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Original Article

Inter-relationships among Delay, Defaulting, Deformity and De-habilitation in Leprosy: Markers for Eradicating Leprosy in India

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In order to unravel the inter-relationships among the four D's viz. delay, defaulting, deformity and de-habilitation, a critical analyses was taken together on estimating conditional probabilities and their relationship to specific demographic, social and economic factors. In a descriptive, cross-sectional in-depth study design, all the qualitative and quantitative types of social science research methods have been used to collect data from a total representative random sample of 450 leprosy affected persons and their families in rural and urban areas of 2 states of Uttar Pradesh and West Bengal in India. Findings from univariate, bivariate and multivariate analysis confirm the significance of correlation among the 4 D's- delay, defaulting, deformity and de-habilitation; and also independently with all the possible influencing factors viz. type of leprosy, age, gender, religion, marital status, educational status and occupation, except for delay with religion and gender and de-habilitation with religion and type of leprosy. This study also arrives at conclusions that each of the four variables is strongly multiple correlated with the other three variables, may be explained as viz. Delay is responsible for defaulting, deformity and de-habilitation, while defaulting is responsible for deformity and de-habilitation; further Deformity is responsible for delay, defaulting and de-habilitation, subsequently. De-habilitation is the main feature that resulted by and results in delay, defaulting and deformity. Established complex association among the four variables confirms that any intervention addressing any one of the 4D's cannot produce any changes unless the intervention is intended to address all the 4D's simultaneously. The study confirms the need for a three arm social multidrug therapy similar to the medical multidrug therapy, where there would be one arm for curing the medical problems of leprosy, a second arm focusing on empowering the people, and a third arm for advocacy and peoples' full participative involvement.

Key words : Delay, Defaulting, Deformity, De-habilitation, Leprosy, Correlations

Introduction

Despite widespread free availability of multidrug therapy for the past three decades, the current scenario in India is dismal with over 120,000 new cases detected each year, most of them reporting late with nearly 20% already manifesting WHO grade 2 disability (WHO 2017). Thus, it seems that leprosy cannot be eradicated through medical

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interventions alone and much more needs to be done through understanding the psychosocial barriers that are preventing early reporting (WHO 2016). Simulation studies have emphasized that among several factors, only early detection and prompt treatment has the best chance of eradicating leprosy (Meima et al 1999). Defaulting from long treatment is well known for several chronic diseases, but the underlying reasons could vary (Rao 2008). Medically, the delay of proper treatment for leprosy would lead to nerve damage and physical deformities, and in fact, only when this happens would a patient report for treatment (Nicholls et al 2005, Samraj et al 2012). On the other hand, Ignorance, misconceptions and some scriptural teachings have been responsible for much of de-habilitation in leprosy (Pfaltzgraff 2003, Barkataki et al 2006). A critical analyses of the four D's, delay, defaulting, deformity and de-habilitation, taken together to unravel the inter-relationships seems long overdue (Lockwood 2005, Rao 2012). Stigma in various forms is suspected to be the major factor that seems to prevent early reporting, prompt and successful adherence to MDT, invariably resulting in progression of disabilities and deformities, ultimately ending with de-habilitation (Frist 2000, Rao et al 2008, GOI 2011). It is only recently that serious research has been undertaken to describe and manage social stigma (Dadun et al 2017, Kazeem & Adegum 2011, Kuipers et al 2013). Such research must be persistently pursued through a variety of community-based approaches (Raju et al 2014) to make an impact along with continued medical interventions. In order to investigate the characteristics and dynamics of these 4D's, a major research project was undertaken during 2015 in two hyperendemic states of India, Uttar Pradesh (UP) and West Bengal (WB), where the Leprosy Mission (TLM) has been actively pursuing leprosy work. In each state, 2 TLM centres were selected for detailed studies. In this paper, the methodology adopted and the findings are briefly reported and discussed, with succinct recommendations for future action.

Material and Methods

The design adopted was a descriptive, cross-sectional in-depth study of a representative random sample of leprosy patients in defined geographical area in 2 states of India, the West Bengal and the Uttar Pradesh. Qualified field investigators with a postgraduate degree in social sciences were trained to carry out the interviews using specially prepared schedules during 2012.

Considering the time lapsed between occurrence of symptoms and start of proper treatment all the cases reported to the treatment centre after occurrence of visible deformity are defined as *delayed*, non completion of a treatment regimen within the prescribed duration is considered as *defaulting,* any visible change in the physical structure of the body (G2) at the time of study (interview) is referred to as *deformity* and non acceptance of patient and his family members by his social network considered as *de-habilitation*.

All patients (450) who registered during the period of 2007-2011 from the The Leprosy Mission treatment centres at Purulia (WB) and Barabanki (UP) were studied. Primary data, included both qualitative and quantitative data of the respondents on the 4Ds (Delay, Defaulting, Deformity & De-habilitation) through interviews and sociodemographic and medical data extracted from the clinical records. In addition, Focused group discussions were carried out with Village leaders, Anganwadi workers, Social workers, Leprosy patients & Villagers (Male, Females & Youths) Thirteen case studies were also conducted, using in-depth interview method.

Results

Nearly a quarter of the patients (119 out of 450) were aged 18 years or under, 251 (55.8%) were 19-50 years and the remaining 80 (17.8%) were above 50 years. Approximately half were women and 279 (62%) were married. Nearly 60% were illiterate or had only primary schooling. Nearly 80% were Hindus, and almost the rest were Muslims. There was only one Christian.

Nearly 80% of the sample noticed skin patches as their first symptoms, about 69% registered for MB treatment and the proportion of un-deformed (Grade-0) patients at the time diagnosis was 70%. Further details about disease related symptoms are given in Table 1. It may be noted that disability status in some patients changed over period of time.

Delay in reporting/starting of MDT: Delay is significantly more among MB patients (56%) compared to PB patients (29.1%), (P<0.01). There are no statistically significant differences by gender or religion, significantly more delay occurred among married patients (53%) compared to unmarried patients (38.6), (P<0.01).

Table 1 : Disease related symptoms of 450 respondents

	WB N=249	UP N=201	Total N=450
First Symptoms			
Anesthesia	17(6.8)	20(10.0)	37(8.2)
Skin Patches	184(73.9)	163(81.1)	347(77.1)
Physical Deformity	14(5.6)	11(5.5)	25(5.6)
Nodules	3(1.2)	5(2.5)	8(1.8)
Type1 Reaction	0(0.0)	1(0.5)	1(0.2)
Weakness	10(4.0)	0(0.0)	10(2.2)
Ulcer	21(8.4)	1(0.5)	22(4.9)
Type of leprosy			
M.B	197(79.1)	112(55.7)	309(68.7)
P.B	52(20.9)	89(44.3)	141(31.3)
Deformity at diagnosis			
Grade-0	160(64.3)	152(75.6)	312(69.3)
Grade-1	45(18.1)	23(11.4)	68(15.1)
Grade-2	44(17.7)	26(12.9)	70(15.6)
Deformity at RFT			
Grade-0	160(64.3)	145(72.1)	305(67.8)
Grade-1	52(20.9)	32(15.9)	84(18.7)
Grade-2	37(14.9)	24(11.9)	61(13.6)
Deformity at the time of interview			
Grade-0	159(63.9)	141(70.1)	300(66.7)
Grade-1	57(22.9)	26(12.9)	83(18.4)
Grade-2	33(13.3)	34(16.9)	67(14.9)

Illiterate patients delayed significantly more (74%), (P=0.000). Significantly more delay occurred among aged patients (70%) (P=0.000).

Defaulting: There are statistically significant associations between defaulting and type of Leprosy (66.7% in MB, 22.0% in PB) (P=0.000), gender (Male 61.0%, Female 43.1%) (P=0.000), Marital status (Married 62.7%, Unmarried 36.3%) (P=0.000), Religion (Hindus 55.8%, Muslim 40.4%) (P<0.019), Educational status (Illiterate 64.5%, Graduate 33.3%, Secondary 41.5%) (P=0.001), Occupational status (Labourers >75%, Others 43.5%) (P=0.000), and Age (Aged 60%, younger 40%), (P<0.000).

Deformity: There are statistically significant associations between Deformity and Type of Leprosy (MB 43.0%, PB 13.5%) (P=0.000), Marital status (Married 39.4%, Unmarried 24.6%) (P=0.000), Educational status (Illiterate 59.2%, Secondary and above 21.1%) (P=0.000), Occupational Status (Labourers 48.2%, Others 25%) (P=0.000) and Age (Aged 63.8%, Younger 18%) (P=0.000). However, there were no significant associations with gender or Religion. Thus proportion of deformed is directly proportionate with the duration of the time gap and correlation is statistically significant (P=0.00).

De-habilitation: The rate of de-habilitation is not significantly correlated with type of leprosy (MB 22.7%, PB 17.0%), but shows significant association with gender (Male 15.4%, Female 27.3%) (P<0.002), Marital Status (Married 24.4%, Unmarried 15.2%) (P<0.020), Religion (Muslims 28.7%, Hindus 18.9%) (0.099), Educational Status (Illiterate 40.8%, Secondary 13.6%, Primary 20.6%) (P=0.00) and Age (Aged 50.0%, younger <20%) (P=0.00).

Maximum rate of de-habilitation (27.4) is among those who delayed for 25-36 months while minimum is among those who delayed for less than one year.

In summary, the univariate analyses reveal that:

- Delay is significantly influenced by type of leprosy, age, marital status, educational status, occupation, but not influenced by gender and religion.
- Defaulting from treatment is significantly influenced by all the 7 factors viz. type of leprosy, age, gender, marital status, educational status, occupation and religion.
- Deformity is significantly influenced by type of leprosy, age, marital status, educational status, occupation & time gap but not influenced by gender and religion.
- De-habilitation is significantly influenced by age, gender, marital status, educational status, occupation & time gap but not influenced by religion and type of leprosy.

Bivariate Analysis:

Results of bivariate analysis are summarized in Table 1a.

(a) Delay and Deformity: Among those delayed (diagnosed with G2 deformity), about 55% are found to be deformed (at the time of interview) and that among those total deformed (152) majority (77%) are of delayed; Chi-square test shows there is significant statistical association (p=0.000) between delay and deformity, which shows delay strongly contributes for deformity. However, the fact that as many as 45% of those delayed in reporting for treatment (diagnosed with G2 deformity) did not possess deformity (at the time of interview) and that 14% of those not delayed also possessed deformity shows that delay is not the only factor contributing for deformity and there is possibility of also other factors

contributing for deformity among those started treatment in time.

(b) Delay and Default: Among those delayed, majority (64.5%) are defaulted, which shows delay has positive association with defaulting and chi-square test shows there is significant statistical association (p=0.000) between delay and default. The fact that 42.4% among those not delayed also defaulted shows that there are other factors contributing for default.

(c) Delay and De-habilitation: Among those delayed, 72.4% are not de-habilitated, comparatively less than that of not delayed (85.2%) which shows delay's positive contribution towards de-habilitation and the fact that 14.8% of those not delayed are found to be de-habilitation shows that there are other factors contributing for de-habilitation. The Chi-square test shows there is significant statistical association (p=0.001) between delay and de-habilitation.

(d) Default and Deformity: Among those defaulted, majority (57.6%) have no deformity, which shows default doesn't contributes for deformity and 24.1% of those have deformity are defaulted shows that there are other factors contributing for default. The Chi-square test shows there is significant statistical association (p=0.000) between default and deformity.

(e) Default and De-habilitation: Among those defaulted, majority (82.4%) are not de-habilitated, which shows default doesn't contributes for de-habilitation and 24.5% of those de-habilitated are not defaulted shows that there are other factors contributing for de-habilitation. The Chi-square

Table 1(a) : Delayed Vs Deformed/Defaulted/De-habilitated

	DELAYED		NOT DELAYED		TOTAL	
	N=214	%	N=236	%	N=450	%
Deformed	118	55.1	34	14.4	152	33.8
Not deformed	96	44.9	202	85.6	298	66.2
Defaulted	138	64.5	100	42.4	238	52.9
Not Defaulted	76	35.5	136	57.6	212	47.1
Dehabilitated	59	27.6	35	14.8	94	20.9
Not Dehablitated	155	72.4	201	85.2	356	79.1

Table 2 : Logistic regression analysis of De-habilitation with the other 3 D's

Parameter			Bivariate analysis			Multiple variable analysis*		
			OR	95% CI	P-value	Adj OR	95% CI	P-value
Delay	No	35 (14.8)	1.0			1.0		
	Yes	59 (27.6)	2.2	1.4,3.5	0.001	1.1	0.7,1.9	0.754
Defaulted	No	52 (24.5)	1.0			1.0		
	Yes	42(17.6)	0.7	0.4,1.0	0.074	0.4	0.2,0.7	<0.001
Deformity	No	32(10.7)	1.0			1.0		
	Yes	62(40.8)	5.7	3.5,9.3	<0.001	7.1	3.9,13.0	<0.001

test shows there is significant statistical association (p=0.04) between default and de-habilitation.

(f) Deformity and De-habilitation: Among those who have deformity, majority (59.2%) are not de-habilitated, which shows deformity doesn't necessarily contribute for de-habilitation and 10.7% of those de-habilitated doesn't have deformity shows that there are also other factors contributing for de-habilitation. The Chi-square test shows there is significant statistical association (p=0.000) between deformity and de-habilitation.

The findings of the bivariate analysis may be summarized as that:

- Delay is significantly associated with Default, Deformity and De-habilitation.
- Default is significantly associated with deformity and De-habilitation.

Table 3 : Multivariate analysis of all Four D's

D1	D2	D3	D4				Total	Sig. (2-sided)
			Not Dehabilitated		Dehabilitated			
NOT DELAYED (236)	Not Defaulted	Not deformed	111		19		130	0.054 (SIG)
		deformed	85.4	97.4	14.6	86.4	95.6	
		deformed	3		3		6	
			50.0	2.6	50.0	13.6	4.4	
		Total	**114**		**22**		**136**	
			83.8		**16.2**			
	Defaulted	Not deformed	65		7		72	0.182 (NOT SIG)
			90.3	74.7	9.7	53.8	72.0	
		deformed	22		6	46.2	28	
			78.6	25.3	21.4		28.0	
		Total	**87**		**13**			
			87.0		**13.0**		**100**	
DELAYED (214)	Not Defaulted	Not deformed	29		3		32	0.000 (SIG)
			90.6	63.0	9.4	10.0	42.1	
		deformed	17		27		44	
			38.6	37.0	61.4	90.0	57.9	
		Total	**46**		**30**			
			60.5		**39.5**		**76**	
	Defaulted	Not deformed	63		3		66	0.000 (SIG)
			95.5	57.8	4.5	10.3	47.8	
		deformed	46		26		72	
			63.9	42.2	36.1	89.7	52.2	
		Total	**109**		**29**			
			79.0		**21.0**		**138**	

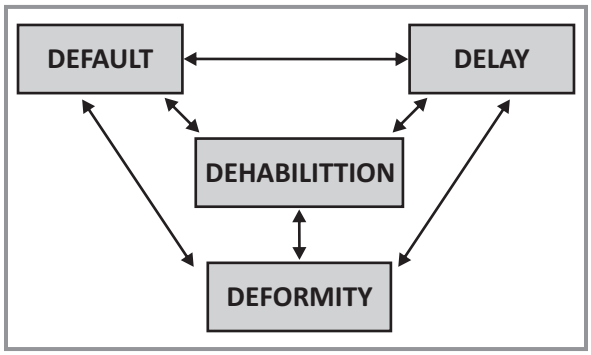

Fig. 1 : Correlation among 4D's

- Deformity has significant association with De-habilitation.

Logistic regression analysis of De-habilitation with 3 predictors (Delay, deformity and default): Table 2 shows the Logistic regression analysis of De-habilitation with the 3 parameters.

The findings show that there is a significant association among delay, defaulting and deformity. Including both delay and defaulted in the same model, there is multi-co linearity as among the subjects with no de-habilitation. From among the delayed subjects about 65% defaulted where as it is only 40% of the non-delayed subjects who defaulted. Therefore there is a significant association between default and delay among non de-habilitated subjects whereas this association is absent in the de-habilitated subjects. There is a similar significant association between default and deformity as well. Removing delay from the model only slightly modifies the adjusted OR of defaulted and deformity.

The multivariate analysis of the total sample of 450 respondents, has given rise to a total of 16 categories of leprosy patients representing the major 4 D groups, the multivariate frequency of which is presented below in Table 3.

Discussion

While much research has been reported on each of the D's individually (Nicholls et al 2005, Pfaltzgraff 2003, Raju et al 2015), there have not been many publications on the correlations among these 4 D's. Some of the associations described in this paper were well known such as between delay and deformity, or deformity and de-habilitation, the analyses shows unexpected associations as shown in the diagram below (Fig. 1), that each of the four variables is strongly multiple correlated with the other three variables, which may be explained as follows viz. Delay is responsible for defaulting, deformity and de-habilitation,

- Deformity is responsible delay, defaulting and de-habilitation,
- Defaulting is responsible for deformity and de-habilitation and

De-habilitation is the main feature that resulted by and results to delay, defaulting and deformity.

Established complex association among the four variables confirms that leprosy related stigma and psycho-social behavior of leprosy affected is a complex phenomenon any intervention addressing any one of the 4D's cannot produce

any changes unless the intervention attempts to address all the 4D's simultaneously.

Nature of association between delay and defaulting, delay and de-habilitation, and multiple correlations, emphasizing that more research is needed to unravel the relationships among the 4D's (Lockwood & Suneetha 2005). This implies that the strategies for reducing the 4 D's needs to be more sophisticated and integrated if an impact is to be achieved (WHO 2016, WHO 1012). It is also clear that the present IEC activities need a thorough and critical review before more money is spent in our five year plans on continuing the present strategies (Rao 2012, Rao 2017, Shetty 2010). Just as the medical solution has evolved through experience to promote a multi-drug therapy, the psychosocial solution also has to be broad-based and multi-pronged (Rao 2015).

Early reporting and starting prompt treatment with MDT goes beyond individual benefit, to protect the household and other contacts in the society from transmission of leprosy through continuing invasion of *Mycobacterium leprae* shed continuously from infectious untreated leprosy patients, particularly those with high bacterial indices, as seen from those reporting late at leprosy centres (Rao 2012, Shetty 2010). Apart from the emphasis now placed on early detection and starting MDT, similar or even greater efforts may be needed to make the patients adhere to the minimum durations of treatment (Raju et al 2015). Some defaulting is not unusual for any chronic disease (Rao 2008), but in the case of a chronic infectious disease such as leprosy, incomplete and insufficient treatment becomes critical if we need to eradicate the disease. The reasons for defaulting especially of those who delayed and further developed deformities could be misunderstanding the treatment as correcting the physical problems such as anesthesia and other nerve damage. The need for better education and change of attitudes about leprosy being a nerve disease and not merely a skin or divine problem is challenging but necessary (Samraj et al 2012, Barkataki et al 2006).

In addition to dispelling such ignorance and misconceptions, there is a need to improve leprosy services and eliminate various hurdles in providing friendly, seamless leprosy care (WHO 2012). Health policies and leprosy care must be dynamic and in keeping with the needs of the public, which requires more active community-based approaches and not top-down (Raju et al 2014).

Finally, the findings from this study clearly show the insidious and subtle damage caused by the continuing stigma for leprosy (Frist 2000, Rao et al 2008, GOI 2011). Goffman (1963) was one of the pioneers in defining stigma as 'spoiled identity', a concept not seriously considered in most leprosy programs (Rao et al 2008, Staples 2011). Weiss et al (2006), van Brakel et al (2006) and other researchers (Sermrittirong & van Brakel, 2014) have tried to measure the perceived and enacted stigma in leprosy and emphasized the need to recognize the high stigma prevailing in leprosy. One should also distinguish between the general health-related stigma and leprosy stigma (Rao 2010). Despite these evidences, IEC programmes continue to be weak and do not adequately address this crucial issue, resulting in poor performances (Rao 2012). Leprosy has a long and tragic history of accepting such stigma, deformity and de-habilitation as inevitable, requiring passive, palliative and terminal care (WHO 2012). Three decades of effective MDT should have transformed the face of leprosy care and proclaimed loudly that deformity is not inevitable and leprosy is curable, but this has not taken place (WHO 2017). Community-based approaches must be actively adopted (Israel et al 2012) and a

more integrated strategy be followed (Rao 2015). The results from this correlational study confirms the need for such an approach to permeate psychological, social, and mental layers of the human mind and result in necessary health-seeking behaviors. In essence, it is a social multi-drug therapy similar to the medical multidrug therapy, where there would be one arm for curing the medical problems of leprosy, a second arm focusing on empowering the people, especially affected persons, through appropriate education, awareness, especially for early detection and treatment, encouraging positive attitudes and perceptions, and a third arm for advocacy, attacking derogatory and discriminatory laws, enabling opportunities for persons with leprosy disabilities to be profitably employed, and providing necessary rehabilitation facilities (Rao 2015, Rao 2017). Further research mainly qualitative, will be required to question the community's perception of leprosy, and their full participative involvement in removing all the D's in leprosy.

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