

A STUDY OF PATIENTS 'LOST' FROM SHORT COURSE CHEMOTHERAPY UNDER THE DISTRICT TUBERCULOSIS PROGRAMME IN SOUTH INDIA

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ABSTRACT

A study was undertaken in North Arcot and Raichur districts in South India to find out the reasons for patients getting 'lost' from short course chemotherapy. There were 545 (40%) patients 'lost' from treatment *in* North Arcot during 14 months and 219 (46%) in Raichur during 72 months. Approximately half of the 'lost' patients from both the districts discontinued treatment within two months from the start of treatment.

Due to inadequate or incorrect address, 84 (15%) and 26 (13%) patients could not be traced at North Arcot and Raichur, respectively. Reasons could not be elicited from 39 (7%) and 16 (7%) patients, respectively, as they had migrated. Eighty-two (15%) from North Arcot and 33 (15%) from Raichur had died. For 55 (10%) patients from North Arcot and 15 (7%) from Raichur treatment had been changed. Twenty-three (4%) from North Arcot had actually completed their treatment at a different Peripheral Health Institution. Reasons for stopping treatment were obtained from 262 (48%) and 127 (58%) patients, respectively, from the two districts. Abatement of symptoms (19%, 35%), adverse reactions (22%, 13%), outstation trips (22%, 2%), lack of faith in diagnosis and treatment (10%, 27%) and taking private treatment (9%, 32%) were some of the reasons given by the patients interviewed respectively from these two districts. Some of the patients gave more than one reason.

Introduction

The District Tuberculosis Programme (DTP) as formulated in India, in 1962 to deal with the challenge of a major public health problem, tuberculosis. Under the programme, tuberculosis control is integrated into the primary health care system, and diagnosis and treatment services are available free of cost to all the people at Government health facilities (1). The programme is based on sound technological, organizational, administrative and sociological considerations. However, despite the functioning of the programme for almost three decades, there is still a gap between expectations and achievements relating to both case-finding and case-holding, which is causing concern. Radhakrishna estimates that only about 16% of the tuberculosis patients in the community are being successfully treated under programme Conditions, and that these results could be appreciably improved by increasing the efficiency of the case - finding and case - holding components of the programme (2).

One of the major constraints faced in the programme is that patients discontinue treatment prematurely. It was estimated that only 27% of the patients diagnosed during the period from 1.7.84 to 30.6.85 and prescribed standard chemotherapy received 12 collections or more of the prescribed treatment (3). It was expected that with the introduction of short course chemotherapy in the programme, patient compliance would improve appreciably. However, drop-out from treatment by patients continues to be a problem and a challenge to doctors as well as social scientists (4). In order to improve case - holding, it is essential that the factors responsible for patients' discontinuation of treatment are identified. Remedial actions can then be planned on the basis of the reasons for discontinuation of treatment. Hence a study of 'lost' cases was undertaken by the Tuberculosis Research Centre, Madras in two of the districts where short course chemotherapy is monitored by the Centre, with a view to find out the reasons for premature discontinuation of treatment (Dr.T. Santha - Personal communication).

Material and Methods

Under the District Tuberculosis Programme, patients who default for short course chemotherapy for a continuous period of one month or more are considered as 'lost' from treatment. The present study of 'lost' cases was undertaken in North Arcot district (prior to its bifurcation) in Tamilnadu and Raichur district in Karnataka. There were 545 'lost' patients from among 1353 patients started on short course chemotherapy in North Arcot district between October 1984 and May 1985 and between January 1986 and June 1986; they were considered for the investigation. In Raichur district, 219 patients 'lost' from among 472 patients started on short course chemotherapy between January 1988 and December 1988 were considered.

In North Arcot district, a fully supervised six month regimen was prescribed, with rifampicin (450 mg), isoniazid (600 mg) and pyrazinamide (2.0 G) given twice a week for the first two months followed by rifampicin (450 mg) and isoniazid (600 mg) given twice a week for the next four months. In all, patients were required to attend the health facility on 52 occasions during the six months of chemotherapy. Most of the patients belonged to low socio-economic strata with low literacy status (the study period preceded the total literacy mission efforts in many districts of the country). The locally literate neighbours were requested to read investigators' letters to the illiterate patients. There were town and village dwellers in both districts. For patients who defaulted, the first defaulter action was taken on the same or the next day and the second action on the eighth day, mostly by letter. Patients who missed some doses due to default were given a grace period of upto two months, i.e., they could complete 80% or more of the prescribed chemotherapy over a period of eight months. In Raichur district, an eight month regimen was prescribed, namely rifampicin (450 mg), isoniazid (300 mg) and pyrazinamide (1.5 G) daily for the first two months, followed by thioacetazone (150 mg) and isoniazid (300 mg) daily for six months. It was an unsupervised regimen and patients attended the health facility to collect a supply of drugs once in 15 days, and were required to make 16 collections during the prescribed period of chemotherapy. In both the districts, streptomycin injections (0.75 gm) were given in those centres where facilities for injections were available during the first two months.

The homes of the lost patients were visited by the Centre's medical social workers using the

addresses recorded in the treatment cards. During these visits, the patients, or responsible family members in the absence of the patients, were interviewed in detail and a structured schedule was filled up for each patient on the basis of the information obtained. Care was taken to establish good rapport with the patients and their family members; the interviews were conducted at the patient's residence in a relaxed and conducive atmosphere. Attempts were made to get the real and underlying reasons for dropping out of treatment through informal and deep-probing interviews. Efforts were made to collect sputum specimens from the patients contacted. Wherever possible, attempts were made to conduct discussions at patients residence to ascertain causes of death (verbal autopsies).

Results

Of 1057 male patients admitted, 453 (43%) were 'lost' from treatment in North Arcot (Table 1).

TABLE - 1

Proportion of 'Lost' patients by age and sex

Age (Years)	Males			Females			Both		
	No. admitted	Lost No.	% Lost	No. admitted	Lost No.	% Lost	No. admitted	Lost No.	% Lost
NORTH ARCOT									
15-24	114	48	42	77	18	23	191	66	35
25-34	239	93	39	96	30	31	335	123	37
35-44	266	107	40	65	26	40	331	133	40
45-54	263	120	46	36	14	39	299	134	45
55-64	138	69	50	20	3		158	72	46
65-74	33	14	43	2	1	18	35	15	44
> 75	4	2		0	-		4	2	
Total	1057	453	43	296	92	31*	1353	545	40
RAICHUR									
15-24	52	23	44	24	8	33	76	31	41
25-34	80	38	48	43	21	49	123	59	48
35-44	89	40	45	33	16	48	122	56	46
45-54	62	34	55	15	7		77	41	53
55-64	48	23	45	11	4	41	59	27	43
65-74	14	5		1	0		15	5	
> 75	0	-		0	-		0	-	
Total	345	163	47	127	56	44	472	219	46

* Difference between female and male lost cases significant (p = 0.001)

Among 296 female patients started on Short Course Chemotherapy, 31% were 'lost'. The percentages of 'lost' patients from different age groups in relation to the total patients admitted varied between 35 and 46. In Raichur, 47% of the male patients and 44% of the female patients started on short course chemotherapy were 'lost'. The percentages of 'lost' patients in different age groups ranged between 41 and 53.

Considering the month at which patients got 'lost' in relation to the number of doses received or collections made before getting 'lost'. 43% of the 'lost' patients had discontinued treatment during the first month itself after the start of treatment in North Arcot district (Table 2).

TABLE - 2

Month at which 'lost' related to No. of doses received in North Arcot district

No. of doses received	Month at which 'Lost'					Total	
	1	2	3 & 4	5 & 6	7 & 8	No.	%
1-5	187	6	4	-	-	197	36
6-10	46	44	8	-	-	98	18
11-15	-	45	23	2	-	70	13
16-20	-	8	37	5	1	51	9
21-25	-	-	26	18	0	44	8
26-30	-	-	19	12	3	34	6
31-35	-	-	7	18	8	33	6
36-39	-	-	-	9	9	18	3
Total No.	233	103	124	64	21	545	
%	43	19	23	12	4	100	

As regards the chemotherapy received before getting 'lost', 197 (36%) had received only one to five doses of the prescribed treatment. Of these, 63 patients had received only one dose, i.e. the first dose. As many as 187 (34%) of the patients were 'lost' during the first month itself after receiving less than six doses. Of the 98 patients who had received six to 10 doses before getting 'lost', 46 had discontinued treatment during the first month, 44 Patients during the second and eight patients during the third or fourth month.

In Raichur district (Table 3), 32% of the losses occurred in the first month and 18% in the second month.

TABLE - 3

Month at which 'Lost' related to No. of collections made in Raichur district

No. of doses collections	Month at which 'Lost'					Total	
	1	2	3 & 4	5 & 6	7&8	No.	%
1	59	-	-	-	-	59	27
2	11	16	-	-	-	27	12
3	-	19	7	-	-	26	12
4	-	5	20	-	-	25	11
5	-	-	16	-	-	16	7
6	-	-	12	5	-	17	8
7	-	-	5	5	-	10	5
8-12	-	-	3	23	13	39	18
Total No.	70	40	63	33*	13	219	
%	32	18	29	15	6	100	

* Mainly due to abatement of symptoms

Twenty-seven percent of the 'lost' patients had made only one collection (i.e. at the start of treatment) while 12% had made two collections and had discontinued treatment within two months after the start of treatment. Of the 26 patients who had made three collections, 19 were 'lost' during the second month and seven in the third or fourth month.

As regards the outcome of home visits (Table 4), of the 545 'lost' patients from North Arcot district, 15% could not be traced at the addresses recorded in the treatment cards; in Raichur district, 13% of 219 could not be traced.

TABLE - 4

Outcome of Home visits

Outcome	North Arcot		Raichur	
	No.	%	No.	%
Inadequate/incorrect address	84	15	28	13
Migrated	39	7	16	7
Expired	82	15	33	15
Treatment changed	55	10	15	7
Treatment completed	23	4	0	0
Reasons elicited	262	48	127	58
Total	545	99	219	100

Seven percent had migrated on a permanent basis in each district and hence could not be interviewed. It was found that 15% had expired at varying intervals after discontinuing treatment in each district. In North Arcot district, 38 patients had died within a period of one month from the date of discontinuing treatment while 44 patients died later. Thirteen patients from Raichur district had died within a month of dropping out from treatment while 20 patients died subsequently. For 10% from North Arcot and 7% from Raichur district, treatment had been changed due to reasons like adverse reactions, and inability to attend for supervised treatment. In North Arcot district, 4% of the patients classified as 'lost' had actually completed their treatment at another Peripheral Health Institution (PHI); this was not documented in the original treatment cards at the PHI where treatment was started and hence these patients were considered as 'lost'. This information was obtained during house visits and verified from the current respective treatment cards.

The various reasons for getting 'lost', as obtained from the remaining 262 and 127 patients from North Arcot and Raichur districts, respectively, are given in Table 5. Some of the patients had mentioned more than one reason for discontinuing treatment.

TABLE - 5
Reasons given by patients for getting 'Lost'

Reasons	North Arcot		Raichur	
	No.	%	No.	%
Abatement of symptoms	50	19	45	35
Outstation trips	58	22	3	2
Job/loss of wage	31	12	16	13
Distance from home to treatment centre	33	13	6	5
Lack money for transport	25	10	13	10
Domestic/personal problems	42	16	22	17
Too old/sick	44	17	3	2
Adverse reactions	57	22	17	13
Dissatisfaction with treatment centre	24	9	20	16
Lack of faith in diagnosis and Rx	27	10	24	27
Taking private treatment	23	9	41	32
Total Patients	262		127	

Abatement of symptoms was given as a reason by 19% and 35% of the patients from North Arcot and Raichur districts respectively; 22% and 2% respectively, attributed outstation trips for their discontinuation of treatment. Sixteen percent of the patients from North Arcot and 17% from Raichur had stopped taking chemotherapy owing to domestic problems. These included sickness and death in the family, non-cooperation of family members in sending the patients to the treatment centres and need to repair the houses. Seventeen percent of the respondents from North Arcot and 2% from Raichur mentioned old age and sickness as a reason. They were thus unable to travel by bus or walk the distance to the treatment centres. Some failed to get escorts to accompany them to the centres. Twenty-two percent of the 'lost' patients from North Arcot and 13% from Raichur mentioned adverse reactions as a cause of discontinuing treatment. Nine percent and 16% of the patients, respectively, were dissatisfied with the treatment centre and hence discontinued treatment. Dissatisfaction with centre resulted from lack of courteous and sympathetic attitude of the clinic staff towards defaulters or patients who did not bring/posses the identification card, transfer of popular doctors of the centres, unhelpful behaviour in general of staff and doctors of the centres and non-availability of injections in the centres. Lack of faith in diagnosis and treatment was mentioned by 10% of the 'lost' patients from North Arcot and 27% from Raichur. It was found that 9% of the 'lost' patients from North Arcot and 32% from Raichur were taking treatment from private practitioners. Though dissatisfaction with the treatment centre, lack of faith in diagnosis and treatment and taking treatment from private practitioners seem to be related, only five patients in North Arcot and three in Raichur gave more than one of these reasons. Sputum specimens were collected from 229 patients in North Arcot district: of these, 104 were positive by smear and culture, 16 were smear negative culture positive and eight were smear positive and culture negative. Of 63 specimens collected in Raichur district. 32 were positive by smear and cultures nine were smear negative culture positive and one was smear positive culture negative.

Discussion

This study brings out that approximately 50% of the patients who were 'lost' from both the six-

month and the eight month regimens had dropped out of treatment within two months. Hopewell et al in an operational evaluation of the treatment of tuberculosis in Peru, reported that 60% of the patients who abandoned treatment with an eight month regimen did so in the first three months of therapy (5).

It is disturbing to note that 36% of the 'lost' patients from the six month supervised bi-weekly regimen in our study had received only one to five doses while 27% of the 'lost' patients from the eight month unsupervised regimen had made only one collection i.e. the first obligatory collection at the start. Seetha and Kale have also observed that drug default and premature stopping is appreciable in the early period of treatment and that almost 25% of the patients do not return for the second collection itself (4). Seetha et al state that about half of the 'lost' patients discontinued treatment at the second or third collection (6). The present investigation on 'lost' patients has brought out the need for obtaining correct addresses of patients at the start of treatment. Fifteen percent and 13% of the patients identified as 'lost' in North Arcot and Raichur districts, respectively, could not be traced due to inaccuracy or incompleteness of the addresses recorded in the treatment cards. When recording the address, it would be useful to note down some landmark like a temple or school near the patient's residence. This will help in tracing patients during home visits. Andersen and Banerji also stress the need for recording the addresses of patients with great care and suggest description in terms of landmarks (7).

Studies in Tamil Nadu have brought out the acceptability and usefulness of the 'address card' system in obtaining correct addresses of patients in Madras city, and in urban and rural areas (8,9,10). These studies have clearly established that the accuracy of address can be significantly improved by using the address card system which is an inexpensive, convenient and acceptable tool. This system can be introduced under programme conditions whenever it is not possible to spend additional time and effort in getting accurate addresses from patients, and also when defaulter action is predominantly by letter posting.

It was found during home visits that 4% of the 'lost' patients from North Arcot district had, in fact, Completed the treatment and that 10% in that district

and 7% in Raichur were receiving changed treatment. These patients were not 'lost' to the programme, but were considered as 'lost' based on the entries in the treatment cards. This brings forth the importance of proper documentation. However, excluding these patients from analyses changes the proportions only minimally; for example, one to five doses were received by 37% of 467 patients with the biweekly regimen and only one collection was made by 26% of 204 patients who received the daily regimen.

The data from this investigation show that abatement of symptoms, adverse reactions and domestic and personal problems (outstation trips, lack of faith in treatment, dissatisfaction with the treatment centre and taking private treatment) were often responsible for patients getting 'lost'. Pathak reported that 30% of the patients who had left treatment did so because of clash of clinic and patients' work timings, 44% on account of long period of waiting involved at the clinic, 44% felt that their disease was cured, 12% were dissatisfied with the treatment and 11% due to domestic responsibilities (11). Mankodi in a study in South Gujarat had found that 40% of the patients who had stopped treatment had done so as they felt cured and 7% due to adverse reactions (12).

The number of patients dropping out of treatment on account of abatement of symptoms, adverse reactions and lack of faith in diagnosis can be minimised by systematic and intensive initial and reseeded motivation and adequate health education. A study done by the Centre at two treatment centres in North Arcot district showed that there was an increase of 10% in treatment completion rate among patients who were motivated by 2 medical social worker initially; among patients who had repeated motivation this increase was 20% (13). Arora and Bedi reported that patients who had been specially motivated were significantly better than patients who were routinely motivated as far as regularity of drug intake was concerned (14). As the family members are interested in patient's health and welfare, they can be motivated whenever possible and used to exert a favourable influence on the patient's regularity. A study by Seetha et al showed that drug collection among patients who were motivated along with their family members was significantly better than among a control group of patients (5). The need for continuing the treatment of symptoms and

the harmful effects of irregular and incomplete treatment should be stressed. Radha Narayan, while bringing out the need to have a health education component for the National Tuberculosis Programme, suggests that health education aspects in case finding and treatment activities could be on group basis, while education for preventive activities needs a mass or community approach (16). In addition, improvements in the provider system like better services at the health facilities have to be thought of in order to improve patients' compliance. Adjustments of timings of clinics to suit patients' convenience, minimising waiting period at the clinic and prompt defaulter retrieval actions will enlist cooperation and reduce default and discontinuation of treatment (17). The personnel at the health facilities should aim to gain patient's confidence and compliance.

The reasons for default and premature discontinuation are many and complex because they involve both the provider and receiver systems. Non-compliance or non-adherence by the receiver appear to depend on human factors, calling for in-depth behavioural and sociological studies.

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