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A Narrative Inquiry into the Lived Experiences of Primary Caregivers of Patients with Pulmonary Tuberculosis in South India

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Abstract:

- ***Background***

Tuberculosis remains a major public health issue in India. Treatment and monitoring systems have improved under the National Tuberculosis Elimination Programme however the daily experiences of family members who care for TB patients have not been thoroughly studied. They play a vital role in ensuring that patients get their treatment, receive proper nutrition and maintain emotional stability.

- ***Objective***

To explore and interpret the lived experiences of primary caregivers of individuals diagnosed with pulmonary tuberculosis in South India.

- ***Methods***

This qualitative study uses narrative inquiry to 15 primary caregivers of pulmonary TB patients registered under NTEP at selected Primary Health Centres and a tertiary care hospital in South India. In-depth semi-structured interviews were done. Audio recordings were transcribed word for word and analyzed using inductive thematic analysis.

- ***Results***

Participants were aged between 24 and 60 years and included spouses, parents, children, siblings, and extended family members. "Caregiving in Tuberculosis: Navigating Burden, Adjustment, and Six categories were identified under a common theme "Caregiving in Tuberculosis: Navigating Burden, Adjustment and Transformation" :

- **Emotional distress and stigma after diagnosis**
- **Restructuring of daily responsibilities**
- **Financial strain and job disruption**
- **Psychological and physical exhaustion**
- **Coping strategies and resilience**
- **Personal growth and meaning-making**

Although anti-tubercular therapy was free, indirect costs and psychosocial challenges impacted caregivers well-being.

- ***Conclusion***

Caregivers of pulmonary TB patients face emotional, social, and economic pressure. Including caregiver support in TB control programs may improve both caregiver well being and patient outcomes.

Keywords: *Tuberculosis; Primary Caregivers; Narrative Inquiry; Qualitative Research; Stigma; India.*

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I. INTRODUCTION

Tuberculosis is one of the leading infection worldwide, with India having a large portion of this burden. Pulmonary tuberculosis, the most common form, requires long-term multidrug treatment and strict adherence to the treatment.

India's National Tuberculosis Elimination Programme has improved case detection and established standardized treatment methods. However, the responsibility of supporting patients through months of treatment falls on family members, especially in low-income families.

➢ *Primary Caregivers Often take on Responsibilities Such as:*

- Checking medication intake
- Preparing nutritious meals
- Following infection control practices
- Guiding patients for clinical visits
- Giving continuous emotional support

However, caregivers often face emotional distress, social stigma, financial difficulties, and disruptions to their personal and work lives. Most of the current research focuses on patients, with fewer studies exploring the experiences of caregivers in India.

Narrative inquiry is an effective way to understand how people interpret and find meaning in life events. By examining caregivers' stories, we can gain some insights into the emotional and social aspects of tuberculosis beyond clinics.

This study aims to understand the lived experiences of primary caregivers of pulmonary TB patients in a South Indian district.

II. METHODS

➢ *Study Design*

A qualitative research approach using narrative inquiry was done to capture their personal experiences regarding Caregiving.

➢ *Study Setting*

The study was conducted in selected Primary Health Centres and the Department of Thoracic Medicine at a tertiary care hospital in South India.

➢ *Study Participants*

Primary caregivers of patients diagnosed with pulmonary tuberculosis were eligible to participate.

➢ *Inclusion Criteria*

- Aged 18 years or older
- Identified as the main caregiver among many other caregivers
- Providing regular care
- Willing to provide informed consent
- Able to communicate in the local language or English

➢ *Exclusion Criteria*

- Caregivers of multidrug resistant TB patients
- Individuals with severe mental illness
- Paid caregivers
- Those unwilling to participate

➢ *Sampling and Sample Size*

Purposive sampling was used to include participants with different backgrounds. Fifteen caregivers were interviewed. Data collection continued until no new themes emerged.

➢ *Data Collection*

Data were collected through semi-structured narrative interviews lasting 40 to 60 minutes. The interview guide covered:

- Initial reactions to diagnosis
- Changing into the caregiving role
- Daily tasks done
- Social and financial difficulties
- Coping strategies
- Any support needs

Interviews were conducted in private settings. All interviews were recorded, transcribed, and translated into English.

➢ *Data Analysis*

An inductive thematic analysis approach was used. The process involved:

- Repeatedly reading to familiarize with the data
- Developing a common theme and categories

Peer review of coding and member validation enhances credibility.

➢ *Ethical Considerations*

Ethical approval came from the Institutional Ethics Committee. Written informed consent was obtained from all participants. Confidentiality and voluntary participation were prioritized.

III. RESULTS

➢ *Participant Details:*

Fifteen caregivers participated (9 females and 6 males), aged between 24 and 60 years. Their relationships include wives (4), husbands (2), mothers (2), children (3), siblings

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(2), and extended relatives (2). Occupations varied, including homemakers, farmers, students, daily wage laborers, and office workers.

➢ *Common Theme Emerged:*

- Caregiving in Tuberculosis: Navigating Burden, Adjustment, and Transformation

This theme includes the varied and complex journey caregivers experience, moving from initial shock to adjustment and personal growth.

- *Category 1: Emotional Distress and Social Stigma*

Diagnosis often brought shock and fear. Many caregivers worried about disease transmission, long-term outcomes, and social judgment. Distancing by neighbors led to feelings of isolation and emotional strain.

- *Category 2: Reorganization of Daily Life*

Caregivers reported significant changes to their daily routines. Medication supervision became a top priority. They paid more attention to hygiene and nutrition. Frequent healthcare visits disrupted work, education, and household schedules.

- *Category 3: Economic challenges*

Indirect costs like transportation, special diets, and lost wages created financial stress. Daily wage earners were very vulnerable to income loss.

- *Category 4: Psychological and Physical Strain*

Continuous stress, anxiety, and fatigue were common among caregivers. Some reported sleep disturbances and emotional exhaustion. Younger caregivers experienced interruptions in their studies or marriages, while older caregivers felt physical tiredness due to prolonged responsibilities.

- *Category 5: Coping and Resilience*

Caregivers found strength from various sources. Religious faith, family support, and encouragement from healthcare providers gave emotional stability. Increased knowledge about TB and its treatment helped reduce fear over time.

- *Category 6: Personal Growth*

Despite challenges, several caregivers noted positive changes in themselves. They described developing patience, empathy, and a strong sense of responsibility. Many saw caregiving as a moral duty and a commitment towards their family

IV. DISCUSSION

This study shows the problems faced by people who take care of pulmonary TB patients in South India. When someone is diagnosed with TB the people taking care of them get very upset. Feel ashamed because of what other people think about TB.

Even though the government provides treatment for TB the people taking care of patients still have to spend a lot of money. They also have to stop working. That causes them a lot of stress.

The people taking care of TB patients often feel anxious and tired. They do not usually go to see a doctor to talk about their feelings. What helps them is their faith, their family and the fact that they trust the doctors and nurses who are treating their loved ones.

It is also important to note that the people taking care of TB patients are very strong and they try to make sense of what's happening to them. They see taking care of someone with TB as a way to show they care. As a way to grow as a person.

These results show that programs for TB patients should not just focus on the patients but on the people who take care of them. These programs should include:

- Psychological counseling, for the people taking care of TB patients
- Help with money problems
- Policies that allow people to take time off work to take care of their loved ones
- Classes to teach people how to take care of TB patients

V. CONCLUSION

The people who take care of patients with TB have a lot of emotional and financial problems. They also have a lot of personal issues. Even though the national TB services help with the costs, the people who take care of the patients still have a lot of other expenses to worry about. If we can give the people who take care of the patients some support, it might help them feel better. It might also help the patients get better. The people who take care of the patients are very important for the patients to get the treatment.

➢ *Strengths*

- Narrative inquiry helpedto really understand what the people who take care of the patients are going through.
- We talked to people who're spouses, parents, children and siblings of the patients, so we got a lot of different points of view.
- The people we talked to were of different ages and had different jobs, which helped us understand things better.
- We did the interviews in private, so the people felt comfortable talking openly.
- We also looked at what the people said and Found some common themes.

VI. LIMITATIONS

- Only 15 people were interviewed, so we cannot be sure that what we found out is true for everyone.
- We only did the study in one area of South India, so we might not know about other areas.

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- We did not talk to the people who take care of patients with XDR-TB, so we do not know how they feel.
- What we found out is about the people we talked to, and we cannot say that it is true for everyone.
- The people we talked to might have said what they thought we wanted to hear about what they really think

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