

A Study on Non-adherence to MDT among Leprosy Patients

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Abstract

MDT has proven to be a powerful tool in the control of leprosy, especially when patients report early and start prompt treatment. Adherence to and its successful completion are equally important. Unfortunately, due to a number of personal, psychosocial, economic, medical and health service factors, a significant number of patients become irregular and default from MDT. In this paper, the extent of such defaulting, its correlates and reasons are described, based on a study of six leprosy mission hospitals. Nearly 50% of patients closer to the hospitals as compared to 60% beyond have defaulted. Patients from outside the district had significantly higher default rate for all types of leprosy cases as compared to patients living close by to the centres. Motivation, counselling and frequent contact with the patients will help. Health services should also be more patient-friendly. Possible solutions and suggestions are given.

Key words: MDT, Non-adherence, Defaulting rate, Leprosy

Introduction

Adhering to a treatment schedule and successfully completing it are crucial to the control of any disease (WHO 1997, WHO 1998). Poor adherence to self-administration of treatment of a chronic disease is a common behavioural problem (Anandaraj 1986). Multidrug therapy as formulated by WHO is a powerful and effective tool for control of leprosy and its complications (WHO 1997). Low treatment completion rates nullify the effects of MDT and jeopardize the control and eradication program (WHO 2006, Joshi et al 2007).

The World Health Organization defines a defaulter as a patient who has not collected

MDT treatment for 12 consecutive months (WHO 1998). However, in common parlance, a defaulter is someone who does not complete the stipulated course of treatment. Other terms used synonymously are absentees, discontinuation, non-compliance, non-adherence etc, each having slightly different connotation.

In a number of national programmes, as many as 40% of newly detected patients have been considered defaulters (Griffiths and Rean 2001, Coebergh and Buddingh 2004). Several studies in India have addressed the issue of non-compliance to treatment and defaulting (Anandaraj 1986, Gopalakrishnan 1986, Kannan and Sivaram 1992). As long as

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defaulters continue to live in their place of residence and have yet to complete the full course of MDT treatment, they remain potential sources of infection, and the patients suffer from irreversible complications.

The reasons for defaulter rates will be not only due to several sociodemographic and economic factors but may depend on a variety of leprosy service variables (Langhorne et al 1986, Vadher and Laljee 1992, Heijnders 2004, Williams 2005), which at present are in the state of flux due to the process of integration in several countries, including India. There may also be disease related factors such as incidence of complications, worsening of the symptoms, etc. which might affect the health seeking habits of the affected persons (Wong 2002), or even quality of health service factors, especially in the integrated setups (Heijnders 2004). A comprehensive study of defaulters is therefore essential at this stage of national eradication programme, for taking appropriate remedial actions including counselling, improvement of integrated leprosy services, etc. In this paper, the defaulter rates in a sample of Leprosy Mission Hospitals are described and the reported reasons for defaulting.

Material and Methods

This study was done in two phases: In the first phase, out of 18 TLM hospitals located all over India, a representative sample of Six TLM hospitals in UP (Faizabad, Naini), Delhi (Shahdara), West Bengal (Kolkata, Purulia), Maharashtra (Kothara) were chosen for estimating the defaulter rates and their association with selected sociodemographic factors. All newly diagnosed untreated leprosy patients registered during 2001-2004 at these centres were included in this study. For the second phase, three of these centres were randomly chosen for ascertaining the

reasons for defaulting. As per the current policy of TLM, every newly diagnosed untreated case of leprosy is given the 1st dose and referred to government dispensaries close to the place of residence of the patient. Only when the patient returns with the intention of continuing the MDT at the TLM centre will s/he be registered from the 2nd dose onwards and the record is maintained in the separate MDT register. The following essential information were collected from the MDT register and cross-checked with the patient's charts: the date of starting MDT (1st dose), date of 2nd dose of MDT, and number of pulses, date of last MDT, date of RFT, age, sex, type of leprosy, address, disability grade and bacterial index. A sub sample check was done by the Supervisory staff. Data were entered on microcomputers on Excel sheets, checked for inconsistencies, and analysed using SPSS statistical software.

In this study, a defaulter is defined as a patient who has not collected the MDT for 3 consecutive months and had discontinued the treatment.

Defaulter rates were computed for each centre, noting the point of defaulting.

For the second phase, a post-graduate social worker was recruited to visit the homes of defaulting patients as well as a control group of patients who were released after successful completion of treatment during the same period. The field investigator was trained in collecting the relevant data on reasons for defaulting, using a special interview checklist.

Results

A total of 6291 new untreated cases of leprosy who received MDT in the six TLM hospitals were followed up. Of these, 2754 are from within the districts in which the TLM centres were located and 3536 from outside. Since there are only minor variations in the

defaulter rates and its correlates among the 6 TLM centres, the data are pooled.

Including the 1st dose, the overall defaulter rate for patients within the district was 46%, and for those outside the district, 60%. Excluding the 1st dose, the defaulter rate reduces to 37% for patients within the district and 50% for the outsiders. The defaulter rates by sex and type of leprosy are presented in table 1.

Although women in general had higher defaulter rates as compared to men, the differences did not attain statistical significance. Patients from outside the district had significantly higher defaulter rates for both MB and PB ($p < 0.05$), as compared to patients living close by to the centres.

The Defaulting rates varied according to the number of pulses taken, and the findings are given in table 2. Maximum defaulting seems to occur at the beginning of MDT.

The reasons given by patients for defaulting will now be presented based on the second stage of the study, where 3 centres were chosen. Despite noting down the addresses as given by the patients at the time of registration, the field investigator could

not locate the defaulters in nearly half the cases, mainly due to wrong or incomplete address given. Other reasons are as shown in table 3.

Of those who were contacted, the reasons for defaulting were classified into 3 categories (a) Personal factors (b) Medical problems and (c) Health service related factors.

Personal factors included stigma and other social, psychological reasons and economic reasons such as travel costs, loss of wages, etc. Under the medical problems were the worsening of the disease, reactions, non-disappearance of patch or other symptoms, or even a feeling that they have been cured as their symptoms disappeared. Health service related factors included complaints about health staff behaviour, lack of proper instructions or guidance, drug shortage, etc. In many instances, there were multiple factors and poor motivation for continuing the MDT. The salient summary of reasons is presented in table 4.

Despite defaulting, nearly 80% of patients expressed the feeling they had improved and 15% stated that there was no change in their disease status. Only about 20 patients (5%), felt that the disease worsened.

Table 1 : Defaulter rates by sex and type of leprosy

| Dose | Residence | MB | | | | PB | | | |
|--------------------------------|------------------|------|------|--------|------|------|------|--------|------|
| | | Male | | Female | | Male | | Female | |
| | | n | % | n | % | n | % | n | % |
| Including 1 st dose | Within district | 666 | 48.9 | 291 | 51.7 | 186 | 35.4 | 109 | 37.5 |
| Including 1 st dose | Outside district | 1406 | 64.3 | 470 | 61.4 | 156 | 40.1 | 83 | 43.9 |
| Excluding 1 st dose | Within district | 480 | 40.8 | 222 | 44.9 | 106 | 23.8 | 73 | 28.6 |
| Excluding 1 st dose | Outside district | 952 | 54.9 | 332 | 52.9 | 73 | 23.9 | 48 | 31.2 |

Table 2 : Early / Late defaulter rate

| Defaulters | | MB | | | | PB | | | |
|--------------------------------------|--------------|------|------|--------|------|------|------|--------|------|
| | | Male | | Female | | Male | | Female | |
| <i>Including 1st dose</i> | | n | % | n | % | n | % | n | % |
| Within district | NO | 696 | 51.1 | 272 | 48.3 | 339 | 64.6 | 182 | 62.5 |
| | After 1 dose | 186 | 13.7 | 69 | 12.3 | 80 | 15.2 | 36 | 12.4 |
| | During 2-6 | 317 | 23.3 | 150 | 26.6 | 106 | 20.2 | 73 | 25.1 |
| | During 7-11 | 163 | 11.9 | 72 | 12.8 | - | - | - | - |
| Outside district | NO | 782 | 35.7 | 296 | 38.6 | 233 | 59.9 | 106 | 56.1 |
| | After 1 dose | 454 | 20.7 | 138 | 18 | 83 | 21.3 | 35 | 18.5 |
| | During 2-6 | 688 | 31.4 | 229 | 29.9 | 73 | 18.8 | 48 | 25.4 |
| | During 7-11 | 264 | 12.2 | 103 | 13.4 | - | - | - | - |
| <i>Excluding 1st dose</i> | | | | | | | | | |
| Within district | NO | 696 | 59.2 | 272 | 55 | 339 | 76.2 | 182 | 71.4 |
| | During 2-6 | 317 | 26.9 | 150 | 30.4 | 106 | 23.4 | 73 | 28.6 |
| | During 7-11 | 163 | 13.9 | 72 | 14.6 | - | - | - | - |
| Outside district | NO | 782 | 45.1 | 296 | 47.1 | 233 | 76.1 | 106 | 68.8 |
| | During 2-6 | 688 | 39.7 | 229 | 36.5 | 73 | 23.9 | 48 | 31.2 |
| | During 7-11 | 264 | 15.2 | 103 | 16.4 | - | - | - | - |

Table 3 : Reason for not able to contact the defaulters

| Reason for not Contacted | Number | Percentage |
|----------------------------|------------|--------------|
| Wrong address | 89 | 40.1 |
| Incomplete address | 58 | 26.1 |
| Address not found | 26 | 11.7 |
| Patient change residence | 10 | 4.5 |
| Patient left home town | 32 | 14.4 |
| Denied to give information | 4 | 1.8 |
| Slum demolished | 3 | 1.4 |
| Total not Contacted | 222 | 100.0 |

Generally, the women patients defaulted more due to medical problems. Defaulting was more among the MB patients, especially after the initial pulses.

Discussion

It is generally assumed that defaulting is more when the patient's residence is far from

Table 4 : Reason for defaulting

| Reasons | Number | Percentage |
|--|------------|--------------|
| Psychosocial | 176 | 43.3 |
| Health related | 102 | 25.2 |
| Economic | 13 | 3.1 |
| Medical reasons Health care system related | 54 | 13.3 |
| | 61 | 15.1 |
| Total Defaulted | 406 | 100.0 |

the treatment centre due to travel costs and time taken. While this is true to some extent, defaulting rates are quite high even for patients closer to the centre. In fact, some patients prefer a further place from their residence as they wish to remain anonymous (Anandaraj 1986, Wong 2002, Williams 2005). The Government of India has integrated the leprosy services to make them more accessible (Joshi et al 2007), and to reduce non-compliance to MDT. While strict

adherence to any long term therapy is often not possible due to a variety of factors or circumstances, it is imperative that we aim for a reasonable degree of adherence, which will help not only in preventing transmission, but enabling the patients to not deteriorate further (Coebergh and Buddingh 2004). Reasons for defaulting or nonadherence vary from loss of confidence in the therapy to social issues such as societal stigma, and include a number of personal, financial, and other economical issues.

Apart from a firm resolve and inner strength, the patient needs the support of the family members, especially those close to the patient, as well as constant encouragement, education and counselling to complete the required course of treatment. Suitable strategies such as social marketing techniques (Wong 2002), and greater emphasis on operational guidelines on tackling the social and psychological aspects of the disease by the health staff should help.

Occurrence of complications or worsening of the disease can be a serious threat to adherence of treatment, unless proper measures are taken to reassure the patient, sufficient education on the reasons for such complications, and efficient management of the problems, medical or social (Heijnders 2004). For patients who have delayed anti leprosy treatment and developed sensory or motor loss, or have a multi bacillary form of the disease, there is a greater probability of complications, recurrences of specific problems, and consequent hospitalizations or complex medical care (WHO 1998). Combined with the strong stigma and a number of misconceptions surrounding the curability of the disease, it is necessary to institute strong support systems right from the inception of treatment. Emphasis of regularity, alertness in reporting any adverse effects, constant

encouragement from the health service staff will improve adherence to therapy, and result in more successful release from treatment (Heijnders et al 2000).

The problems of poor adherence are not unique to leprosy, and are often simpler to handle in the case of leprosy. However, it appears that the health system has not taken serious action to improve adherence and counsel patients adequately to ensure that they all complete the required course of therapy despite problems, difficulties, and constraints, either personal in nature, or arising out of disease complications. The study has identified the major reasons for defaulting, and suitable measures must be urgently taken if we have to reap the benefits of an excellent therapy for leprosy, and eventually eradicate this disease and its horrendous image.

Conclusions

Defaulter rate was quite high and did not differ by males and females. The MB defaulter rates were higher as compared to PB excluding first dose but the difference was not statistically significant. Due to wrong or incomplete address many defaulters could not be contacted. This problem was high in urban areas. The main reasons for defaulting were personal problems-69% (psychosocial & health related) Developing a different registration system for patients in urban areas will be useful. Motivation and education of the patient to complete the course of treatment is needed.

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