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Exploratory, cross-sectional social network study to assess the influence of social networks on the care-seeking behaviour, treatment adherence and outcomes of patients with tuberculosis in Chennai, India: a study protocol

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ABSTRACT

Introduction Poor treatment adherence and outcomes among patients with tuberculosis (TB) lead to drug resistance, and increased risk of morbidity, mortality and transmission of the disease in the community. Individual patient-level psychological and behavioural risk factors and structural-level social and health system determinants of treatment adherence and outcomes had been studied widely in India and other countries. There is an evidence gap on how care-seeking behaviour, treatment adherence and outcomes of patients with TB are influenced by their social network structure and the different support they received from social network members.

Methods and analysis We propose an exploratory, cross-sectional social network study to assess the social network structure of patients with TB in Chennai who recently completed their treatment under the Revised National Tuberculosis Control Program in India. We will employ egocentric personal social network survey to 380 patients with TB to generate their social network relationships and will retrospectively assess the types of support they received from different network members. Support received will be categorised as emotional support, resources support, appraisal support, informational support, spiritual support, occupational support and practical support. Social network size, composition, density, centrality and cohesion for individual patients with TB will be calculated and sociograms will be developed. Multinomial logistic regressions will be used to assess the relationship between the 'structure of social network members' and 'social network supports' and the differential treatment-seeking behaviour, treatment adherence and outcomes among patients with TB.

Ethics and human protection The proposal was approved by the Institutional Review Board and Ethics Committee of the School of Public Health, SRM University in Kancheepuram. Confidentiality and privacy of participants will be protected. Duty of care for patients who have not completed treatment will be ensured by taking all possible measures to bring them back for treatment.

Strengths and limitations of this study

► The study will generate evidence on the social network characteristics of patients with tuberculosis (TB) and the different social support enabled by the network members.
► Evidence from this study will complement existing evidence on individual behavioural determinants and structural determinants of TB treatment adherence and completion.
► The findings of this study will lead to further development and testing of individual patient-centric interventions to address barriers and challenges faced by patients with TB in completing treatment.
► The retrospective collection of information may lead to recall and respondent bias among participants in accurately reporting the social network support they received during the treatment period.

INTRODUCTION

Antituberculosis treatment through the Directly Observed Treatment Short course, as an effective strategy for tuberculosis (TB) treatment, had saved millions of lives in India.[1 2] In spite of effective treatments available, challenges in adherence to medication remain a key barrier in programme settings.[3] Improper TB medication leads to poor treatment outcomes among patients, leading to drug resistance, morbidity, mortality and disease transmission in the community. Studies have identified individual patient-level factors that lead to poor treatment adherence, which are 'relief from symptoms' at the initiation of treatment, 'adverse reactions or side effects' of drugs, 'alcoholism', psychosocial problems such as 'depression' and 'stigma', familial and occupational problems, lack of money and loss of

wages, non-supportive health staff, lack of awareness and knowledge about treatment, and so on.[4–7]

Psychosocial and behavioural factors of patients with TB and structurally determining economic and health system-related factors had been widely studied with regard to their impact on TB treatment adherence and outcomes in India and other countries. However, there is still a paucity of research on how the social networks of patients with TB influence healthcare-seeking behaviour, access to treatment, and treatment adherence and completion. There is a need to assess how the social networks of patients with TB enable them to receive the different types of social, psychological, economic and practical support during the treatment period.

Social network analysis (SNA) is the study of social structure which connects individuals. Social network has three subcomponents: (1) network relationships, that is, the characteristics or attributes of individuals; (2) network structure, which refers to the position of individuals within the network; and (3) network function, which refers to the influence of network members on each other.[8] Social network is a novel research discipline which is increasingly applied for diverse purposes in health research settings. Social network studies generate data which are different from conventional data in providing insights into the relationship dynamics between members of a social group and its impact on health behaviours. A study which examined the association between network diversity and health behaviours among patients with cancer showed that low network diversity was significantly associated with sedentary and risky health behaviours (lack of physical exercise, increased weight and obesity, smoking, and alcohol intake).[9] A study in Ethiopia used social network data to understand the duration and adoption of modern contraception among rural residents and found that friendship or spatial network has minimal influence on contraception use.[10] A study conducted among aboriginal communities that assessed social interaction patterns showed that specific community members have higher betweenness, degree and closeness centrality and thus facilitate the flow of health information among members of the social network.[11] A study in Bangladesh highlighted the importance of social networks as a medium and means to support the needy and vulnerable mother in changing their healthcare-seeking behaviour to effectively access maternal health service.[12] SNA had also been successfully employed to identify the social structure and key individuals who influence safe condom use and client management of key populations (such as sex workers, men who have sex with men [MSM] and injecting drug users).[13] Social network research had been used to describe how critical social partnerships helped these key populations to increase their social support and social capital.[14]

Social network as a novel research discipline had been used in many countries to understand TB transmission dynamics in the community. Still the potential of social networks in influencing the healthcare-seeking behaviour

and treatment status of individual patients with TB within their familial and social context has not been given sufficient research focus.

Rationale of the study

We define the social network of patients with TB as 'those individuals with whom the TB patients had lived, socialized, worked, shared resources and had reciprocal relationships during their treatment period'. The social network members are inclusive of family members, relatives, friends, occupational relations, neighbourhood relations, community relations and so on. Social support for patients with TB enabled through their social networks is of different types with respect to their needs during treatment and care for the disease. The following are the broad domains of support: emotional support (motivation, care, sympathy and understanding received); resources support (money, food, transportation help, job support, economic and related needs); appraisal support (decision-making in terms of treatment continuation and completion); informational support (advice, knowledge and referrals); spiritual support (building trust and value in life); and instrumental support (helping in daily activities such as accompanying them to the hospital, sharing housework and childcare).

Social networks impact the health behaviour and health status of individuals by acting as a medium for generating social capital and support. Social networks of individuals enable social learning, and expose the individuals to social influences through which the values, norms and behavioural patterns of individuals are reinforced or new ones are diffused. Individuals who have dense network connections have highly cohesive networks, and individuals who are centrally located within social networks are more likely to learn about new information, access resources and have newer experiences.

Social network research evidence highlights that some network properties such as 'reciprocity' (the relationship being reciprocated by network members) are correlated with better psychological status of individuals and also influence their health behaviour and health status. Increased 'density' and 'cohesiveness' (meaning more ties between network members) may help individuals receive emotional support. Alternatively social network may also have risky impact on individuals, when network members with risky behaviours (such as alcohol and smoking) may have deleterious peer effect on their health status and health behaviours. On this background this study proposed to assess the social networks of patients with TB to help understand how social networks could impact treatment adherence and outcomes.

Study objectives

► To assess the social network structure of patients with TB with varying treatment-seeking behaviour, treatment adherence and outcomes.
► To assess the different support needed and perceived by patients with TB from their social network members

(resources, information, psychological, spiritual, appraisal, occupational and practical support) in the context of their care-seeking behaviour, treatment adherence and outcomes.

► To assess the influence of the personal social network structure of TB patients on their on their care-seeking behavior, treatment adherence and outcomes.

► To assess how personal social network supports influence the care-seeking behavior, treatment adherence and outcomes of TB patients.

Hypotheses

► There is a significant difference between the social network size and composition of patients with TB with favourable and unfavourable treatment outcomes.

► There is a significant difference between the social network support received by patients with TB with favourable and unfavourable treatment outcomes.

► There is a significant difference between the social network size and composition of patients with TB with regular and irregular adherence.

► There is a significant difference between the social network support received by patients with TB with regular and irregular adherence.

METHODOLOGY
Study setting
The setting of this study would be the treatment units of the Revised National Tuberculosis Control Program (RNTCP) of Chennai City, Tamil Nadu, India.

Study design
This study would be exploratory in nature, which will for the first time explore the social networks of patients with TB and their influence on treatment outcome. A cross-sectional social network survey will be conducted among patients with TB in Chennai City who have recently completed their treatment under the RNTCP of Tamil Nadu, India. The type of social network would be egocentric personal social network,[15 16] and the study setting would be treatment units in Chennai, Tamil Nadu. By egocentric, we refer to our study participant of interest (patients with TB) as 'Ego'. The individuals whom the patient with TB is nominating as his/her social network member—relatives, friends, workplace relations, neighbours, advisors and so on—are referred to as alter.

Sample size and sampling method
As there were no studies on personal social network of patients with TB in India, we assume a 50% prevalent network difference.[17] Considering this at 95% CI, with a precision of 5%, and a 10% dropout or missing treatment details, the expected sample size to identify any differences in the social network structure of patients with TB was calculated as 380. The formula used to calculate the sample was ,n=$Z^2*P*(1-P)/d^2$, in which 'n' denotes sample size, 'Z' denotes the Z statistic

for a level of confidence, 'P' denotes the expected prevalence or proportion, and 'd' denotes precision.

These 380 patients with TB will be recruited from the RNTCP treatment units of Chennai Corporation. Out of the 36 Treatment Units (TUs) of Chennai Corporation with varying case loads, TUs will be selected using the probability proportional to size sampling method. Further individual patients who completed treatment with adherence, completed without adherence and patients who were lost to follow-up (LFU) will be recruited consecutively from the treatment registers of all the selected TUs until the required sample size is reached. Our study will include patients who have initiated treatment in the past 6 months before the study commences.

Study duration
The study is planned to be conducted for a period of 1 year, between January 2019 and December 2019. Piloting of study tools has been completed.

Study participants
Inclusion criteria
► Patients with TB who have completed treatment with adherence (n=127).
► Patients with TB who have completed their treatment without adherence (n=127).
► Patients with TB who were lost to follow-up during treatment (n=127).

Exclusion criteria
► Patients with TB with HIV coinfection.
► Drug-resistant patients with TB.
► Patients with TB aged younger than 18 years.
► MSM, transgender and other key populations with TB.
► Participants registered for treatment under the private sector.

Methods of survey
Eligible patients' name, contact details and treatment-related information will be listed for every selected TU. Further with the help of the programme staff at the treatment centre, we will be communicating with eligible patients to inform them about the purposes of the study and to request for their willingness and appointment. Telephone contact will be made where phone numbers are available, or home visits will be made with the help of the health visitor of the treatment centre. We will be making home visits only to those patients who were visited earlier by the health visitor for household contact tracing or for treatment follow-up purposes. Based on the patient's convenience and willingness, an appointment will be made for meeting at the respective treatment centre or at their own house. Further informed consent will be obtained from them after explaining the purpose and details of the study. Patients who are in the near completion of treatment will also be contacted during their visits to

treatment centres and appointments will be fixed. For LFU patients, the contact details of the LFU patient's support person will be obtained and will be contacted to reach the patients. We will plan our home visits to LFU patients along with the health visitor to make an attempt to initiate treatment.

Study variables, methods of collection and sources

Sociodemographic information, including age, sex, marital status, education, personal and family income, and occupational status, will be collected. Treatment-related information, including treatment type, patient type, coinfections, date of treatment initiation and completion, missed doses of medication, and treatment outcomes, will be collected from treatment registers and cards of patients. Information on risky behaviours such as alcohol and smoking habits and co-morbidities will be collected.

Information on the needs and challenges of patients with TB throughout the period of treatment will be enquired initially. Patients will be asked to free-list the needs they felt during the time of treatment, in terms of resources, information, emotional and spiritual support, instrumental or practical support, and occupational and livelihood support. The level of support reported will be categorised as high, moderate and low. Challenges in terms of stigma and discrimination and barriers faced at health facilities will also be enquired.

Social networks of patients will be elicited using name generators. This will require the respondent (patient with TB) to free-list his/her actual social network members (either by name or nickname). The question for name generator will be *'Who are the persons with whom you had lived, cohabitated, had friendship, socialized, worked or had some reciprocal relationships during your treatment period'*. The respondents will be asked to mention the relationship he/she has with these network members by themselves. Other attributes of social network members such as age, sex, occupational status, TB status and risk behaviours will be enquired. The free-listed social network relationships will be broadly classified as family, relatives, friends, neighbourhood, community, and occupational or occasional relationships, or as based on the responses. The disclosure by patients with TB of their disease status to these social network members will be enquired.

The different support (in terms of resources, information, psychological, spiritual, appraisal, occupational and practical support) received by the patient with TB from their social network members to address their needs will be enquired as follows: *Which social network members advised you on the problems you faced during the treatment period? Which social network members gave you the money/nutritious food which you needed during the treatment period? Which social network members offered their practical help for you during the treatment period (like helping in transportation to treatment centre)? Which social network members advised you on problems you faced during the treatment period? Which social network members provided you emotional support when you were feeling psychologically down? Which social network members have you visited for social purposes or with whom you have spent time with during the treatment period? Which social network members gave you moral and spiritual support to overcome your difficulties during treatment?* Support provided by the community-based organisation members and faith-based institutions and hospital staff will also be collected. The level of support received will be coded as supported 'Always', 'sometimes' and 'rarely'. Frequency of socialisation, experiences of stigma and information on quality of life will be collected.

Information on the nature of relationship and frequency of meeting will be enquired. Perceived closeness between the patient with TB and his/her social network members will be collected from the perspective of the patient only and will be graded as high, moderate and low. The nature and closeness of relation between the network members of patients with TB will also be enquired from the patient's perspective only and will be graded.

Patient and public involvement

The research question and objective of the proposed study were informed by the past experiences of investigators in interviewing patients with TB about their out-of-pocket expenditures for TB treatment and the coping mechanism they used to address financial and related burden. During the development phase of the proposal, we have conducted many informal talks with patients who have completed treatment and who were lost to follow-up and their families and friends to understand the importance of social support. We heard from patients directly how important social network support was for them. We will conduct a patient–provider meeting at the TU level to explain and disseminate the outcome of this study.

Data validity and relevance

The accuracy of the social network data collected from patients is crucial and key to this study. We will be using the following methods and steps to ensure accuracy and reliability.

► Respondents will be asked to free-list social network members and the type of relationship they have with them. No preconceived relationship categories will be used to question the participant. This validated method will be followed to avoid respondent bias when participants are presented with preconceived relationship categories to fit in their networks.[18]

► To assure reliability and validity of the egocentric networks obtained in our study, testing–retesting method will be used. Reinterview by a second interviewer will be done among 5% of our sample after a time gap of 1 month for re-collecting only the social network information. Pearson's correlation coefficient

will be used to compare the aggregated network characteristics reported in both interviews. Reinterviewed respondents will be provided additional incentives for cooperation and time spent on the study. This method has been validated in earlier studies.[19]

► An inbuilt mechanism to check for consistency of social network reporting by patients will be used. The strength of relation of any two-network member reported by respondents will be recoded to check for consistency in responses. Any discrepancy will be clarified with the respondent.

► Participants will be explained about the importance of social network information they have provided, which could make an impact in ensuring social network support for other patients in the future. This will motivate them to provide valid responses. Considering gender sensitiveness in reporting personal information in the Indian context, interviewers who are of the same gender as that of the participant will be assigned. Health staff of the treatment centre who had delivered medication to the patient will be referred at the time of interview initiation, which will improve the respondent's confidence in sharing personal network information. Participants will be provided monetary incentive for the time spent in the interview.

Calculation of personal social network metrics

Personal network metrics of patients will be calculated by constructing and analysing the proximity matrix using standard methods that have been successfully used and tested for their validity in earlier studies.[18] These metrics will be used to understand the structure of the personal social network metrics from the ego's perspective, in addition to the attributes of the network members. Personal network measures will be calculated after the removal of the ego from the adjacency matrix, since the personal networks of the ego are the primary actor who connects all his personal networks. The key network metrics which will be used in this study are as follows:

► Network size: the total number of unique personal network members (alters) reported by each patient.

► Network density: the per cent of connection that exists in the personal network of the patient out of all possible connections.

► Component: a portion of personal network in which the network members of a patient are connected to one another directly or indirectly by at least one tie.

► Degree centrality: the number of direct ties a personal network member has with other network members.

► Cliques: a set of personal network members of the patient who are directly connected to one another.

► Betweenness centralisation: the number of times a network member of a patient connects pairs of other network members, who otherwise cannot reach one another.

► Number of isolates: the personal network member of a patient who does not have any contact with other members of personal networks.

DATA ANALYSIS PLAN

Descriptive analyses will be performed to examine the characteristics of the study population, and the results will be presented as mean and SD or percentages and numbers. We will generate the following statistics for patients and their network members: proportion of patients by key sociodemographic characteristics, mean social network size, proportion of social network members segregated by perceived closeness, frequency of meet, disclosure status (with whom disease status was disclosed or not by patients), proportion of social network members segregated by risk behaviours (having alcohol and smoking habits), mean network size segregated by relationship types (family members, extended family members, friends, neighbours, occupational contacts, community contacts, faith groups, hospital-based contacts), and mean number of network members who provided support (segregated by different types of support received).

To assess the differences between participants with different adherence and treatment outcome status, χ^2 test, analysis of variance and Kruskal-Wallis test will be used as appropriate. Multinomial logistic regression analysis will be used to examine the association of the social network properties of patients with TB with different treatment outcome and adherence status as dependent variables. Regression will be adjusted for key sociodemographic characteristics of patients with TB, including age, sex, occupation, marital status, income status, alcohol intake, smoking and comorbidities. Disclosure status of TB by patients with social network members, socialisation levels and experiences of stigma will be used as instrumental variables to address the endogeneity of regressors using the validated methods reported earlier.[20 21] These instrumental variables will be used since they could cause variation in the network size and the type of social network support received by the participant but does not have any direct impact on treatment outcomes or adherence. ORs and 95% CIs will be reported. Associations with p≤0.05 will be considered for statistical significance. Missing data statistical interactions (effect modification) of the social network characteristics with individual characteristics (gender) will be tested, and if found significant a stratified analysis will be done. Cluster analysis will be used to group networks and cliques of similar kinds.

To handle missing values with regard to the attributes or nature of relationship in social network data, statistical correlation between complete data set and missing data set will be performed to check for significant differences, and further appropriate imputation methods will be used.[22] Descriptive and inferential statistics will be conducted using IBM SPSS V.20.0 software. Social

network data will be analysed using NodeXL (V.1.0.1.92) to generate social network metrics and sociograms.

ETHICS AND HUMAN PROTECTION

The data collection process will be conducted at the treatment centres of RNTCP or at the place of residence of patients with TB as per his/her willingness. Prior permission for conducting interviews at the centres will be obtained and will be done in a private place to ensure privacy and confidentiality. Interviews which are conducted at the patient's residence will be done only with the patient alone and not in the presence of others. Appointments will be fixed with patients at their convenience. Informed consent will be followed by a detailed explanation of the objectives and the information expected from them about their social networks and related support. It will be clarified to the participants that interviews will involve only them and that no contacts will be made with any of their social network contacts. Confidentiality of network information will also be assured. Participants will be requested to provide information on social networks based on their complete willingness. We will ensure that the interviewer is of the same gender as the participant if the participant feels discomfort in sharing network relations with the opposite gender. Participants will not be compelled to disclose the actual names of their network members and will be provided the option to use nicknames. If participants are not willing to disclose all their network relations but only some, they will not be compelled further. Participants will be provided the option to withdraw from the interview if they feel uncomfortable. As interviews will involve personal questions related to the social networks and related support, we will involve trained and experienced study staff to make the interview comfortable for participants. Participants will be provided compensation for travel, food and time spent on the study. We will motivate and counsel patients who were lost to follow-up to continue treatment. We will work in coordination with the programme staff to support LFU patients to continue treatment. For willing patients, we will link them with local community organisations and community volunteers—who are already working as part of the TB-free city project—to meet their needs. All data forms will be kept confidential, and all analyses will be performed by delinking the names of patients. Names/nicknames of the social network members will not be entered during the data entry process, and only relationship types will be entered. All data forms will be kept strictly confidential and data access will be password-protected. We will also be disseminating our findings to programme and research stakeholders involved in the TB programme in India, and possible interventions will be discussed and communicated with policy makers. A manuscript with the key findings of this exploratory study will be published in a peer-reviewed journal. After completion of the study and after the key findings have been published, data requests could be submitted to the researchers at the School of Public Health, SRM University.

DISCUSSION

This exploratory SNA will highlight the size and composition of social network of patients with TB and the different types of support they received during the treatment period. The study will throw light on the complexity of the multiple needs of patients with TB and the network relations which have enabled them to address these multiple needs. Study findings will highlight whether the social network supports received by patients with TB will influence their treatment outcomes and adherence or not. Identifying the gaps in social network support between patients with TB and different treatment outcomes and adherence will further lead to the design and testing of the effectiveness of tailored social network-driven interventions to address gaps in patient support systems through randomised network intervention trials at the community level. The findings of our study could single out the specific support which is deemed essential to patients with TB, and which for them are lacking in the context of treatment adherence and completion. The findings of our exploratory study, which is limited by its cross-sectional design, could be further rigorously assessed for their causality on treatment outcomes and adherence through larger randomised network intervention trials. Our finding on the social network of patients with TB would thus address gaps in individual patient-level support mechanisms in a scientific and evidence-based way, which has not been tried anywhere before. The evidence generated by this study would be the first of its kind and would certainly encourage novel patient-centric, tailored interventions to address treatment barriers and challenges experienced by patients in resource-poor settings.

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