

Qualitative Analysis of the Factors Associated with Dehabilitation of Leprosy Affected Persons

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Dehabilitation of leprosy affected persons (LAP) is unique for the disease and totally undesirable. This becomes more regrettable with availability of MDT, integrated services, and proper referral care. This study has been carried out to determine the specific factors through qualitative data analysis, contributing towards Dehabilitation of the leprosy affected persons and to identify community based solutions to prevent the phenomenon. All the qualitative methods of social science research viz. observation, in-depth interview and focus group discussions (FGDs) have been used in the study for conducting case studies. A total of 13 case studies of dehabilitated patients have been carried out in two states of India, Uttar Pradesh and West Bengal. A brief summary of case studies and findings have been presented in the paper. The case findings show various reasons such as delayed due to ignorance, economic and financial problems, defaulted from treatment due to side effects of MDT, embarrassing look of dressings of ulcers, miss interpretation of leprosy as mental illness and lack of immediate improvement after taking MDT etc., are responsible for dehabilitation of leprosy affected individuals. The qualitative analysis of case studies gives rise to the following inferences: Qualitative findings provide evidence for delay i.e. starting of proper treatment after development of deformity is a common phenomenon among the deformed, the specific phenomenon found to be prevented through special approaches include-delay of treatment after reporting to treatment centre and getting dehabilitated while treatment is going on, delay in reporting for treatment after noticing the symptoms has been found to be due to the reasons viz. ignorance, economic problem and carelessness of the family members (husband), defaulting of MDT is due to various reasons viz. psycho-social, economic and nature of treatment facilities etc. in the PHC. Discussion with the patient's family members and the neighborhoods brought out their perceptions on how to prevent the phenomenon of defaulting, which is the primary reason for Dehabilitation. The study also highlights various specific factors of the above phenomenon, with special reference to female patients and the factors promoting colonization of the dehabilitated. The community activities that have been proved to be successful in preventing/managing dehabilitation and replicable in similar situations are of three broad categories viz. Patient Involved Community Actions (PICA) such as - cured patients convincing of family members with ignorance, disbelief on MDT treatment, Financial support, Non-patient Involved Community Actions (NICA) including - somebody from family accompanying the patient to proper treatment centre, community's willingness to accept patient's family and Actions of Social Institutions (ASI) that include - IEC with details of RCS and facilities of colony, knowledge about regularity and side effects of MDT, counselling to family members about their required appropriate involvement in patient's treatment.

Key words : Leprosy, Dehabilitation, Qualitative, India

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Introduction

The leprosy affected people not only face physical impairments but also suffer psychosocial repercussions due to the community's attitude and the long-term physical and psychosocial restrictions, and this slowly push the leprosy-affected person out of the society, which is called debilitation. It has been found that debilitation is a continuous process for such leprosy affected individuals, ending in a state of beggary for some. Earlier studies pointed out that begging may be the chosen profession among people living in a leprosy colony (Kaur & Van Brakel 2002). Debilitation of leprosy patients continues in this post-elimination era of rehabilitation. A large segment of preventable disability and resultant debilitation is likely being missed. There is an urgent need for corrective and preventive measures (Seshadri et al 2015). Though the concept and need for prevention of debilitation in leprosy was realized pretty early (Mehta 1977), has not been successful in practice till post elimination era, due to lack of proper understanding of the process.

The available literature shows that, both the sociological phenomena of delay (Van Veen et al 2006) in reporting to the treatment centre for diagnosis and defaulting (Griffiths & Ready 2001) from the treatment result in development of the deformities and the visible category of the deformities (Grade-2) make the patient to exhibit the disease in the family and community. However, there have been no specific studies

establishing the relationship of these processes with the ultimate social phenomenon of de-habilitation of the leprosy patients. Availability of no reliable statistics on the quantum and degree of de-habilitation of leprosy patients has been one of the major limitations in the process.

The current study is intended to address the research question - What is the profile of correlation between the degree of debilitation and the specific associated processes and factors of the leprosy afflicted and what are the possible solutions to prevent the process of debilitation.

The main objective of the study is to determine the specific factors through qualitative data analysis, contributing towards De-habilitation of the leprosy afflicted persons (LAP) and identify community based solutions and resources to prevent the phenomenon.

Materials and Methods

Social Disability Grade

De-habilitation in general refers to non acceptance of the patients and his family members by the social network and the review of existing literature on social disability assessments shows that few scales have been described for this purpose including P-scale (van Brakel et al 2006, Stevelink et al 2012), SALSA scale (Ebenso & Velema 2009, Nardi et al 2012) and others' etc. However, after discussions with experts and community leaders, for the purpose of this study, it was decided for easy comparison, to measure de-habilitation using a simple grading similar to

Table 1 : State, District and - study centre

STATE	DISTRICT	CENTRE
UP	Barabanki	Study centre 1: Banki (urban) Study centre 2: Masuli(rural)
WB	Purulia	Study centre 3: Purulia(urban) Study centre 4: Puncha(rural)

Table 2 : Issues of Case studies and Profile of the case study respondents

Issues of Case studies	Age	Gender	Marital Status	Educa- tion	Occu- pation	Diag- nosis
1 A case of delay after noticing the symptoms due to ignorance	66	F	W	ILL	House-wife	MB
2 A case of delay after noticing the symptoms due to economic problem.	67	F	UM	ILL	House-hold laborer	MB
3 Delay of treatment after reporting to treatment centre and got dehabilitated while treatment is going on.	65	M	UM	ILL	Beggar	MB
4 A case of default from MDT due to financial problem	14	M	UM	8std	Student	PB
5 A case of default due to side effects of MDT & lack of knowledge.	22	M	M	10std	Driver	MB
6 A case of defaulter due to miss interpretation of leprosy as mental illness and seeking mental treatment.	25	F	M	ILL	Laborer	MB
7 A case of default because of changing skin color due to MDT and time consumed in the hospital for treatment	45	F	M	ILL	House-wife	MB
8 A case of defaulter due to lack of immediate improvement after taking MDT.	50	F	M	8STD	House-wife	MB
9 Defaulter of treatment due to non-availability of MDT in PHC	50	F	W	ILL	Laborer	MB
10 A case of default due to side effects of MDT and dependence on the parents.	50	F	UM	ILL	House-hold laborer	MB
11 A case of default due to embarrassment of dressing of ulcers and self care	28	M	UM	8STD	Tea Vender	MB
12 A case of default as afraid of shouting from the doctor for the delay to collect MDT.	25	M	M	ILL	Labourer	MB
13 A case of defaulting due to high cost of MDT & travelling expenses	51	M	W	ILL	Farmer	MB

M-Male, F-Female, UM-Unmarried, M-Married, W-Widowed, ILL-Illiterate

the one defined by WHO (WHO 2001) for physical grading. This study led to the following Social Disability Grade i.e.

0=living with own family, no participatory

restriction (no discrimination)

1= living with own family, with some participatory restriction (discrimination)

2= Not living with own family, De-habilitation.

Table 3 : Factors identified to be contributing towards de-habilitation

Issue of the case study	Findings from the case study
1. A case of delay after noticing the symptoms due to ignorance	a) Due to ignorance of patient's husband or close relatives, could not be diagnosed and did not receive proper treatment on right time. b) Family members (Father in laws & mother in laws) of patient's husband did not accept her in the family, but accepted latter, as treatment was available. c) Patient's mother took her to health camp for diagnosis and her husband took her to proper place of treatment. d) Though, patient's husband was not a patient, settled with her in a leprosy colony, knowing that free facilities are available for leprosy patients in the colony.
2. A case of delay after noticing the symptoms due to economic problem.	a) Due to ignorance of parents and financial problem her conditions got worsened. b) Father's friend related the disease with the Gods Curse and played major role for her de-habilitation. c) Her Granny was aged and unable to take care of her and as nobody supported her when she was in the problem, she was very upset from the entire incident and decided to stay alone in their village for rest of her life. d) Other leprosy affected helped her to cope up with the disease.
3. Delay of treatment after reporting to treatment centre and got dehabilitated while treatment is going on.	a) Dehabilitation started at his early childhood as his father died and mother got married with some another man. b) No care taker as the paternal uncle was poor, unable to give so much attention and the hotel manager did not take his problem seriously. c) Government hospital doctor has given the suggestion to him to go to the leprosy hospital after developing deformity and at the time of diagnosis he had already developed Left hand claw. d) He shifted to Purulia because in his family, there is nobody to take care of him and he developed the claw of hands and as he can get free medicine, food and shelter in the leprosy colony, he planned to stay there for rest of his life.
4. A case of default from MDT due to financial problem	Discussion with patient's family members and neighborhood has brought out the following findings. Reasons for defaulting: a) Treatment center is far off from his village and his father was a farmer and with has poor economical condition has no money for travel.

	<p>b) He was dependent on his family members and irresponsibility from his family side, played a major role.</p> <p>c) Long duration of time consuming in the treatment centre.</p> <p>Perceptions on solutions to prevent defaulting:</p> <p>a) Doctors should tell the patients & his family members about importance of regularity of treatment.</p> <p>b) MDT must be available at any nearest referral center.</p> <p>c) More IEC activities are required in the villages.</p> <p>d) For dependent patients we have to provide MDT at the patient's house itself.</p>
<p>5. A case of default due to side effects of MDT & lack of knowledge.</p>	<p>Reason of Defaulting: The discussion with his wife & family members brought out the following reasons for his defaulting:</p> <p>a) After taking MDT his skin color becomes black.</p> <p>b) His wife was not aware about his disease.</p> <p>c) Self stigma, to prevent changing of skin color and hide the disease</p> <p>d) Irresponsibility from his father side.</p> <p>e) Misguidance/ No proper education about side effects of the MDT.</p> <p>Methods for completion of MDT: Discussion with his family members & his neighborhood suggested methods of preventing defaulting as follows:</p> <p>a) Proper counseling to the pts and his family members also.</p> <p>b) Emphasis on side effects of MDT in the counseling.</p> <p>c) More IEC activities are required.</p>
<p>6. A case of defaulter due to miss interpretation of leprosy as mental illness and seeking mental treatment.</p>	<p>Reason of defaulting: Because of mental illness she defaulted, involvement of her family members played the major role in her defaulting. They mixed her condition with her mental illness and shown the irresponsibility towards the patients' treatment and her condition.</p> <p>Suggestion to completion of MDT: She suggests that in such cases it is necessary:</p> <p style="padding-left: 40px;">To give proper counseling to her husband so that they do not mix the two diseases.</p> <p style="padding-left: 40px;">Proper knowledge of leprosy & its consequences.</p>
<p>7. A case of default because of changing skin color due to MDT and time consumed in the hospital for treatment</p>	<p>a) She spent almost one year getting treatment but her condition did not show visible improvement.</p> <p>b) Her poor economical condition & frequent visit of so many private doctors was very difficult.</p>

	<p>c) Her husband is laborer and suffering from economic problem, working pressure is more and could not spend more time in the hospital for treatment.</p> <p>d) Taking the medicine from the hospital is very time consuming and in the TLM Barabanki they have spend full day for the medicine.</p> <p>e) After taking the medicines her skin becomes darker. Drugs side effects made her afraid and she discontinued the treatment.</p>
8. A case of defaulter due lack of immediate improvement after taking MDT.	<p>a) According to her son, even after taking medicine his mothers condition remained same; that is what made them to discontinue the treatment.</p> <p>b) She summarized the reasons of her problem as follows: Ignorance of herself when she developed ulcer for the first time. Poor socioeconomic condition of family. Family members did not take her condition seriously until the deformity developed. Her son is a laborer and hardly gets the free time to take his mother to the treatment center. Long distance of treatment center from her village. She is dependent for her treatment on his son.</p>
9. Defaulter of treatment due to non-availability of MDT in PHC	<p>a) Patient is widow and having no children; Her economic condition is poor, she worked as laborer and unable spend any money for treatment.</p> <p>b) MDT is not available in the PHC.</p>
10. A case of default due to side effects of MDT AND dependence on the parents.	<p>a) Her mother and father both are working as laborers and due to poor economical condition she remained illiterate.</p> <p>b) She was afraid of the drugs side effects as there was no proper counseling.</p> <p>c) Distance of treatment center is so far and she dependent on her parents.</p> <p>d) Her Parents did not give the moral support to her and did not bother about her defaulting.</p>
11. A case of default due to embarrassment of dressing of ulcers and self care	<p>a) He being a tea vendor with no parents, staying along with his brother.</p> <p>b) There is no support in completion of MDT from his family side.</p> <p>c) At time when he started the MDT, the Self Care given to him but he was so embarrassed to do his work with dressings.</p> <p>d) His poor economical condition & Poor education.</p>

	e) The compounder in the PHC did not give him enough and the correct information.
	f) MDT is not available in the CHC and PHC.
12. A case of default as afraid of shouting from the doctor for the delay to collect MDT.	a) Poor economical condition of the pts. b) His friend misguided him that doctors will scold him. c) Due to working pressure he was late for MDT and he was afraid of the shouting from the doctor for his delay.
13. A case of defaulting due to high cost of MDT & travelling expenses	a) Economic problem to buy MDT b) Absence of immediate relief makes the health not priority in villages, which was a cause for defaulting c) Based on his experiences, he suggests the following are very essential to prevent defaulting: Provision of free medicines and Free registration in hospitals and availability of medicines at a nearby treatment centre so that travelling cost to collect MDT is not there

Study area

This study has been carried out at 4 selected centres, 2 (1 rural and 1 urban) from each district, Barabanki (Uttar Pradesh) and Purulia (West Bengal) districts in India (Table 1).

Tools of data collection and Sample size

In order to understand the process of functioning and influence of different factors responsible for the de-habilitation of leprosy patients, a case study method was used for the collection of primary data from defaulted and de-habilitation patients, that have been selected from all the study centers. In-depth interviews of respondents (i.e. patient, care takers, family members, neighbors and other community members and also treatment providers has been carried out for the collection of required information and data for each and every sampled patients. A total number of 13 case studies have been conducted, and each case study required more than 4 in-depth interviews of the patient, and other associated respondents, and each interview lasted on an average for 30 minutes. Proper

arrangement was made for the interviews to provide comfort and maintain the privacy of patients.

Data analysis

Data collected through case studies were analyzed using qualitative data analysis techniques, in order to establish correlation between de-habilitation of leprosy affected individuals and responsible socio-cultural, demographic and economic factors.

Profile of the case study respondents

Out of all the 13 case studies of de-habilitated individuals, 6 were males and 7 females patients, and a majority are defaulted MB cases. 9 out of 13 cases were illiterate, 4 have up to secondary level education, representing the age groups viz. 14-25, 26-50 & 51-67 years, with low economic occupations or dependents.

Details of respondents and specific issues of each case study are summarized in Table 2.

Findings

Identification of the factors contributing towards

de-habilitation, has been attempted though analysis of these 13 case studies of de-habilitated patients, and brief summary of the case study findings are summarized in Table 3.

Discussion

The current study is unique as it aimed to understand the process of dehabilitation and has attempted to find some possible solutions. Earlier research covered several areas of vital importance which highlights the Social Problems of leprosy patients (Kurup 1991), acceptance and social inequality of the deformed leprosy patients and their families (Kopparty 1993, 1995), effect of leprosy-induced deformity on the nutritional status of index cases and their household members (Diffey et al 2000), impact of leprosy on health-related quality of life (Lustosa et al 2011) and more recently with regard to the role of impairment on activity, social participation, stigma and discrimination (van Brakel et al 2012). However, the emphasis has been only towards identification of individual factors, but not to describe process of dehabilitation. Activities such as patients cured of leprosy convincing of family members with ignorance, disbelief on MDT treatment, providing financial support to a patient when nobody from family or community supported etc are categorized as Patient Involved Community Actions (PICA), actions such as somebody from family accompanying the patient to proper treatment centre, community's willingness to accept patient's family, etc are as Non-patient Involved Community Actions (NICA) and actions such as IEC with details of RCS and facilities of colony, knowledge about regularity and side effects of MDT, counselling to family members about involvement in patient's treatment are as Actions of Social Institutions (ASI). The community's activities that have been proved to be successful in preventing/managing dehabilitation and replicable in similar situations.

While application of qualitative methods in leprosy research was a very rare phenomenon, one of the earlier examples of such research was only confined delay in presentation in the context of local knowledge and attitude towards leprosy (Nicholls et al 2003). Methodology used in the current study i.e. development of the case studies through employing qualitative methods of data collection has provided adequate scope to understand the phenomenon of de-habilitation and interfering factors at various levels. One of the qualitative findings of the study that starting of proper treatment after development of deformity is a common phenomenon among the deformed supports the main conclusion of Meima et al (2001), that the impairment status at intake was by far the most important determinant for future impairment.

Conclusions

Findings of the above qualitative analysis lead to the following conclusions viz.

1. Qualitative findings provide evidence for delay i.e. starting of proper treatment after development of deformity is a common phenomenon among the deformed.
2. The following phenomenon needs special approach to be prevented:
 - Delay of treatment after reporting to treatment centre and
 - Getting de-habilitated while treatment is going on
3. Delay in reporting for treatment after noticing the symptoms has been found to be due to the reasons:
 - Ignorance
 - Economic problem
 - Carelessness of the family members (husband)

4. Defaulting of MDT is due to:
 - Economic problem / Distance from residence to treatment centre
 - Long duration of time consuming in the treatment centre
 - Side effects of MDT (skin coloration) and lack of related knowledge.
 - Self stigma, to prevent changing of skin color and hide the disease
 - Misinterpretation of leprosy as mental illness and seeking wrong treatment.
 - No immediate improvement in her condition (almost one year)
 - Due to non-availability of MDT in PHC
 - Embarrassment of dressing of ulcers and self care
 - Afraid of shouting from the doctor for the delay to collect MDT
 - High cost of MDT & travelling expenses.
5. Discussion with the patient's family members & his neighbors, to find out their perceptions on how to prevent defaulting, brought out the following solutions:
 - Doctors should tell the patients & his family members about importance of regularity of treatment.
 - MDT must be available at any nearest referral center.
 - More IEC activities are required in the villages.
 - For dependent patients we have to provide MDT at the patient's house itself.
 - Proper counseling to the patients and the family members also.
 - Emphasis on side effects of MDT in the counselling
6. With reference to female patients the common phenomenon that could be observed:
 - Provision of free medicines and
 - Free registration in hospitals and
 - Availability of medicines at a nearby treatment centre/Involving no travelling cost to collect MDT
7. Factors promoting colonization include:
 - Initial taking of the patients to the health centre/camp for diagnosis is by patient's mother and her family side
 - After the patient starts treatment, taking the patient to proper place of treatment is done by husband.
 - Knowing the fact about availability of treatment could make the Husband's family members (Father in laws & mother in laws) accept the female patients in the family
8. Decision making about the patient's treatment and acceptance / dehabilitation is influenced by the knowledge and interpretations of the
 - availability of free facilities for leprosy pts in the colony (non leprosy suffered spouses accept the patients and settle in leprosy colony)
 - Unavailability of proper timely care from own family members and
 - Better cooperation from leprosy afflicted,
 - Free medicine, food and shelter in the leprosy colony developed tendency among leprosy afflicted to settle in leprosy colonies and planned to stay there for rest of his life.
 - Parents

- Parents' friends
- Second marriage of the widowed parents
- Employers

Way Forward

As the cured leprosy patients present in a village proved to be effective towards motivating others for better interaction and improving the understanding among the patient, family members and community members, this strategy deserves to be replicated in a more systematic way in the form of establishing some sort of 'Leprosy Care Village Committees' (LCVC) by the cured leprosy persons. Such committees should try involving village leaders, ASHA, family members of the current patients. When early symptoms happen to be identified, LCVC has to play an important role to ensure that a proper treatment centre is identified and a family member or the committee member may accompany the patient to the treatment centre. If the concept of LCVC in every village and importance of an accompanying person to any treatment centre could be introduced in the system, importance of IEC in treatment would be meaningful. This will be basically community activity based on realizing their own responsibilities and may be facilitated by any NGO functioning in the area concerned. The NGOs who work as facilitators can be trained in a systematic way. Health system research should focus on these aspects and proposed model to improve the care of LAP and prevent their debilitation.

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