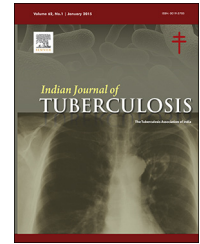


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## Original Article

# Patients' perception towards directly observed treatment – A qualitative study from Kollam district, Kerala, southern India

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## ABSTRACT

**Background:** The Direct Observation of Treatment (DOT) is an important component of the country's TB Control strategy. Standards of TB care in India and the End TB strategy emphasised the importance of a patient-centered approach to foster adherence. A qualitative study was conducted to explore the perception of people with Tuberculosis in Kerala regarding DOT, mechanisms to make the treatment of TB more patients centered and to identify the preferable mechanisms to ensure adherence.

**Methods:** Six focus group discussions were conducted – two among people with TB from rural area, two among people with TB in urban area, one among multipurpose health workers of rural area and one among key field staff of TB control in urban area.

**Results:** Patients who were on a strict DOT were unhappy about the issues of *confidentiality, patient inconvenience and provider centered approach*. A flexible, patient centered approach where a family member can act as the DOT provider with guidance from a trained health worker was evolved as the most acceptable and comfortable mode of treatment to majority of the TB patients. They felt that a strict external monitor as a DOT provider was not a necessity in majority of the cases. Only practical way to effectively incorporate ICT in monitoring patient compliance in current scenario was identified as daily phone call reminders. Patients also expressed their concerns in keeping the medicines for entire duration at home.

**Conclusion:** A flexible patient wise individualized system based on patient's behavior, literacy and awareness along with attitude of family members is needed to ensure adherence to anti TB drugs.

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## 1. Background

Revised National Tuberculosis Control Program (RNTCP) in India is shifting from intermittent regimen to daily fixed dose combinations for treating drug sensitive TB. The principle of treatment for TB henceforth will be to administer daily fixed dose combinations of first line anti-TB drugs in appropriate weight bands. Kerala is identified as one among the five States implementing daily regimen in first phase in India.

Adherence to regular and complete treatment is one of the important factors for relapse-free cure from TB.<sup>1</sup> Treatment adherence is also a critical determinant of treatment outcomes, prognosis and further emergence of drug resistance.<sup>1-3</sup> The Directly Observed Short course Strategy (DOTS) has been the backbone of country's TB programs for the last two decades.<sup>4</sup> The Direct Observation of Treatment (DOT) is an important component of the strategy and is an attempt to improve adherence by active monitoring and recording of the consumption of each and every drug dose by an 'observer' acceptable to the patient and the health system.

Some systematic reviews challenged the dogma that DOT improved cure in TB.<sup>5</sup> Also, there have been opinions that DOT is a coercive model which leaves the patient only as a passive recipient of therapy. There are also debates as to the best delivery of DOT, for example, should it be through healthcare workers or family members. Literature shows that there are varied perceptions of DOTS among TB patients and providers.<sup>6</sup>

Standards of TB care in India (STCI) and the End TB strategy emphasized the importance of a patient-centered approach to foster adherence. It has also been laid down in STCI that treatment adherence goes beyond the realm of DOTS.<sup>7</sup> Many Information Communication Technology (ICT) based models has also been piloted in the country for ensuring adherence with success.

On this background, we conducted a qualitative study to explore the perception of people with Tuberculosis regarding DOT, how the treatment of TB could be made more patient-centered and effective and preferable mechanisms to ensure adherence. Perceptions of health workers experienced in TB control were also captured. The results of this study would enrich the understanding of DOT from patient's perspective and help the policy makers and the program managers to tailor the treatment support mechanism to ensure adherence in Kerala State.

## 2. Methods

Kollam district has a population of 2.6 million and represents a typical mix of urban and rural population. Literacy rate of females is 92%. Kollam district reflects the typical state scenario in terms of geography and health care delivery. The district examined 278 per lakh TB suspects and notified 38 per lakh new smear-positive TB cases in 2014.

A total of six focus group discussions (FGD) were conducted two among people with TB from rural area, two among people with TB in urban area, one among multipurpose health workers of rural area and one among key field staff of TB control in urban area.

A FGD guide was developed and the key themes of the FGDs were (a) What is your view about DOT? (b) What do you think from your personal experience are the advantages and disadvantages of DOT? (c) What is your view about Family member acting as DOT provider? (d) What do you think should be the role of an external person or health worker in helping you? (e) How, from where, from whom, and how frequently do you prefer to get anti-TB medicines for your treatment? (f) What do you think are the reasons for non adherence to anti-TB medications? (g) What are the factors which help a person to complete his anti-TB treatment without fail? and (h) What do you think is the role of Information, Communication, Technology to help a TB patient with his/her treatment.

Multipurpose workers identified adult TB patients registered in RNTCP who had either just completed their treatment (within one month) or are in the last month of treatment and were willing to share information as participants. FGDs were conducted at the conference halls of nearest primary health centers or training centers without interference from outside. Even health workers were not allowed inside the hall. Wives of two of the patients accompanied them were allowed to hear the discussion.

The aims of the investigations and implication for participation were explained at the start of the FGDs. What is ideal DOT was also explained in the beginning. Confidentiality was ensured and participants were given a chance to opt out freely at that stage without giving any reason. Demographic details were also collected from the participants. All

**Table 1 – Socio-demographic characteristics of the study participants.**

| Characteristics       | Categories                  | Rural area<br>N = 14 | Urban area<br>N = 15 |
|-----------------------|-----------------------------|----------------------|----------------------|
| Age                   | 15–30 years                 | 1 (7.1%)             | 1 (6.7%)             |
|                       | 31–45 years                 | 3 (21.4%)            | 4 (26.7%)            |
|                       | 46–60 years                 | 6 (42.8%)            | 7 (46.7%)            |
|                       | More than 60 years          | 4 (28.5%)            | 3 (20%)              |
| Gender                | Male                        | 9 (64.2%)            | 10 (66.7%)           |
|                       | Female                      | 5 (35.7%)            | 5 (33.3%)            |
| Socio economic status | BPL                         | 11 (78.6%)           | 9 (60%)              |
|                       | APL                         | 3 (21.4%)            | 6 (40%)              |
| Educational status    | Illiterate                  | 2 (14.2%)            | 1 (6.7%)             |
|                       | Upto 4th standard           | 4 (28.5%)            | 2 (13.3%)            |
|                       | 5–9th standard              | 3 (21.4%)            | 3 (20%)              |
|                       | 10 standard pass            | 3 (21.4%)            | 3 (20%)              |
|                       | 10–12th standard            | 2 (14.2%)            | 3 (20%)              |
|                       | Graduate/post graduate      | 0                    | 3 (20%)              |
| Occupation            | Not going for work          | 4 (28.5%)            | 3 (20%)              |
|                       | Household activities        | 4 (28.5%)            | 3 (20%)              |
|                       | Student                     | 1 (7.1%)             | 1 (6.7%)             |
|                       | Unskilled/semiskilled       | 5 (35.7%)            | 3 (20%)              |
|                       | Skilled work/petty business | 0                    | 2 (13.3%)            |
|                       | Clerical/Office work        | 0                    | 1 (6.7%)             |
|                       | Semi/Professional           | 0                    | 2 (13.3%)            |

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