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What stops people completing multi-drug therapy? Ranked perspectives of people with leprosy, their head of family and neighbours - across four Indian states

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Summary

To maximise successful completion of multi-drug therapy (MDT) and optimise treatment outcomes for people with leprosy, it is vital to understand the relative importance of perceived factors which prevent them from completing the required number of doses in time.

Objective: To explore personal, family, social, community, attitudinal, practical, geographical, cultural and traditional factors which may influence adherence to treatment, a two-phase study was undertaken comprising issue identification via focus groups, and a ranking exercise via individual interview.

Study Design: The perspectives of 895 respondents (320 people affected by leprosy who were not able to complete treatment, 302 of their 'operational heads of family', and 273 of their nearby community members) across four states of India namely i.e. Andhra Pradesh (Salur), Chhattisgarh (Chandkhuri), Maharashtra (Kothara) and Uttar Pradesh (Barabanki) were collected, using a checklist interview method.

Results: Findings suggest that seeing positive changes in their symptoms as well as not seeing improvement can lead to non-completion of MDT. Problems with scheduling and travel expenses were also key issues. Better management of the expectations of people affected by leprosy and reducing the burden of treatment may

be important strategies. The importance of stigma and poverty were noted through a number of issues, none of which were particularly highly ranked.

Conclusions: The nature and diversity of perceived issues identified across respondent type and particularly region, suggest that the determinants of adherence are complex and multi-factorial. More community based approaches with greater coordination at the community level are recommended.

Introduction

A number of studies have been conducted in India, which have highlighted factors that influence completion of treatment with multi-drug therapy (MDT) for people affected by leprosy.^{1,2} Identified factors include: stigma,³ psycho-social issues,⁴ dissatisfaction with services,⁵ economic reasons,⁶ disease-related factors including worsening of symptoms⁷ and factors related to health services and facilities.⁸ Many of these factors are inter-related, and it is assumed their relative importance is also influenced by geographical, socio-cultural, demographic, disease-related and other factors.

This diversity of factors is also reflected in the array of issues identified in other countries. A study in Nepal identified major factors influencing the quality of care experienced, particularly by poor people and women.⁹ These include, attitudes and behaviour of health workers, practitioner-centeredness of the care, information sharing, the organisation of the health services, barriers to accessibility, and the referral processes. In Nigeria, it was found that scarcity of automobile fuel resulted to an increase in transportation costs which influenced adherence to treatment in the case of tuberculosis.¹⁰ In Nepal, behavioural and knowledge factors were noted,¹¹ while in China the attitudes, beliefs and behaviour of people affected by leprosy, family members and primary health care (PHC) workers towards MDT were seen as highly influential.¹²

Poverty-related variables, such as family income, household size, and migration have been noted as influential in Western Sudan,¹³ while the person's level of health education, duration of treatment, the flexibility of arrangements, and the distance between home and clinic were identified as key factors in Nigeria.¹⁴ Further, the role of gender,¹⁵ culture¹⁶ and the actions of health workers¹⁷ have also been noted to be influential in adherence to leprosy treatment in some settings.

This diversity of potential factors underlines the importance of understanding and prioritising the multifaceted nature of treatment completion and potential non-adherence. First, it would appear that across this array, the identification of the most important or key issues would provide a meaningful foundation for research and service planning. This study sought to determine the relative importance of a variety of key attitudes, beliefs, circumstances and perspectives of people affected by leprosy, and specifically identifying the most important of these.

Second, the social dimension of many of these factors indicates the possible benefit of also comparing these priorities across family and community stakeholders. Recognising that such health-related factors are not just individual decisions, but are influenced by others,¹⁸ this study also sought to explore the relative importance of these factors according to their operational head of family and a close but unrelated community member or neighbour. Culturally, most Indian families are managed by the head of the family (HoF). Within this structure, the activities of all family members are greatly influenced by the HoF, and dissent is rare. Likewise, conformity with the values of the local community is common, and local community members also influence individual behavior. As such, the views of the HoF and

close community members may be seen as highly influential in decisions regarding adherence to treatment and should be explored in seeking greater understanding of this issue.

Third, the array of issues noted in the literature across different locations suggests the potential value of comparing these priorities across different regions, using the same methodology. This study focused on four different regions in which non-adherence with MDT had been noted as problematic.

Objectives: The broad objective of the study was to identify and prioritise the main factors associated with non adherence to MDT in leprosy. Specific objectives were:

1. To compare these priorities across key stakeholders (people affected by leprosy, their respective heads of family and local community members).
2. To compare these priorities across four geographical regions.

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Methods and materials

STUDY AREA

In order to draw meaningful information for the current study, key centres were identified in four Indian states where the issue of non-adherence with treatment had been noted as problematic.¹⁹ They were Barabanki, (Uttar Pradesh); Chandkuri, (Chhattisgarh); Kothara, (Maharashtra) and Salur, (Andhra Pradesh) (Figure 1).

FOCUS GROUPS TO IDENTIFY ISSUES

Substantial exploratory research was undertaken to identify issues relevant to this topic. Thirteen focus groups were conducted to 'scope' or document issues of relevance to adherence and non-adherence with MDT in the different study areas noted above. Each focus group consisted of 8–12 individuals within each of the following groups (specifically chosen to provide a diverse range of perspectives on the topic – Table 1).

- People affected by leprosy, including those registered for leprosy treatment, some of whom continued with MDT, some who did not.
- Village leaders, including local leaders, and local teachers, also including non-medical assistants and multi-purpose workers in the National Rural Health Management Programme, who were living in a local village setting.
- Primary health care workers involved in the National Leprosy Elimination Programme, and who are often external to the local village.

All focus groups were conducted by a local Research Assistant (RA) in each region. Each RA was a social science graduate and was trained in focus group and interview research methods, and oriented regarding psycho-social aspects of leprosy. Detailed hand written notes of each focus group were taken by the RA and thematically categorised to identify common reasons why people may not adhere to MDT. Thematic summaries of all focus

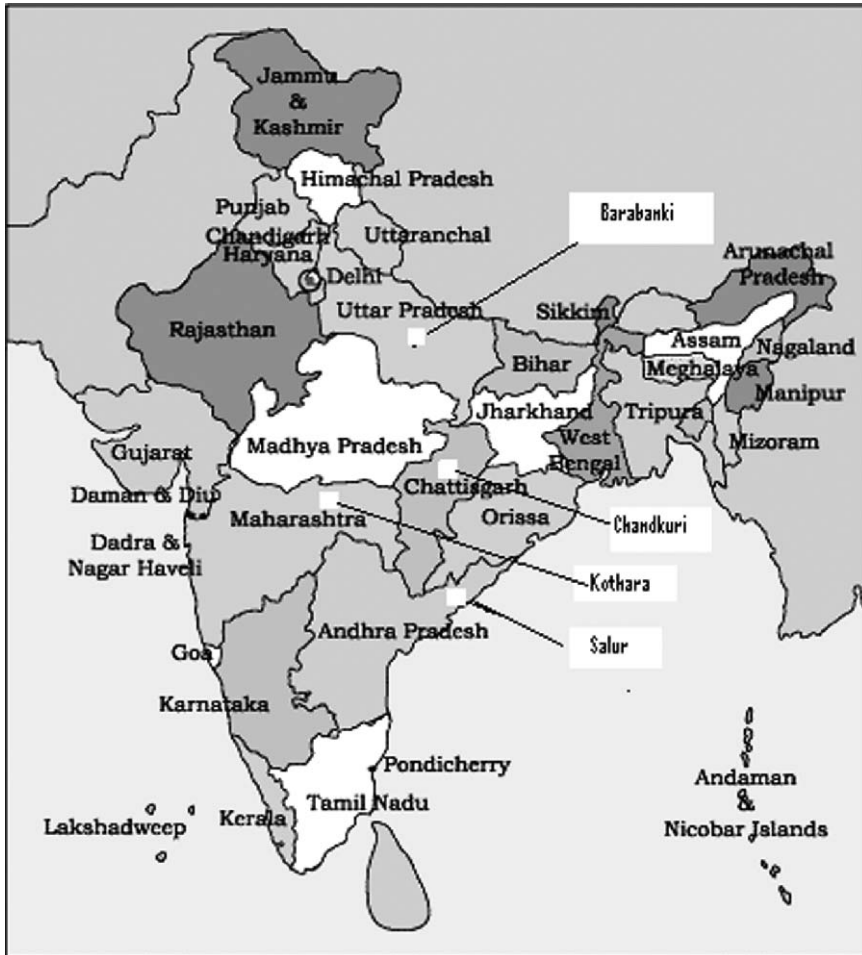


Figure 1. Map of India showing study area.

groups were combined by the first author, and the 14 most commonly noted reasons across all focus groups were defined.

Based on these 14 most commonly noted reasons, a structured interview checklist was developed (Appendix 1). This interview checklist was then used in 895 brief interviews to identify the relative importance of these key issues across regions and respondents.

Table 1. Number of focus groups across regions and participant type

	Andhra Pradesh	Chhattisgarh	Uttar Pradesh	Maharashtra	Total
People with leprosy	1	1	1	1	4
Village leaders	1	1	2	2	6
PHC workers	–	1	1	1	3
Total	2	3	4	4	13

BRIEF INTERVIEWS TO PRIORITISE ISSUES

Using the structured interview checklist, quantitative and some qualitative data were obtained in brief individual interview format from:

- People with leprosy who had been unable to complete the required number of doses of MDT as prescribed (according to data available from the treatment centres). People were selected who had been registered for treatment during 2007–2010, and who lived within 30 kilometres of the treatment centres/hospital, but who did not complete treatment.
- The respective head of family of each of the above people with leprosy. Relevant heads of family were selected purposively after contacting (and with the consent of) the person affected by leprosy.
- A nearby, but unrelated community member/neighbour, who was also selected purposively with the consent of the person affected by leprosy.

Thus a total of 895 people were interviewed using a brief interview format in which the trained Research Assistant asked each respondent about the factors they perceived as influential in contributing to non-completion of MDT in this case. With reference to reasons given by each respondent, the RA and the respondent completed the checklist noting which issues were most important in this case.

All ranking interviews were conducted by, and data were collected by the trained Research Assistants in each region. Primary data collection (including both focus groups and ranking interviews) extended over a period of 6 months, and was conducted across the four states noted above. Data from the brief interview checklist (Appendix 1) were entered into an excel spreadsheet and sent to the first author on a weekly basis. The uniformity and quality of recruitment process, data collection, and data entry was verified by a research supervisor through periodical field visits to each site.

Basic analyses, exploring means and frequencies of each response across types of respondent and regions were conducted using SPSS. Further analyses of these non-parametric data to explore homogeneity of responses across regions and across respondents applied the Kruskal Wallis test, also using SPSS for Windows.

Results

FOCUS GROUPS FOR ISSUE IDENTIFICATION

Based on focus groups, 14 key issues were identified from the analyses of focus group transcripts. The key issues noted by focus group participants as contributing to non-adherence to MDT were as follows.

- *Scheduling.* Focus group participants noted that confusion regarding the correct time or date to attend for treatment, was an important issue. They noted that in many cases, the reason people do not attend for MDT as recommended, is that they are not aware of the specific date, or that they become confused regarding when to attend. It was noted that this is a particular issue with people with limited or no literacy. When the scheduling cycle is broken, it can be difficult to restore and can lead to dropping out from treatment altogether.

- *Not Seeing Improvement.* Focus groups described a situation when people affected by leprosy undergoing MDT do not see visible changes or do not experience improvement in clinical symptoms, they may lose confidence in the effectiveness of the treatment. Participants noted that when expectations of improvement are not met, people affected by leprosy or their significant others may become unsure of the value of the treatment and may lose motivation to continue with MDT.
- *Seeing Improvement.* Conversely, it was also noted through focus group discussions that in some cases, when people affected by leprosy observe beneficial changes or experience a reduction in symptoms, they may discontinue MDT. In this case, the noticeable outcomes of early treatment may lead to stopping treatment. This issue was described in focus groups as related to a lack of awareness of the importance of consistent and ongoing treatment.
- *Being Seen at Clinic.* In cases where the treatment centre or clinic was close to the person's village or local community, they may fear being recognised by neighbours and community members as a person with leprosy. This was noted by focus group participants as a reason that some discontinue treatment. It may be attributable to social stigma associated with leprosy.
- *No Companion.* It was noted that for some, not having a companion available to assist them to attend a clinic or treatment centre was a reason for not continuing with treatment. Particularly for older people, children and women, a companion is often essential while visiting for treatment. Focus group participants described a common situation in which when no companion is available, an appointment is postponed, and when the person can then not be accompanied for subsequent appointments, people affected by leprosy lose their treatment momentum and do not continue with MDT.
- *No Family Support.* Focus group discussions noted that lack of support from family members was also a factor affecting completion of MDT. Family support to attend the clinic and adhere to treatment was regarded as important. In some instances, family members may not want to be recognised as related to a person with leprosy. They may discourage the person from attending for treatment or from attending the closest treatment centre, thereby increasing the degree of inconvenience, time and expense required.
- *No Community Support.* Focus groups highlighted the point that in the Indian context, the degree of support or hindrance provided by community and neighbours is also important. In some cases community discouragement may prevail against the positive motivations of the person or their family. The person may therefore not consistently attend the treatment centre or clinic, (or may seek treatment at a distant clinic) thereby increasing the likelihood of not completing treatment.
- *Labelling.* For some it was noted that the risk of being identified and labelled as a person with leprosy, and particularly a person with leprosy undergoing treatment, was a major concern. Focus group members felt that in order to avoid this risk, some would not attend clinics for treatment, or be inconsistent in appointments for MDT.
- *Work Commitments.* It was recognised that for some people, particularly those engaged in daily wage employment, they may be unable or unwilling to take leave from employment to attend a treatment centre. This was particularly the case where attending such a centre or clinic is likely to take substantial time. For people in such conditions, being absent from daily employment may compromise their livelihood.
- *Travel Expenses.* As expected, focus group participants confirmed that for some, the time and expense of travelling to a treatment centre or clinic was prohibitive and was a cause for not completing MDT. For some, the costs and inconvenience of travel by public (or even private) transport was a major barrier.

- *No Transport.* In some instances people with leprosy, particularly those from remote areas, may not have any access to transport (public or private). When a treatment centre is not within walking distance, the person with leprosy is likely to have to depend on unreliable means such as getting a lift or being picked up. When such rides are not available, the person may miss appointments and ultimately is likely to drop out of treatment.
- *Illness.* It was noted that in some cases, a person with leprosy is unable to attend for MDT treatment due to illness. The person's health problems (which may be related to leprosy or the actual treatment or unrelated to leprosy) or the illness of a companion may prevent people attending a centre and collecting MDT for leprosy. Missing such appointments leads to the likelihood of discontinuing treatment.
- *Alternative Treatment.* Focus group participants noted that in some instances, people with leprosy may opt to use alternative and culturally traditional treatments rather than conventional MDT. Particularly in cases where such treatments are available locally and are believed to be effective for leprosy, the person with leprosy or other influential people may prefer them to try these remedies and discontinue MDT.
- *Staff Disapproval.* It was noted that in some cases, particularly those where the person with leprosy may have not have followed instructions, missed appointments, been late, lost their ID card or tried alternatives, they may anticipate disapproval and poor treatment by staff. If people with leprosy have been unhappy with how they have been treated, or anticipate such disapproval they may be reluctant to attend appointments, which leads to discontinuing treatment.

INDIVIDUAL ISSUE RANKING

As noted in the methods section, based on the 14 issues identified through focus groups, the study then sought to prioritise the most important factors; to document the relative priorities that key stakeholders assigned to these issues. In light of the strong social dimension of many of the focus group findings (which include social concerns, fear of recognition and particularly the importance of family and community members in the choice not to continue with MDT), the ranking phase of the study specifically sought to include the views of influential family and community stakeholders. Issue ranking was conducted with people with leprosy who did not complete MDT treatment, their head of family, and also with a nearby community member/neighbour, across all four regions (Table 2).

Table 2. Number of ranking interview respondents across regions and participant type

	Andhra Pradesh	Chhattisgarh	Uttar Pradesh	Maharashtra	Total
People with leprosy who were not able to complete MDT (no of males)	93 (m = 61)	39 (m = 24)	99 (m = 55)	89 (m = 54)	320 (m = 194)
The respective 'heads of family' of each person (above)	93	39	81	89	302
A local community member/neighbour of each person (above)	93	39	52	89	273
Total	279	117	232	267	895

Table 3. Cumulative percentages of issues identified as affecting completion of MDT, by type of respondent

Issue	Person with leprosy (n = 320)	Head of family (n = 302)	Community member (n = 273)	All respondents (n = 895)
Scheduling	33.8	22.2	21.2	27.6
Not Seeing Improvement	29.1	20.3	15.3	23.1
Seeing Improvement	44.7	34.4	22.5	36.3
Being Seen at Clinic	8.1	5.3	10.9	8.7
No Companion	10.9	6.2	9.1	9.3
No Family Support	4.4	2.5	8.8	5.5
No Community Support	2.5	0.3	8.1	3.9
Labelling	14.4	8.8	13.4	13.1
Work Commitments	10.9	7.5	8.1	9.5
Travel Expenses	20.6	14.7	15.0	17.9
No Transport	6.9	4.7	6.9	6.6
Illness	21.2	8.8	11.2	14.7
Alternative Treatment	11.6	5.0	9.1	9.2
Staff Disapproval	4.4	2.8	0.9	2.9

The gender breakdown for people affected by leprosy shown in this table indicates that approximately 61% were male. The gender of their respective head of family and community member/neighbour was not recorded, however it is noted nearly all heads of family were male, and the majority of neighbour respondents were also male.

The ranking exercise sought to identify which of the 14 issues were the most important contributors resulting in discontinued treatment in each case. That is, the main reason (or reasons) which people with leprosy, their head of family and a nearby community member saw as contributing to the person not completing MDT treatment. All instances in which respondents identified a particular issue as important in their case were tallied. Cumulative percentages of respondents (across type of respondent and region) who identified each of the 14 issues were derived. Cumulative percentages across respondent type and for all respondents are noted in Table 3.

In keeping with the main objectives, this study sought to map which were the most important barriers to completing MDT. As noted in Table 3, the cumulative percentages of identified issues across all respondents showed some issues were clearly important to a substantial proportion of respondents (well over 20%) noted that Scheduling, Not Seeing Improvement, and Seeing Improvement stopped them completing MDT. Approximately 15% of respondents stated that Travel Expenses, Labelling and Illness were influential causes. The remaining issues were reported by around 10% or less of all respondents, and are not the main focus of this paper. Table 4 highlights those issues which were consistently ranked among the top priorities across respondent types and regions. For ease of interpretation, this table highlights the top 7/14 priorities, across respondent type and region and notes which were ranked in the top 7/14 consistently across respondent type and region.

Beyond highlighting the key barriers to completion of MDT, the current study also sought to explore the degree of consistency or diversity of these responses across types of respondent and region. Table 5 reflects a very high degree of diversity of responses across regions, and considerable diversity of responses across respondent types for issues, particularly those which were ranked as the most important priorities.

Table 4. Top ranked priorities across respondent type and region, (noting priorities which were ranked highly across all respondents or all regions – shaded)

Issue	All Respondents			All Regions			
	Person with leprosy	Head of family	Community member	Uttar Pradesh	Chhatisgarh	Maharashtra	Andhra Pradesh
Scheduling	2	2	2	3	2	2	3
Not Seeing Improvement	3	3	3	1	7	5	2
Seeing Improvement	1	1	1	4	1	1	1
Being Seen at Clinic			7		5		6
No Companion				7		6	
No Family Support							
No Community Support							
Labelling	6	5	5		3	3	
Work Commitments		7		5			
Travel Expenses	5	4	4	2	6	4	7
No Transport						7	
Illness	4	6	6	6	4		5
Alternative Treatment	7						4
Staff Disapproval							

Discussion and Conclusions

In order to focus on the key barriers to completing MDT, the study has (a) highlighted the most highly ranked priorities across respondent type and region, (b) noted which of these are ranked highly across respondent type and region, and (c) identified the degree of consistency of ranking each of these priorities across respondent type and region.

Table 5. Kruskal-Wallis test, noting diversity of responses across respondents and regions

Issue	Respondent		Region	
	Chi-Square value	<i>p</i> -value	Chi-Square value	<i>p</i> -value
Scheduling	16.216	0.000**	168.232	0.000**
Not Seeing Improvement	18.310	0.000**	36.968	0.000**
Seeing Improvement	35.195	0.000**	202.039	0.000**
Being Seen at Clinic	7.584	0.023	269.361	0.000**
No Companion	4.457	0.108	88.808	0.000**
No Family Support	13.321	0.001**	219.517	0.000**
No Community Support	29.562	0.000**	158.194	0.000**
Labelling	5.425	0.066	301.851	0.000**
Work Commitments	2.656	0.265	100.356	0.000**
Travel Expenses	5.114	0.078	114.937	0.000**
No Transport	1.768	0.413	114.269	0.000**
Illness	23.585	0.000**	158.451	0.000**
Alternative Treatment	8.978	0.011	66.905	0.000**
Staff Disapproval	7.187	0.027	49.538	0.000**

** Significant at the 0.01 level.

RANKED PRIORITIES

Two of the most highly (and most consistently) ranked issues across respondent type and region were *Seeing Improvement* and *Not Seeing Improvement*. Discontinuing treatment because a person observes substantial improvement (and therefore assumes treatment is no longer required), or conversely discontinuing because the person doesn't see any improvement and assumes treatment is ineffective, have a number of similarities. These two somewhat contrary but parallel findings are an interesting aspect of the present study, and are partially consistent with other studies in which worsening of symptoms⁷ or not seeing improvement²⁰ were noted as a barrier to completing MDT. Interestingly the converse issue of discontinuing treatment due to seeing an improvement in symptoms, appears not to have been picked up in previous studies, but was a key finding in the present study. It was identified by 29% of people affected by leprosy and 23% of respondents in general (Table 3), and ranked as the third most important issue across respondents and regions (Table 4). It might be observed that not completing MDT because of symptom improvement or because of worsening of symptoms are both in part a function of a breakdown or failure in clinical communication. Both pertain to the level of understanding of the person with leprosy and other stakeholders regarding the importance of consistent treatment, course and effects of treatment, and health effects. In response it would seem that orienting MDT services towards more effective communication, ensuring that the person with leprosy and their community have a greater understanding of the likely trajectory of the condition and responses, and importantly ensuring adequate 'expectation management' may be an important priority.²¹ Understandably people with leprosy often expect dramatic and observable change.²⁰ Expectation management recognises that a person's expectations are a key driver for their actions and decisions, and that these can be influenced by establishing trust, explaining carefully, and educating in a practical and timely manner.

Also highly and consistently ranked across respondents and regions, *Scheduling* issues were associated with confusion regarding the correct time or date to attend for treatment. This was reported in the present study as the second most important barrier to completing MDT (Table 4) and by over a third of people affected by leprosy as a key factor (Table 3). Scheduling difficulties may be linked to limited literacy, and relate to the coordination and organisation of service delivery.⁹ Ensuring that people are able to consistently attend as scheduled is clearly an important issue in leprosy treatment. One solution recently offered in India to address such coordination, education and scheduling concerns is the use of Social Health Activists at the community level.²² It should be noted that effective scheduling and expectation management are both key issues that mostly pertain to the consumer/service provider (or patient/clinic) interface. Neither is the sole domain of a single stakeholder and effectively addressing these issues requires multifaceted action with a focus on the interaction between the service and the person affected by leprosy.

The notion of *Travel Expenses* as a barrier to completion of MDT was also highly and consistently rated across types of respondent and region. Time, inconvenience and cost were noted as a key issue by almost 18% of participants (Table 3) and this issue was consistently ranked as the fourth most important concern across type of respondent and region (Table 4). These issues have been noted in a number of studies, and these findings are consistent with this body of research.^{14,23,24}

Beyond the main findings noted above there are numerous aspects of this study that overlap with previous research. For instance, in a similar, but smaller study, located in one state in India, it was noted that 'adverse drug reactions' were a key reason for non-adherence.²⁴ In the current study the highly ranked and consistently noted issues of *Not*

seeing improvement and *Illness* may encompass this issue. Kar and colleagues also found loss of occupational income and work commitments to be the primary reason for non-attendance at clinics. In the current study, difficulties due to *Work commitments* were noted as a relatively minor issue, and in most cases not in top 7/14 reasons. This may in part be a consequence of the smaller population and limited geographical focus of that study,²⁴ which may have targeted a less diverse range of respondents.

Heukelbach and colleagues²⁵ found that poverty-related variables such as family income, household size, and migration were linked to non-completion of MDT. While this was not an issue specifically addressed in the current study, poverty is clearly linked with, and reflected in concerns such as *Travel Expenses*, *Work commitments*, *No Transport*, and may even relate to the availability of a *Companion*. As such, the current study may echo these observations of the importance of poverty to non-completion of MDT, but reflecting it as manifest in a number of dimensions.

STIGMA

Stigma has been seen as a key issue across leprosy treatment and rehabilitation.^{26,27} More specifically, stigma has been identified as a very important issue relating to non-adherence to MDT in India.²⁴ Interestingly, the importance of stigma was not strongly borne out in the current study, with the issue of *Labelling* only ranking just above 10% (Table 3) and just within the top 7/14 issues (Table 4). To some extent this may be due to the fact that the notion of stigma is much larger and more complex than simply *Labelling*, so *Labelling* may not have captured the extent of the issue for respondents. Stigma may be evident in fear of *Being seen at clinic*, and to a lesser extent may also be reflected through lack of *Community support* and limited *Family support*. If reflected across a number of issues, the importance of stigma is acknowledged, however it should also be noted that none of these issues were among the key concerns of respondents, regardless of type of respondent or region. As such the findings of current study may suggest that for those on MDT, for whom the initial stigma in the immediate family and community associated with diagnosis and disclosure may have faded, stigma may not be a primary factor affecting adherence to MDT.

CONSISTENCY AND DIVERSITY OF HIGHLY RANKED PRIORITIES

Table 5 depicts the degree of diversity (or heterogeneity) of responses across respondent type and region. First it is noteworthy that across regions, responses to all issues showed a very high degree of diversity, and interestingly, the top three barriers to completing MDT were the most diverse across type of respondent and region. These findings suggest that although some issues were clearly ranked more highly than others, opinions across respondents and regions were still quite diverse. Based on these findings, it is important to recognise that there are many factors that influence adherence to MDT, and that there is an array of perspectives regarding barriers to completion. This acknowledgement is supported by the multiple factors suggested in the literature and the current data (Table 3) which shows that none of the issues was noted by over 50% of respondents by respondent type or region. It may be concluded that the issue of barriers to completion of MDT is characterised by complexity.

Having noted this point, it is clear that there is much greater diversity of response by region than by respondent (Table 5). The current study suggests that there is much less consistency in reporting of key issues across the four regions. This is an important

contribution of the current study. It suggests that contextual, environmental or regional factors may be highly influential in affecting adherence to MDT. This may be a function of variations in socio-economic status across regions, pockets of disadvantage in certain regions, the number of remote areas within a region, variations in infrastructure, variations in service model, different models of service delivery, or other regional factors. The key point however is that these issues are highly complex and that a contextually and geographically responsive approach is required. Simple one-size-fits-all solutions to enhance completion of MDT will be inadequate in the face of such diversity of responses.

BURDEN OF TREATMENT

It may also be noted that collectively, a few of the issues prioritised by respondents may be associated with 'burden of treatment'. Concerns which clearly relate to the burden of MDT treatment (including difficulties with *Scheduling* and *Travelling Expenses*) were within the top concerns across all respondents and all regions (Table 4). Likewise, less highly ranked priorities (Table 3) including *No Transport*, juggling *Work Commitments*, and *No Companion* to attend clinics are all aspects of the burden of treatment experienced by people affected by leprosy undergoing MDT treatment. Even concern over *Staff Disapproval* as a result of not having adequately fulfilled the demands of treatment may be related to the burden of treatment. A study with some close parallels to leprosy, emphasised that burden of treatment includes physical demands, economic factors, scheduling issues and other impacts.²⁸ These researchers emphasised that burden of treatment is the result of an interplay of factors, and pointed to community based responses to address aspects of this interplay as a meaningful step. It would appear that a particularly important focus for future studies seeking to promote adherence and completion of treatment would be to clearly document, investigate and conduct interventions to reduce this burden of treatment.²⁸

LIMITATIONS

While this study is considerably larger than many previous studies and includes a variety of respondents across four regions, the methodology also had a number of limitations. First, our selection of 14 key issues was limited to those identified by the focus groups. While using 13 focus groups to highlight key issues may be seen as a logical and systematic way of focusing the research emphasis, it was also a limitation in that if other issues were noted by participants they were not immediately classified by the research assistant and had to be separately classified under 'other'. 'Other' issues were not enumerated in the current study and (with other demographic and disease variables) will be the focus of a future publication.

The focus of the current research on the key issues across types of respondent and region has revealed important new insights, however, detailed analysis of these data according to demographic, disease and gender variables has not been undertaken. As such, conclusions suggested in previous studies (that gender, poverty and geographic location were key barriers to completion of MDT^{9,13,15,24} have not been analysed to date. In light of the gender bias in respondents in this study (for people affected by leprosy as well as other respondents), this would appear to be an important area for further in-depth analysis. The implications of gendered patterns of non-adherence, and the influence of predominantly male heads of family warrants greater exploration.

Further, as identified in the current study, regional variations in issues noted suggest a need for more context specific approaches to maximising adherence to MDT. Despite this

finding, a limitation of the current study is that districts are very broad, and data were not collected in geographically specific ways to identify potential pockets of disadvantage or of variation. As such the nature of context specific responses requires further research.

Finally, another limitation of the current study is the person and micro system focus. The study explored the views of people affected by leprosy, their head of family and a neighbour (a social micro-system). While this is a meaningful contribution to the research base, it has not provided information of the crucial perspectives of service providers, clinic managers, primary health care workers, etc. More systemic and service relevant conclusions would have emerged from such a focus.

In conclusion, this study ranking key barriers to completion of MDT across types of respondent and region has highlighted that better management of the expectations of people affected by leprosy and other stakeholders may be important strategies. It has noted the importance of scheduling support and other actions at the patient/clinic interface. The current study has specifically highlighted the potential burden of treatment of MDT and suggested that this may also be a focus for future research. The importance of stigma and poverty were noted through a number of issues, none of which were particularly highly ranked.

The nature and diversity of issues noted across respondent type and particularly region suggest that the determinants of adherence are complex and multi-factorial. Other researchers who have recently noted the same conclusion have suggested that adherence support interventions will need to address multiple barriers. Weland and colleagues concluded that programmes which more effectively engage and support the community around the person affected by leprosy will be vital.²³ Gautam and colleagues likewise emphasised the need for alternative, more community based approaches with greater coordination at the community level.²² While the consistency of current findings with these studies is noted, a key priority for future research should be more in-depth exploration of the views of people affected by leprosy and other key respondents as to the way in which these factors impact, and how completion can be enhanced. In this regard qualitative explorations, including additional data obtained in the current study, will be important. Conversely, it will also be informative to conduct in-depth qualitative explorations of the perspectives, experiences and contexts of those who have successfully completed MDT, to further inform this important question.

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Appendix 1. Individual brief interview checklist (*translated interpretation*)

Interview checklist to identify key factors associated with non-completion of MDT				
Study NO:	Reg. No/Date:		Centre/PHC:	Block:
Name:	Age:	Sex:	Caste:	Religion:
After establishing consent, ask the following: - person with leprosy who did not complete MDT, - their respective 'head of family', - a local community member/neighbour, what factors stopped them from completing MDT. Match their response to the items below, or note "other reasons" if not covered by 1–14.			According to:	
			Person with leprosy who did not complete MDT	Their head of family.
1. Scheduling problems (including confusion about the date/time of appointments).				
2. Not seeing improvement (and being unsure whether the treatment is working).				
3. Seeing improvement (and feeling that it is OK to stop treatment).				
4. Not wanting to be seen at centre/clinic (being recognized by community members).				
5. No companion (no-one was available to accompany the person to the centre/clinic).				
6. No family support (Family members did not support the person to complete MDT).				
7. No community support (Community members did not support the person to complete MDT).				
8. Not wanting to be labeled (or be identified as a person with leprosy).				
9. Work commitments (unable to take leave from work to attend centre/clinic).				
10. Travel expenses (cost of travel to centre/clinic was too high).				
11. No transport (no reliable means of getting to the centre/clinic in time for appointment).				
12. Illness (missed appointments due to illness or health problem – self or companion).				
13. Alternative treatment (preferred alternative or culturally traditional medicine/cure)				
14. Staff disapproval (anticipated disapproval or poor treatment due to difficulties).				
Other reasons, please note				