ORIGINAL ARTICLE

PERIODICITY OF TUBERCULOSIS PATIENTS ON FAMILY SUPPORT AND CARE IN RURAL MAHARASHTRA

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Summary

Background: Role of patients’ family in TB-control programme has received least attention in research and negligible attention is paid to support and care experiences of patients in rural societies.

Aim: Present study aims at collecting qualitative data on how tuberculosis patients define support and care during illness, and document their experiences and perspectives about care and support.

Methods: This is a qualitative study with grounded theory approach. Data were collected by conducting series of 15 focus group discussions (FGD) covering 113 patients from rural Pune district of Maharashtra. Thematic analysis was undertaken after preparing detailed transcripts of each FGD.

Results: Good support and care was considered as receiving necessary attention and help in daily routine, monetary help, emotional and moral support and motivation for early recovery. Family provided support by accompanying to the health centre, reminding about medicines, giving meals. Female patients reported less sympathetic attitude and unfair treatment at husband’s home while males received emotional and physical support from spouse. Stigma led to discrimination and hindered the support and care mechanism.

Conclusion: Family awareness and preparedness for providing support need to be strengthened. Counselling and motivation during each visit are the keys to successful completion of treatment. There is need to make counsellors/psychologists available in the existing system.

Key words: Tuberculosis, Family support, Stigma, Rural, India

INTRODUCTION

Despite the availability of highly efficacious treatment for decades, India is the highest TB burden country accounting for one fifth (21%) of the global incidence.¹ Studies on care seeking behaviour of chest symptomatics², are ample in numbers but studies dealing with family support and care offered to tuberculosis patients are dismal. Moreover, in case of TB, a chain of events starting from exposure to infection, manifestation of symptoms, access to health facility, treatment and recuperation, family support and care play a pivotal role and decide outcome to an extent.³ TB patients face various barriers in day-to-day life; so also isolation and rejection from families and communities.⁴ Concerns and expectations of TB patients are required for improving quality of care, their compliance and completion of the treatment.⁵ Family and society are the major constituents of social structure. Last two decades have witnessed the research on patients’ health seeking behaviour which is influenced by gender, culture and family.⁶-¹² However, studies on patients’ definition of support and care and their expectations from family are rarely documented. Objectives of this paper are to study perception about support and care of TB patients, to understand availability and kind of support received during illness, and to document their experiences and perspectives about care and support.

MATERIAL AND METHODS

The study was conducted in the rural areas of Pune district, located in the western part of Maharashtra, India. The Revised National Tuberculosis Control Programme (RNTCP) which follows the policy guidelines of the WHO’s DOTS strategy, after its successful testing was launched in 1997.¹³ Pune rural has eight TB units and 50 microscopy centres while the treatment recommended under RNTCP is

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Indian Journal of Tuberculosis
available at 105 primary units at village level. The current paper is based on the data collected from purposively selected five units which primarily covered Dehu, Fursungi, Urali, Khed and Khanapur villages and surrounding areas. These units were selected because of a sizeable number of patients registered for treatment and available for FGD.

**Data collection tools and techniques**

Participants in the study were tuberculosis patients. They were approached to explain the study when they visited DOTS centres for their regular treatment. The study included patients who were more than 18 years and less than 60 years of age. Those patients who were very sick were not included in the study. Patients were first assessed for their willingness to be a part of the study and availability for FGD. FGD was arranged only after enough number of patients agreed to participate. For those who showed willingness to participate, the details of the study were elaborated and explained to each one of them and written informed consent was obtained. Prior to the initiation of the study, study protocol including informed consent form and its translation in local language was scrutinized and approved by the University’s Ethics Committee. Male and female patients, currently on anti-tuberculosis treatment, participated in the FGD. In each primary unit, three discussions (one male, one female and mixed group) were conducted. A total of fifteen FGDs were arranged comprising 6-12 tuberculosis patients in each FGD. Thus, the findings are based on the opinions expressed by more than 113 tuberculosis patients.

**Description of study population**

There were more males (n=58) than females (n=55) and nearly 35 per cent were between 18 to 30 years. There was almost equal distribution of young, middle aged and late middle aged patients. Majority of them were married (65.5%) and from extended family (63.7%) set up. Nearly forty per cent were illiterate and equal number had studied upto secondary school. Therefore, none of them were in any skilled job employment, majority were landless labourers (31.8%) and farmers (26.5%) while one fourth (24.7%) of them were unemployed.

**Tools and techniques**

FGD guide was developed based on the review of current literature and in the light of objectives of research. FGDs were arranged at familiar and convenient places for the patients, mostly community halls nearby a DOTS centre. Following questions were discussed in each session: what are the commonly seen symptoms of TB? What do you think causes TB? What are the changes observed in personal, family, and social life due to the disease? What was your own and family members’ first reaction after diagnosis of disease? What do patients expect from family in terms of support and care? Can you share positive/negative experiences with regard to support and care? How do families provide day-to-day support and who is likely to get involved more in providing support? What other support and care does one expect from family? Was there a gap between expected care and actual experiences? FGD guide was pilot-tested prior to the study. A team of three researchers conducted the discussions. One was responsible for recording the information, making detailed notes and the second researcher was observing and noting down expressions, body language. A moderator handled the proceedings and ensured participation of all members. FGD session was concluded when intended information was obtained. The information collected was expanded in detailed notes on the same day and thematic analysis was carried out. Validity of these findings was augmented by presenting them to some of the participants during subsequent visits. Thus validated results are summarized here.

**RESULTS**

Results are organized as per the themes discussed during FGDs.

**Awareness about TB symptoms**

Reported chief symptom was persistent cough, fever and loss of appetite. Men mentioned cough with streak of blood in sputum while women mentioned breathlessness, general weakness along with weight loss and loss of appetite. Commonly reported cause of the disease was ‘contact with a
tuberculosis person’, known or unknown case. Inhalation of dust, exposure to cold weather while working on agricultural farms and prolonged and recurrent episodes of cough and cold progressed to tuberculosis were other causes reported. Respondents mentioned that men caught infection quickly when they came in contact with an infected person at the time of travelling in crowded buses during their visits to cities. Drinking alcohol, smoking and childhood asthma were other perceived causes of disease among men. Men in multiple relations (referred as ‘baher, dusarikade janara’) were more vulnerable to tuberculosis according to some of the respondents. Women participants felt that eating less food, hard agriculture labour, and black magic predisposed them to the disease.

Effect of TB diagnosis on personal and social life

Discussion began by eliciting their responses on perceived effect of TB diagnosis on their personal as well as social life. This question was asked to understand primary concerns of patients and reactions of immediate family and relatives. Concerns and reactions helped in identifying domains where support was anticipated and nature of the ‘support and care’ received.

Consequences on personal life

Participating patients mentioned leading tough life at personal as well social level. Female patients mentioned that husband and family often taunted them for contracting the disease. Younger children were prevented from interacting with such mothers and were given misleading information about mother’s moral character and behaviour. Some opined that personal life of married women ruined and they were forced to live in a fear of abandonment or husband’s remarriage. Female respondents felt that eating less food, hard agriculture labour, and black magic predisposed them to the disease.

First reaction after diagnosis

Participants were asked about family’s first reaction upon learning about their diagnosis. All discussions yielded similar information, majority of the families could not believe the ‘news’, they were shocked, deeply saddened and in some cases denied the diagnosis. It appeared that the families were not prepared to receive such news. Later on, patients were asked to share their expectations from families immediately after diagnosis and current expectations till completion of their treatment. Emotional support and physical help provided by family at the beginning, that is immediately after diagnosis, was different from support and care received in day-to-day life. Participants were pleased with the support provided to them by their families during diagnosis. It was also stated that they received good emotional support and care from their families but it might not happen with all the patients and very few TB patients were lucky to get continued care from their family members.

Concept of Support and care

Their expectations can be categorized into two distinct terms, that is support (madat) and care (kalaji). They were further asked to define these terms by citing examples. Good support and care was defined (by patients) as receiving necessary attention and help in daily routine, monitory help,
emotional and moral support and motivation for recovery. According to them, 'support' could be measured in terms of accompanying somebody for treatment, reminding about medicines, food and water served in the bed, allowing to take rest and all other care as and when demanded. While 'care' was described as speaking words of encouragement, motivate to fight with the disease, provide hope and positive thinking, discouragement from negative thoughts like suicide or running away from home.

**Support and care provided by family**

In order to extract information on actual role of family, participants were asked several questions. The selection of questions was dependent on the way earlier discussion had taken place. Questions used during FGDs are as follows:

a) All of us require help during illness, according to you, who should take care of TB patients and what is your experience about it?  
b) Illness may change our daily routine, did your routine get affected? How do TB patients set their routine and what was the role of family members in day-to-day activities?  
c) Now that you have this illness for the last few months, how do your family members cope with your disease and treat you at home?

These questions helped us in gaining information about patients' daily routine, role of family, their attitude and level of support and care provided by family. When question was thrown out for discussion, everybody tried to give a positive impression of their family. According to the participants, families were very co-operative and sensitive to their needs. Majority of them were reluctant to express negative feelings about their families. Probing and appeal to share positive as well as negative experiences brought out the real information.

**Patient's expectations about family support and care**

Participants unanimously mentioned that women in the household should take care of TB patients. Most of the female patients reported discrimination and alienation in day-to-day life and mentioned 'nobody' to take care. It was expressed that married female patients face non-cooperation from in-laws and also received unsympathetic treatment. Most of the respondents mentioned that unmarried female patients have parents or siblings to remind about medicines, serve food in the bed and, if necessary, to take them to hospital. Married women could not expect all this; neither husband nor other members were willing to help. A female patient aged 46 years expressed that, ‘…. men do not have patience to take care of a sick person, by nature they are rowdy. They cannot be as warm as women. My husband accompanies me to the hospital. However, he would not care to ask if I have eaten meal. I expect him to have understanding about my illness and suffering, show sympathy and speak at least a few good words that will reduce my stress. But my expectations are futile.’

According to one of the female participants aged 24 years who was feeling very awkward to comment but finally mentioned that, ‘…..being a female, family members expect you to do domestic as well as the farm work. For them ‘getting the work done’ is more important than individual. I receive no help in my daily work, except in cooking. Mother-in-law has taken over cooking after learning about my illness. I take care of other domestic work like washing and cleaning and other household activities. I cannot ask for help, though I want them to give me some relief from work. Days when I am very sick, I do not get up at all. Other days, I do my work slowly and sleep under a shade on the farm.’

A middle-aged female, who was deserted by her husband and was feeling depressed, was very articulated and narrated a few incidences which forced her to leave husband's house. ‘….daily routine is not affected much but interaction with other members in family, kin group and neighbours definitely undergo changes. Everything cannot be explained in words. One has to feel and go through the experience. It is difficult to express isolation in words but food is served last, touch is avoided, even words are used sparingly, we can read rejection in their eyes. Overnight change in attitude and behaviour of family members can be observed’. She demanded alternative staying
arrangements for affected women who might get deserted and need somebody to rely on. She continued, ‘…. it is not possible to go and stay with parents, always. There is a need to have somebody to pat on our back and encourage to lead life with the same vitality.’

Sympathetic environment that is referred to as ‘care’ and physical help that is ‘support’ was more readily available for male patients as compared to female patients. This impression was created during FGDs of females. During FGDs of male patients, following information was gathered, majority said that, ‘….women cannot just sit and rest whole day because they have responsibility of the entire household. They have to cook and feed children and husband. They are required to do washing and cleaning. Therefore, care received by men and women would always remain different. However that does not mean that men are not discriminated.’

As narrated by a male TB patient aged 57 years, who was a farmer and had irrigated land, ‘I have to demand for care and support from my family members. It did not come willingly to me. All three daughters in law refused to wash my clothes, give me food on time but I have learnt to get my work done from them.’ Family members had to comply with his demands because the patient was the main bread earner of the family. He might be an exception and all other patients might not be able to command such a respect. Yet, rest of them listened carefully and nodded vigorously to some of his statements. Therefore, views expressed by other male members were very important to us in the analysis. In cases where the patient could not earn their daily wages due to the disease, their family members showed very less sensitivity towards their illness. Both males and females suffer same degree of stigmatization, discrimination and pressure from family. Following excerpt confirms this view, ‘….we understand patient should complete treatment, but men constantly feel the mounting pressure of economic responsibility. We need food and meals for two times in a day. Who is going to bring it? They get caught between demands of families and their own health needs. Therefore they need motivation and assurance that recovery will happen soon.’ This was narrated by a male patient, 48 years’ old and was unemployed due to the illness. Some of the participants looked very disheartened and discussed these matters in a very depressing voice. One of the male participants aged 33 years felt, ‘I have no idea what is going to happen after completion of the treatment. My wife has stopped respecting me and does not interact openly ever since she learnt about diagnosis. Fights over trivial matters have now become inevitable.’ Participant aged 53, who owned a small piece of land believed, ‘I got TB because of dust and working in sunlight for long hours every day. It is not my fault’. Participants arrived at conclusion that all TB patients received support and care but not necessarily ‘best support and care’. Family’s cooperation depended on the affected person’s status and role in the family. There were very few young men who participated in FGD. Young men from poorer families with financial responsibility linked care and support to their deteriorating economic status. Financially dependent patients faced humiliation and embarrassment. Those who had regular income, demanded care and support from family members. These views were shared with lot of guilt and shame in their eyes. Regarding the acceptability of patients among extended family and relatives, most of them reported discrimination and alienation. A story of TB affected woman was narrated by one of the members. Young lady with two kids, was deserted by husband and she was sent back to her parents’ house for the treatment. She recently came to know that her husband got remarried and now not willing to accept her. In such circumstances, very few relatives cared to visit or offer help in solving such problems. Those who came down showed lip sympathy and nothing beyond that. Most of the participants in that group profoundly agreed to the descriptions of behaviour of the relatives.

DISCUSSION

The major contribution of this particular research is clarity of concepts ‘support and care’ as described by TB affected individuals. We believed that these fifteen FGDs yielded the factual results in less time. This method has been proved as an useful
tool to collect information on the perceptions, beliefs, values and understanding of health issues and has been used by some of the studies in India.\textsuperscript{14} It appears that the major barrier in assuming role of family is their unpreparedness, notions about TB, impact of stigma and discrimination. Earlier studies\textsuperscript{16,17} have proved that in chronic conditions, family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from the formal health care providers. Encouraging informed and active involvement of family in care, as seen in other diseases like cancer\textsuperscript{18} may raise awareness and reduce stigma. It is a well-known fact that stigma attached with disease always hampers care and support. As evident from the research on HIV/AIDS,\textsuperscript{19} stigma can lead to discrimination, denial of healthcare, employment, education, and other fundamental rights. In case of TB, family and community are guided by several such misconceptions\textsuperscript{20} leading to stigmatization of the disease and hence, need to adopt support strategies that are required to enhance acceptance of patients.\textsuperscript{21} As seen in the present study, instead of empathy and cheering pat on back, they experienced discrimination, neglect and disgrace. The findings are similar to that of a study done among women TB patients sometime back in the neighbouring geographical area.\textsuperscript{22} The study has demonstrated that difference exists in the ‘expectations’ of patients and the ‘real care and support’ provided by family. This is how lack of support, stigma and discrimination contribute to the existing burden of TB at individual level. Research on families’ involvement in TB programme is limited but there are some examples where families have shared responsibilities with public health system.\textsuperscript{21} Research carried out in Tamilnadu\textsuperscript{24} suggests that there is a need to alleviate fears from patients’ mind by providing counselling and health education to community. We would like to include families prior to communities.

**RECOMMENDATIONS**

Following recommendations are provided in the light of above discussion and based on the existing information, education and communication (IEC) component of the RNTCP. Current IEC component\textsuperscript{25} focuses on awareness raising, advocacy, social mobilization and improving patient provider communication. Families are one of the target groups in the health communication strategy, but nothing has been elaborated on how family should get involved and help TB patients complete treatment. Efforts to change family’s attitude and behaviour towards tuberculosis patients are not specified. Families should understand the diverse needs patients may have during the long treatment period. They should be thoroughly educated and prepared to provide support to help reach the goal of completion of treatment. Therefore, it is recommended that health providers should expand their role of health education and counsel family members to get more actively involved in the care of patients. If RNTCP staff faces problems in awareness building or involving family in care, a trained counsellor or a visiting psychologist is called for help. It is recommended that s/he should counsel such family members using various communication strategies and negotiate family’s role in patient care. These techniques and education material used by counsellors can subsequently be handed over to the staff. This will definitely help us achieve objectives of RNTCP.

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