimes they feel anxiety and suicidal thoughts. So, we try to spend more time with our patient and also take them for outing."

My son suffered from mental problem and anxiety during the treatment period. He couldn't bear the pain of injections and also had suicidal thoughts but somehow we convince him not to lose hope and continue the treatment. Now he motivates other patients as well to complete the treatment with patience." (Patient's party, 51, Female, FGD).

Another participants during FGD explained as

"Our patient have to take other medicines of blood pressure and diabetes, he never refused to take TB medicine but still one of the family member is always available to assure the diet and medicine of the patient." (Patient's party, 40, Male).

Social support

Majority of the participants have disclosed their status to the close ones only. They thought that it is not necessary to share with others. It is due to social stigma and discrimination. One of the participants during interview responded that

"People who lack knowledge regarding the disease may show discrimination in the society. We have shared the status within our family

members and closed ones." (Patient party, 22, Male).

But those who have disclosed responded as

"All neighbors are well known about the disease. We even suggested our neighbors whose children came to our house to play with my infected child to have TB screening so that timely preventive measures could be adopted." (Patient's party, 38, Female).

Similarly, another participants added

"We have disclosed status of our daughter-in-law, our society people are much concern about her recovery." (Patient's party, 60, Female).

"As my wife is job holder and to continue it during the treatment was very much difficult. At those situation, her office administration manages the leave and suggested her to rejoin after the she fully recovers." (Patient's party, 32, Male).

According to the participants, different behavior were experienced from the people who were less aware about the disease. At the initial stage, unusual behaviors like ignoring, less communication and few home visit was experienced. It was found that people who are living away from family generally don't tell their parents regarding the disease status as well.
From the service provider's perspective

"Patients have a kind of fear that they will not fit in the society in future. They do not share the status in community. Even they keep their name private while registering." (Public Health Nurse, 55, Female).

Availability of medicine and equipment

In present context, there is regular supply of the medicine and no any patient had to return back due to stock out. But regarding distribution of masks the service providers were not satisfied and complained as

"We are provided with the limited number of masks. Though it seems impractical but we use single mask for long."

For diagnosis of the disease, health workers responded that

"*As there are many diagnostic centers and hospitals for GENE Xpert which have been easy for the diagnosis of the disease. All other necessary tests during the follow ups will be done at hospital and some tests are performed outside by patients due to limited service facility. But the Line Probe Assay (LPA) test is available only in two of the centers which is expensive as well so, it would be better if the test is provided in other health facilities as well." (Senior Nurse, 28, Female).*

Discussions

This qualitative study aims to explore the role of family and social support needed for the treatment adherence of MDR-TB. Those family members who are close to the patient and can play crucial role for encouraging the patient to complete the treatment. The treatment procedure of MDR-TB is very complicated, hence patient tend to drop the treatment which may result to more severe conditions. One of the reason of non-adherence in this study was due to side effects of the drugs is similar to the study done in TB clinics of Southern Ethopia, Nepal and Indonesia (Gube et al., 2018; Bichha, Karki, Jha, Salhotra, & Weerakoon, 2018; Ruru et al., 2018).

The role of family in maintaining optimum level of health cannot be neglected. According to a recent study conducted in Nepal, family problem was also one of the barrier for treatment adherence (Bichha, Karki, Jha, Salhotra, & Weerakoon, 2018). Family status play vital role in treatment adherence. The participants of FGD have reported to be supportive towards their patient for their effective treatment. A study in Pune of Maharashtra showed that good support in daily activities, economic help, emotional and moral support and motivation were needed from the point of patients (Samal, 2017). Parents were the main members in the family whose support was more in comparison with other. A family based pilot study conducted among TB patients and their family members asked the patients and their family members to evaluate the level of family support from the scale of 1 to 5 where TB patients reported a mean score for family support of 4.90 at baseline, which increased to 4.98 during follow-up. While family members reported a mean of 4.78 at baseline which reached 4.81 at follow-up. (Truzyan, Crape, Harutyunyan, & Petrosyan, 2018).

Along with the family support, social support also motivates for the completion of treatment. In this study, social aspects had been measured through disclosure of disease, experience of different behavior from community, involvement in social gatherings and income generating activities. Patient as well as service provider

believe that TB had always been associated with various kinds of social stigmas. Studies have shown that disclosure of disease may result in less economic opportunities hence patients and their family members do not disclose the status (Yin, Wang, Zhou, & Wei, 2018; Paz-Soldán, Alban, Jones, & Oberhelman, 2013, Gebreweld et al., 2018). Our findings also show similar findings as most of the patients have disclose their disease status to limited people. The number of participants involved in social activities are very less. A study in Peru showed increased withdrawal from the social connections in a fear of infecting others and also fear to be noticed in the community as being ill (Paz-Soldán, Alban, Jones, & Oberhelman, 2013). A study in India showed that some patients have given wrong information to avoid being exposed in community as TB patient. Similarly, a study in Nepal showed that majority of the patient have discussed about their disease with family members where some still don't talk with anyone regarding their disease (Aryal et al., 2012). A study in Thailand showed that less knowledge regarding the disease may often create fear in the people to come close with a TB patient which may later leads to stigmatization (Sengupta et al., 2006).

Similarly, a case study done in 2019 in Bangladesh showed that community DOTS and small support from the community may also encourage the patient to complete the treatment. A comparative study done among community showed that person and few people believed community will avoid infected person and the disease may leads to unemployment (Sermrittirong, Van Brakel, Kraipui, Traithip, & Bunders-Aelen, 2015).

Conclusion

This study intended to find out the importance of family and social support in the treatment adherence of MDR-TB, in which side effect was the main reason behind non-adherence. Similarly, family are the one who are crucial to maintain the adherence through various means as their support is necessary during the treatment whereas social support is also necessary but still there are stigmas associated with the disease. So, people does not disclose their status in the society for which awareness campaign is necessary and also the social support should be more strengthen to improve the adherence. Similarly, proper counseling is also necessary to the family members so that they can take good care of their patient.

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