

# Role of Active Communication in Reducing Loss to Follow of Registered Childhood TB Cases at Tertiary Care Facility, Karachi, Pakistan

Allah Rakhia,<sup>1</sup> Taj Muhammad Laghari,<sup>2</sup> Muhammad Ayaz Mustufa,<sup>1</sup> Asif Ali Khan,<sup>3</sup> Rahila Bhutto,<sup>3</sup> Ashfaque Ahmed Memon<sup>1</sup>

Pakistan Health Research Council, Specialized Research Centre on Child Health,<sup>1</sup> Jinnah Sindh Medical University,<sup>2</sup> National Institute of Child Health,<sup>3</sup> Karachi.

## Abstract

**Background:** Loss to follow up from anti tuberculosis treatment (ATT) can result into, increase in cure time, drug resistance development, reduced probability of treatment compliance and increased chances of death. Therefore, interventions focused at improvement of treatment adherence can play a pivotal role in containment and control of TB.

**Objective:** To reduce the loss to follow up rate from existing 9% at our settings i.e. National Institute of Child Health (NICH) Karachi, Pakistan.

**Study design, settings and duration:** This prospective observational study of 18 months was conducted among children at TB clinic NICH, Karachi, Pakistan.

**Subjects and Methods:** After taking informed written consent from parent/guardian, a Performa containing demographic and clinical information was filled and a pamphlet about adherence to treatment was given to them. After one week, every patient was contacted on mobile phone; in case of no response, home visit was made and a monthly follow up was also done. Those found to have stopped taking ATT were given awareness about complications of discontinuing ATT.

**Results:** Out of 167 patients, 83 (49.7%) were males, mean age was 7.82 years and mean weight was 8.95 kg. Pulmonary TB was most prevalent (52.0%) followed by TB of lymph nodes (22.9%). More than 91% patients were cured, 8 (4.8%) were expired; one had MDR TB and loss to follow up rate reduced to 3.6% from previous 9% as per our hospital records.

**Conclusion:** A visible decrease in loss to follow up rate has been achieved through multi step facilitation via mobile phone calls, messages and house hold visits of enrolled patients.

**Key words:** Anti TB treatment, Loss to follow up rate, home visits, intervention, SMS.

## Introduction

**T**uberculosis (TB) is among the major killer diseases in children in developing countries.

### Corresponding Author:

Allah Rakhia  
Pakistan Health Research Council  
Specialized Research Centre on Child Health, Karachi.  
Email: [allahrakhia\\_pmrc@yahoo.com](mailto:allahrakhia_pmrc@yahoo.com)

**Received:** 04 March 2018, **Accepted:** 15 January 2019,  
**Published:** 29 March 2019

### Authors Contribution

AR received grant for the study. AR, TML and MAM contributed to design, conducting of the study and preparation of the manuscript. AAM participated in data analysis. MAM contributed in preparation of final draft of manuscript. TML, AAK and RB contributed to the data collection and supervision. All authors read and approved the final manuscript.

Children acquire the infection mostly from their adult contacts that can be traced by contact screening. Symptoms of the childhood TB include cough, fever, anorexia, weight loss, sweating, breath difficulty, lymph adenopathy, wheezing etc.<sup>1</sup> About one third of the world's population is infected with TB and 95% of the diseased population belongs to developing countries like Pakistan with 98% burden of global mortality owing to TB.<sup>2</sup> In 2017, among 10.4 million new cases worldwide; 1.0 million were below the age of 15 years and 250,000 of them died that year.<sup>3</sup> Unfortunately, Millennium Developing Goals (MDGs) 4 and 5 aimed at reducing the childhood mortality and improvement of maternal health do not include childhood TB however, two TB indicators have been included in MDG 6 (combat HIV/AIDS, malaria and other diseases), but there is no reference to tracking childhood or maternal TB.<sup>4</sup> High incident rate of TB and low compliance rate

with treatment even upto 40% in developing countries is leading cause of treatment failure.<sup>4</sup> The main TB control strategy includes early diagnosis and treatment of patients. It also stresses for control of the sources of infection and blocking the disease.<sup>2,4</sup> Treatment of TB requires access to appropriate health care setup and to comply with the proposed treatment if such services are available.<sup>5</sup> Delay in initiation of the treatment or incomplete treatment may result in prolonged infection, drug resistance, relapse and death.<sup>6</sup> Failure to initiate the treatment particularly in smear positive cases is a big challenge; this must be taken seriously while controlling the disease in the community.<sup>7</sup> TB is a communicable disease and negligence or non-adherence to a prescribed treatment increases the risk of morbidity, mortality and spread of disease in the community. Initial acid-fast bacilli (AFB) smear positive defaulters are one of the major barriers in preventing and treating the disease globally.<sup>8</sup> The World Health Organization (WHO) has recommended the DOTS strategy (Directly Observed Treatment, Short Course) to be used by all countries as a mean to control TB. Keeping in view the challenges of diagnosis and treatment of child TB at National TB Control Program, Pakistan has recommended scoring system to get cumulative evaluation of the disease; children are placed in various categories for treatment regimens. There is no denying of the fact that direct therapy observation is the main key of treatment success but treatment default still remains as high as 80% in certain populations.<sup>9,10</sup> According to WHO, TB treatment defaulter is a patient whose treatment was interrupted for two consecutive months or more. Immediate facilitation measures are vital for improved treatment adherence.<sup>11</sup> A study conducted in India showed that early improvement and high cost were the major causes of loss to follow up.<sup>12</sup> A work from Nepal showed that poverty, distance to treatment center, unavailability of transport, social stigma, illiteracy, trust on private clinicians and traditional healer; were major causes of loss to follow up.<sup>13</sup> Published data from Ethiopia highlighted direct relationship between loss to follow up and poor treatment outcome.<sup>14</sup> Similar findings were reported from Pakistan.<sup>15</sup> Estimated loss to follow up rate in Sindh was 7%.<sup>16</sup> It was reported 15% in Peshawar.<sup>17</sup> Consequences of loss to follow up were severe like increase in cure time, drug resistance development, need for longer treatment regimens, and high cost and reduced probability of successful treatment.<sup>18</sup>

## Subjects and Methods

It was a prospective observational study and convenient sampling technique was used for

enrolment of study population. Sample size was 167 for the said study calculated on the basis of previous study with 7% loss to follow up rate in Sindh.<sup>16</sup> It was calculated at 95% confidence interval with 3% precision using EPI info version 6.

Ethical clearance was taken from Institutional Ethical Review Board (IERB) of National Institute of Child Health (NICH) Karachi. (ERC Ref number: 14/2012) After informed written consent from parent/care givers, a pre coded questionnaire was used to collect demographic and clinical information including contact details, family history and lab parameters. A follow up questionnaire was used to collect data regarding adherence to treatment, clinical parameters, weight gain, possible adverse drug reactions (ADRs). Due to transient nature of reported ADRs, parents/ guardian were counseled accordingly and managed by attending clinician on case to case basis. Further details of execution plan are given below;

It was a four tier strategy including counseling, reminder messages, phone calls and household visits.

At the beginning of treatment, parents / care givers of each patient were vigorously counseled and a pamphlet about the need of adherence to treatment and severe consequences in case of discontinuation of the treatment was handed over to them. After counseling, contact cell phone numbers were verified for further strategies. During course of treatment, parents / accompanying individuals were debriefed about the treatment stage and counseled by senior research team member about possible ADRs on case to case basis.

Parents / care takers of every patient were reminded about their due appointment via short messaging service (SMS) and visit was noted on follow up sheet including improvement in weight, symptoms, adherence to treatment protocol, any adverse drug reaction and diagnostic tests suggested by attending clinician. During initial intensive treatment phase (two months), reminder SMS were sent on weekly basis. Later on, the procedure was repeated every 15 days till the completion of treatment.

Any of the patients, missing the visit on due date was contacted on provided phone number and was convinced to come for treatment.

If the patient did not come on committed date or could not be contacted on provided phone number, a household visit was made to bring patient back on treatment course. Furthermore, patients were also helped in their problems of communication with staff, clinicians and adverse drug reactions.

All collected data was checked for errors and completeness before it was entered on SPSS 15. Mean and range was calculated for quantitative variables. Percentages were calculated for qualitative variables.

## Results

Among 167 enrolled patients, 83 (49.7%) were males and 84 (50.3%) were females. Mean age was 7.82 years within the range of 1 to 15 years. While, mean weight was 8.95 kg.

**Table 1: Socio Demographic family profile. (N=167)**

Variable	No. of Subject (%)	%
<i>Gender</i>		
Male	83 (49.7)	49.7
Female	84 (50.3)	50.3
<i>Age (years)</i>		
	Mean ± S.D	
	7.82 ± 3.55	
<i>Weight (Kg)</i>		
	8.95 ± 7.91	
<i>Education of father</i>		
Illiterate	108	64.7
Primary	38	22.8
Matric	18	10.8
Inter	2	1.2
Graduate	1	0.6
<i>Education of Mother</i>		
Illiterate	129	77.2
Primary	29	17.4
Matric	6	3.6
Graduate	3	1.8
<i>Occupation of the father</i>		
Govt. servant	5	3.0
Private job	29	17.4
Own business	11	6.6
Skill worker	38	22.8
UN skilled	78	46.7
Retired / jobless	6	3.6
<i>Mother tongue</i>		
Urdu	48	28.7
Sindhi	31	18.6
Punjabi	10	6.0
Pashto	46	27.5
Balouchi	5	3.0
Others	27	16.2
<i>Family Income</i>		
Up to 10000	107	64.1
> 10000-,20000	54	32.3
> 20000-50000 &>	6	3.6
BCG Vaccinated	63	37.72
Family History of TB	114	68.6
History of contact	111	66.47
Past history of anti-tubercular (ATT)	9	5.4

Both mother (77.2%) and father (64.7%) did not receive formal education and belonged (64.1%) to lower income group i.e. Up to Rs: 10000/Month. Un-skilled workers were 46.7%. Predominant ethnicity was Urdu speaking (28.7%) followed by Pashto speaking (27.5%). Most of the participants

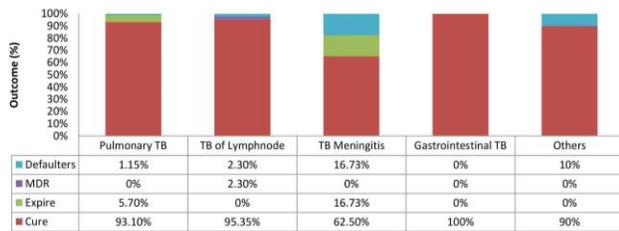
(62.28%) were BCG unvaccinated, 68.6% patients had family history of TB, 66.47% had history of contact but very few (5.4%) had history of anti TB treatment. Mean score was 9.19 as per Pakistan Pediatric Association Scoring chart derived from Kenneth Johns Criterion.

**Table 2: Laboratory profile of study participants.**

Lab Test	No. of Subject	% of Suggestive of TB
<i>TST</i>		
>10mm	109	65.26
<10mm	9	5.3
Negative	49	29.34
<i>CXR Finding</i>		
Suggestive of TB	136	82.03
Non Specific	31	11.07
<i>CSF DR</i>		
Suggestive of TB	7	87.5
Non Specific	1	12.5
<i>CSF Gene expert</i>		
Negative	2	50
Suggestive of TB	2	50
<i>ESR</i>		
<20	14	8.2
>20	153	91.8
<i>AFB smear</i>		
Positive	36	21.56
Negative	131	78.44
<i>Sputum culture</i>		
Positive	1	6.25
Negative	15	93.75
<i>Biopsy(FNAC)</i>		
Suggestive of TB	49	87.5
Non specific	7	12.5
<i>MRI / CT Scan</i>		
Non Specific	2	12.5
Suggestive	14	87.5

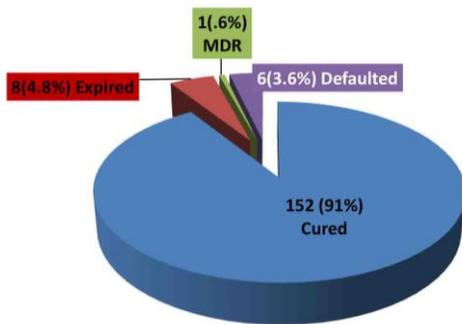
Lab parameters including X ray of 82.0% patients and ESR (Erythrocyte sedimentation rate) of 91.8% of patients were suggestive of TB. Similarly, most of the patients (65.2%) were TST positive, while AFB smear and culture on LJ media were less positive (21.5% and 6.2% respectively). Other specific tests done for particular cases of extra pulmonary TB like MRI (magnetic resonance imaging) was performed for 16 cases of TB Meningitis and 14 among them were suggestive of TB Meningitis. FNAC (fine needle aspiration cytology) was performed for 56 cases of lymphadenopathy and 49 of them were suggestive of lymph node TB. About 50% CSF gene expert were suggestive of TB while 87% CSF DR were suggestive of TB Table-2.

Pulmonary TB was most prevalent (52.0%) followed by TB of lymph nodes (22.9%), TB meningitis (9.5%), gastro intestinal TB (5.9%), while, remaining 11 (6.5%) cases were from other forms of TB. Cure rate of gastro intestinal TB



**Figure 1: Treatment outcome of various forms of TB after follow-up through active communication.**

remained 100% succeeded by TB of lymph nodes (95.34%) and pulmonary TB (93.10%). TB meningitis showed lowest cure rate (62.5%), while other forms of TB showed 90% cure rate (Figure-1). Out of 167 patients, 152 (91%) were cured, 8 (4.8%) were expired, one had MDR TB and loss to follow up rate reduced to 3.6% from previous 9% as per our hospital records Figure-2.



**Figure 2: Overall outcome of intervention.**

### Discussion

Loss to follow up rate after intervention reduced to 3.6% at our settings as compared to previous loss to follow up rate of 9% without any intervention based on our hospital records. When compared with provincial data, our study revealed almost 50% reduction in the loss to follow up rate from existing 7% in Sindh and it was achieved by using mobile phone to contact the parents /guardian of the patients to remind them about treatment completion at respective facility. This study reflects the significance of pretreatment counseling, continuous monitoring and evaluation in reducing the loss to follow up rate.

Report on Brazilian children loss to follow up rate was higher (24.2%) in first two months without any mediation.<sup>19</sup> Another study in Kenya showed 16.6% loss to follow up rate due to different factors.<sup>20</sup> In studies from India and Baluchistan,

patients receiving treatment under National TB Control Program showed remarkable decrease in loss to follow up rate i.e. 5% and 2.4 % respectively.<sup>21,22</sup> Similarly, a study from Senegal showed remarkable reduction in loss to follow up rate among interventional program (5.5%) as compared to non-interventional program (16.8%) and this was achieved via improved patient counseling, communication, decentralization of treatment, patient's choice of DOTS support.<sup>23</sup> In a study from Karachi, Pakistan, loss to follow up rate among patients with drug susceptible TB was 14.2% without intervention as compared to loss to follow up rate of 8.2% in a study from Peshawar Pakistan without intervention.<sup>17,24</sup> A Chinese study at Shanghai, rural to urban migrants providing financial assistance loss to follow up rate in interventional population was 9% as compared to non-interventional population that was 23%.<sup>25</sup>

Our results showed that most of our study population was not formally educated (64.7%), lower income (64.1%), unskilled parents (6.7) while, 68.8% children were not vaccinated for BCG. Moreover, prolonged TB treatment course, improvement of symptoms after two to three months of treatment, drug's side effects, lack of knowledge and direct or indirect economic losses incurred by the parents remained the major causes of drop outs. Through telephone calls and house visits, 11 (65%) out of 17 patients intending to loss to follow up were put back on treatment resulting in successful treatment of 91% patients (n=152) that is almost similar to an Ethiopian study that showed 93% success rate of treatment and 3% loss to follow up rate after intervention.<sup>14</sup> The findings were in contrast to 74.8% success rate denoted earlier in the same region without intervention.<sup>26</sup> Similarly, a study conducted in Baghdad, Iraq showed success rate of 94% after intervention.<sup>27</sup> Mortality rate was observed 4.8% (n=8), majority of expired patients had late stage TB meningitis and pulmonary TB, referred from multiple sites without documented proof of treatment and adherence. Prolonged TB treatment course, improvement of symptoms after two to three months of treatment, lack of knowledge and direct or indirect economic losses incurred by the parents remained the major causes of drop outs. Through telephone calls and house visits, 11 of 17 patients intending to loss to follow up were put back on treatment. We failed to bring back remaining 6 patients because their mobiles numbers went powered off and addresses were unverifiable. These results were suggestive of inclusion of phone calls and SMS (short message service) to the main TB control strategy at national level to achieve sustainable millennium development goals

proposed by WHO. It will not only help in improvement of success rates of TB treatment but will also help in minimizing spread of disease in the community and MDR development.

There are few limitations including; (1) study findings may not be generalized because study was conducted at a public sector tertiary care setting in urban area. (2) There is a chance of predictability bias of our findings due to no control arm.

Although, a visible reduction in pediatric tuberculosis loss to follow up rate has been achieved through facilitation via mobile phone and house hold visits. Additional efforts are needed to further enhance treatment compliance rate.

It is recommended that more accurate way of registration and follow up should be adopted using information communication technology for national TB registry; may be available at all TB centers. Incorporation of phone calls and SMS (short message service) to registered patients will increase the treatment compliance rate of TB control strategy at national level. Staff of TB clinics may also be enhanced for proper counseling and treatment decisions.

### Acknowledgement

Investigators are grateful to Pakistan Health Research Council for financial support via grant No:4-17-1/1/13/HPA/RDC/NICH, Karachi.

**Conflict of interest:** None declared.

### References

1. Shakoor S, Qamar FN, Mir F, Zaidi A, Hasan R. Are TB control programmes in South Asia ignoring children with disease? A situational analysis. *Arch Dis Child* 2015; 100(2): 198-205.
2. World Health Organization. Tuberculosis. *Saudi Med J* 2013; 34(11): 1205-7.
3. Tuberculosis. WHO, 2017. (Accessed on 12th February 2016) Available from URL: [www.who.int/mediacentre/factsheets/fs104/en/](http://www.who.int/mediacentre/factsheets/fs104/en/)
4. Sandgren A, Cuevas LE, Dara M, Gie RP, Grzemska M, Hawkridge A, et al. Childhood tuberculosis: progress requires an advocacy strategy now. *Eur Respir J* 2012; 40(2): 294-7.
5. Abubakar I, Zignol M, Falzon D, Raviglione M, Ditiu L, Masham S, et al. Drug-resistant tuberculosis: time for visionary political leadership. *Lancet Infect Dis* 2013; 13(6): 529-39.
6. Sagbakken M, Frich JC, Bjune G. Barriers and enablers in the management of tuberculosis treatment in Addis Ababa, Ethiopia: a qualitative study. *BMC Public Health* 2008; 8: 11.
7. Volmink J, Garner P. Directly observed therapy for treating tuberculosis. *Cochrane Database Syst Rev* 2007; 4: CD003343.
8. Gopi PG, Chandrasekaran V, Subramani R, Narayanan PR. Failure to initiate treatment for tuberculosis patients diagnosed in a community survey and at health facilities under a DOTS programme in a district of South India. *Indian J Tuberc* 2005; 52(3): 153-6.
9. Jaggarajamma K, Sudha G, Chandrasekaran V, Nirupa C, Thomas A, Santha T, et al. Reasons for non-compliance among patients treated under Revised National Tuberculosis Control Programme (RNTCP), Tiruvallur district, south India. *Indian J Tuberc* 2007; 54(3): 130.
10. Christmas S, Valente J, Gerhardt G, Penna ML. Prediction model for abandoning the treatment of pulmonary tuberculosis. *Bull Sanit Pneumol* 1999; 7(1): 65-78.
11. Malotte CK, Hollingshead JR, Larro M. Incentives vs outreach workers for latent tuberculosis treatment in drug users. *Am J Prevent Medic* 2001; 20(2): 103-7.
12. Frieden TR. What is intermittent treatment and what is the scientific basis for intermittency? in: Frieden TR Toman's tuberculosis. Case detection, treatment and monitoring. 2nd edn. World Health Organization, Geneva, Switzerland; 2004: 130-8.
13. Gupta S, Gupta S, Behera D. Reasons for interruption of anti-tubercular treatment as reported by patients with tuberculosis admitted in a tertiary care institute. *Indian J Tuberc*. 2011 Jan;58(1):11-7.
14. Lamsal DK, Lewis OD, Smith S, Jha N. Factors related to defaulters and treatment failure of tuberculosis patients in the DOTS program in the Sunsari District of Eastern Nepal. *SAARC J Tuberc, Lung Dis HIV/AIDS* 2009; 6(1): 25-30.
15. Muñoz-Sellart M, Cuevas LE, Tumato M, Merid Y, Yassin MA. Factors associated with poor tuberculosis treatment outcome in the Southern Region of Ethiopia. *Int J Tuberc Lung Dis* 2010; 14(8): 973-9.
16. Munir MK, Iqbal R, Shabbir I, Chaudhry K. Factors Responsible for Failure to Initiate Tuberculosis Treatment among Smear Positive Tuberculosis Patients. *Pak J Med Res* 2012; 51(2): 34-7.
17. National TB control Programme Pakistan, second quarter report for the year 2011, performance indicators. (Accessed on 12th February 2016) Available from URL: [http://www.ntp.gov.pk/performance\\_indicators/TO-Q2-2011](http://www.ntp.gov.pk/performance_indicators/TO-Q2-2011)
18. Wahab F, Ashraf S, Khan N, Anwar R, Afridi MZ. Risk factors for multi-drug resistant tuberculosis in patients at tertiary care hospital, Peshawar. *J Coll Physicians Surg Pak* 2009; 19(3): 162-4.
19. Pablos-Méndez A, Knirsch CA, Barr RG, Lerner BH, Frieden TR. Nonadherence in tuberculosis treatment: predictors and consequences in New York City. *Am J Med* 1997; 102(2): 164-70.
20. da Silva Oliveira VL, Da Cunha AJ, Alves R. Tuberculosis treatment default among Brazilian children. *Int J Tuberc Lung Disease* 2006; 10(8): 864-9.
21. Muture BN, Keraka MN, Kimuu PK, Kabiru EW, Ombeka VO, Oguya F. Factors associated with

- default from treatment among tuberculosis patients in Nairobi province, Kenya: a case control study. *BMC Pub Health* 2011; 11: 969.
22. Satyanarayana S, Shivashankar R, Vashist RP, Chauhan LS, Chadha SS, Dewan PK, et al. Characteristics and programme-defined treatment outcomes among childhood tuberculosis (TB) patients under the national TB programme in Delhi. *PLoS One* 2010; 5(10): e13338.
  23. Ahmad G, Qadeer E, Ahmad N, Fatima R, Khursheed Z. Defaulting Rate of TB Patients among Seasonal Migrants (A Case Study of Balochistan) *J Pak Med Assoc* 2009; 59: 112-4.
  24. Thiam S, LeFevre AM, Hane F, Ndiaye A, Ba F, Fielding KL, et al. Effectiveness of a strategy to improve adherence to tuberculosis treatment in a resource-poor setting: a cluster randomized controlled trial. *JAMA*. 2007; 297(4): 380-6.
  25. Chida N, Ansari Z, Hussain H, Jaswal M, Symes S, Khan AJ, et al. Determinants of Default from Tuberculosis Treatment among Patients with Drug-Susceptible Tuberculosis in Karachi, Pakistan: A Mixed Methods Study. *PloS one* 2015; 10(11): e0142384.
  26. Wei X, Zou G, Yin J, Walley J, Yang H, Kliner M, et al. Providing financial incentives to rural-to-urban tuberculosis migrants in Shanghai: an intervention study. *Infect Dis Pov* 2012; 1: 9.
  27. Yassin MA, Datiko DG, Tulloch O, Markos P, Aschalew M, Shargie EB, et al. Innovative community-based approaches doubled tuberculosis case notification and improve treatment outcome in Southern Ethiopia. *PloS one* 2013; 8(5): e63174.
-