
A Multilevel Exploration of Treatment Seeking Behaviour of Disabled Persons in India

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Abstract

Treatment seeking behaviour of disabled persons is a complex phenomenon in the third world and largely unexplored in the country like India. This paper has been designed with an objective to find out the influence of different individual, household and state level factors in treatment seeking behaviour of disabled persons using the data from NSS 58th round-2002 disabled persons in India. More than one fifth of disabled persons have not received or presently not going for any treatment after the onset of disability in India. From the analysis it is well depicted that Individual as well as household and state level variables have a significant influence in deciding the treatment seeking behaviour of disabled persons.

INTRODUCTION

Disabled persons are the largest deprived group in the world mainly in the third world. To this group, because of physical as well as mental challenges, services and facilities available to the non-disabled are either deprived or limited.

Consequently, they become the least nourished, the least healthy, the least educated, and the least employed. Disabled persons face long events of neglect, isolation, segregation, poverty, deprivation, charity and even humiliation. The plight of the disabled in India is not an exception. The immense responsibility for the care of the disabled is generally left to their families and a few institutions managed by voluntary organizations and the government. In this regard treatment seeking behaviour of disabled persons is a complex phenomenon and remains largely unexplored in India. Treatment seeking behaviour of disabled persons depends not only on socio-economic factors but also on cultural factors. Health care or treatment seeking behaviour is a central issue in all kinds of morbidity, since the duration of any symptoms increases the probability of severe morbidity and harmful sequelae. Illness or deviation from a state of health is mostly a subjective awareness of an individual the relief of which may be sought within or outside of medical and health facilities [1]. Illness behavior refers to the activities undertaken by individuals in response to symptom experience. It typically includes mental debate about the significance and seriousness of these symptoms, lay consultation, decisions about action including self-medication, and contact with health professionals [2]. A

substantial proportion of people experience some symptoms of illness at any given point of time but these go unreported.

Perception on health problem and health care services plays an additional influential role in treatment seeking behaviour. Perception has a well-recognized social and even ethnic dimension [2]. Perception of illness as well as treatment seeking behaviour has been found to vary with cultural, ethnic and socioeconomic difference [1]. Care seeking has been viewed as an interval requiring time for problem "appraisal" (assessment of the nature of the problem and the need for clinical care), as well as time to act on the decision to seek care. It has been labeled as the "procrastination" interval, although some factors that may contribute to delay are not within a patient's control. Socio-economic status, whether measured by education, income or other indices of social class, has long been known to be associated with attitudes and health care practices [3]. The impact of socio-economic status on symptoms, respiratory morbidity and mortality is important because it may influence behaviors towards health seeking also [4]. Patient compliance depends on many psychological and sociological factors and the interaction of patient's own ideas with the disease. Among behavioral aspects, most of the investigators have studied variables like where persons with symptoms go to seek help, who continues with the treatment and who are the defaulters? There has been hardly any attempt to study personal variables like perception about the disease and the primary actions that are taken to get relief. There are a host

of personal variables on which treatment seeking behavior is likely to be dependent.

In India, there are many studies based on health seeking behaviour [5, 6, 7], reproductive and gynaecological morbidities treatment seeking behaviour [8, 9, 10, 11], and infertility health seeking behaviour [12, 13]. But, studies based on disabled person's health/treatment seeking behaviour at different levels are yet to be explored in India. This study has been designed with an objective of finding out the influence of different socio-economic and demographic factors (individual level, household level and state level etc.) on the treatment seeking behaviour of disabled persons in India.

DATA AND METHODS

The data for this study is from the survey of disabled persons in India conducted nationwide by the National Sample Survey Organisation (NSSO), India in its 58th round during the year 2002 [14]. The survey adopts a stratified multi-stage sampling design with census villages as primary sampling units and households as second stage units which are stratified as households having at least one mentally disabled person, having at least a person with speech, hearing or visual disability and having at least a person with locomotor disability for the purpose of selecting nationally representative sample of disabled persons of these categories. The study consider disabled person who have any of the five types of disabilities – mental, visual, hearing, speech and locomotor. We have adopted the NSSO (2002) definition of disabilities to keep uniformity. In NSSO, a person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being is treated as having disability. For the population served per doctor and population served per hospital information, health information of India-2003 data has been used [15].

In the present study, disabled persons treatment seeking behaviour is used to assess the treatment status of disabled persons. For the purpose of this study, bivariate and multivariate (logistic regression) analysis have been used. It is required in order to relate the treatment seeking behaviour with the individual, household and state level correlates, and draw relevant and effective intervention programmes. To deal with this aspect of linkage, a multilevel analysis has been carried out. The dependent variable treatment seeking behaviour was classified into dichotomous responses. Treatment taken and currently undergoing treatment are

coded as 1 and treatment not taken or currently not taking treatment as zero (0). This dichotomized variable denoted as y_{ijk} is the binary response for the i^{th} disabled person in the j^{th} household and the k^{th} state is considered as response variable in the analysis.

If $\pi_{ijk} = P(y_{ijk} = 1)$ then the three level logistic model can be written as:

$$y_{ijk} = \pi_{ijk} + e_{0ijk}$$

Where

$$\pi_{ijk} = \text{const} + v_{1k} + u_{ijk}$$

$$[v_{vk} \sim N(0, \sigma_v) \text{ and } [u_{ijk}] \sim N(0, \sigma_u)$$

Model assessment in terms of variation in the treatment seeking behaviour variable is explained by the contextual covariates at three levels with reference to the empty model:

$$y_{ijk} = \pi_{ijk} + e_{0ijk}; \log \text{it}(\pi_{ijk}) = \eta_{0jk} + e_{0ijk}$$

Individual level variables such as place of residence (rural and urban), sex (male and female), age (<15, 15-59, 60+), marital status (never married, currently married, widowed/divorced/separated), caste (ST/SC, OBCs and others), extent of disability (severe: can't able to take care of himself/herself even with the help of aid/appliance, moderate: can able to take care of himself/herself only with the help of aid/appliance, mild: can able to take care of himself/herself without the help of aid/appliance and others) and types of disability (mental, visual, hearing, speech, locomotor) and household level variables like educational status of principal earner in the household (illiterate, educated upto middle and educated upto secondary and above), monthly per capita consumer expenditure (MPCE) quintiles (poorest, second, middle, fourth and richest), and state level covariates like population served per doctor and population served per hospital were incorporated in a step-wise manner to examine whether treatment seeking behaviour depends on these factors.

RESULTS

State wise Variation in Treatment Seeking Behaviour of Disabled Persons

Figure 1 provides a visual depiction of treatment seeking behaviour of disabled persons by states in India. More than three fourths of disabled persons from Punjab, Uttaranchal, Haryana, Rajasthan, Uttar Pradesh and Gujarat have already taken some treatment after the onset of disability. Whereas,

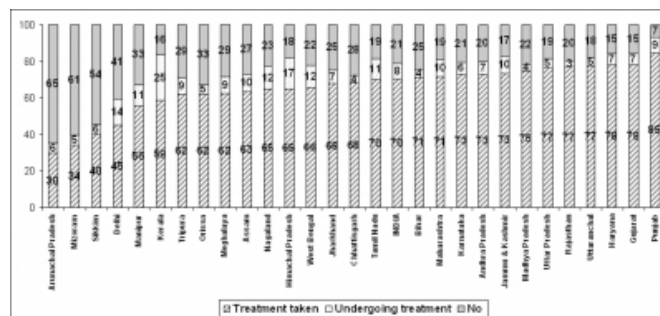
around 65 percent of disabled persons from Arunachal Pradesh have not taken/taking any treatment for disability, followed by Mizoram, Sikkim and Delhi with 61, 54 and 41 percent respectively. Around one fourth of disabled persons from Kerala are presently undergoing treatment, followed by Himachal Pradesh (17 percent), Delhi (14 percent) and Nagaland (12 percent). At the national level, around 21 percent of disabled have not taken or presently are not taking any treatment for disability, whereas 70 percent have already taken treatment and 8 percent are under going treatment.

RURAL-URBAN DIFFERENTIALS IN TREATMENT SEEKING BEHAVIOUR

It is clearly visible from the rural-urban differential results of the bivariate analysis shown in Table 1 that treatment seeking behaviour of disabled person is significantly associated with sex, age, caste, marital status, living arrangements, education of principal earner in the household, MPCE quintiles, extent of disability and types of disability in India. Results show that in rural areas males who have taken or taking treatment for disability are more (78 percent) compared to females (72 percent). In urban areas 86 percent of males have taken or taking treatment compared to 83 percent females. Treatment taken or taking for disability by broad age groups in urban areas do not show much differences, whereas there is differential in the rural areas by broad age groups disabled persons in treatment seeking behaviour. Treatment taken or taking for disability by SC/ST, OBCs and others in rural areas are 70, 77 and 78 percents respectively corresponding to 81, 85 and 86 percent respectively in urban areas. Further, treatment taken or taking for disability among persons in rural areas never married, currently married and widowed/divorced/separated are 77, 77 and 68 percents respectively and for urban areas the corresponding figures are 86, 86 and 80 percent respectively. The proportion of disabled persons staying with or without spouses but living with other family members have taken or taking treatment for disability is higher than persons staying alone, irrespective of their place of residence.

Figure 1

Figure 1: State wise Variation in Treatment Seeking Behaviour of Disabled Persons, India, 2002



Treatment taken or taking by disabled persons who are illiterate, educated up to middle, secondary and above educated principal earners in rural households are 71, 78 and 84 percent respectively compared to 80, 85 and 88 percent respectively of disabled persons going for treatment who were principal earners in urban households. Disabled persons belonging to the richest MPCE quintiles having taken treatment or taking is highest compared to other MPCE quintiles, irrespective of the rural-urban differentials. As expected, among the severely and moderately disabled persons, treatment taken or taking for disability is highest compared to persons with mild disability, irrespective of place of residence.

The results gain importance when treatment seeking behaviour is considered by types of disability. Treatment taken or taking for disability in rural areas among mental, visual, hearing, speech and locomotor disabled persons are 77, 73, 63, 63 and 83 percent respectively compared to urban areas where the corresponding figures are 86, 83, 73, 76 and 90 percent respectively. The treatment seeking behaviour of disabled persons shows wider differential according to different background characteristics in the rural areas, whereas the differential is marginal among urban disabled persons. The plausible reason may be that development has a better effect in urban areas with advanced health care facilities, better treatment and other medical facilities than in rural areas. So, the background characteristics of disabled persons are not playing an influential role in treatment seeking behaviour in urban areas as in rural areas.

FACTORS ASSOCIATED WITH TREATMENT SEEKING BEHAVIOUR: RESULTS OF MULTILEVEL ANALYSIS

The factors influencing the treatment seeking behaviour of disabled persons has been analyzed using multilevel logistic regression analysis considering different modeling strategies.

Model-I (individual level) includes variables such as sex, place of residence, age, caste, marital status, extent of disability and types of disability. Model-II (household level) was designed to explore the household level impact through educational status of the principal earner in the household and household MPCE quintiles (proxy for economic status). The population served per doctor and population served per hospital were added in model-III to know the state level influence on treatment seeking behaviour of disabled persons. Table 2 displays the parameter estimates of these models, for treatment seeking behaviour of disabled persons. For each model, coefficient of covariates in the logistic model is provided and the corresponding standard error is shown in parenthesis. The exponentiation of the estimated parameters of a correlate yields odds of treatment taken or taking by disabled persons associated with the particular category relative to the reference category, while the rest of the covariates are controlled. In order to check the goodness of the model fitted, a summary statistic is included in the form of -2log likelihood. Model-III is the best fit model, which can be seen through its -2log likelihood value.

Figure 2

Table 1: Rural-Urban Differentials in Treatment Seeking Behaviour of Disabled Persons by Different Background Characteristics, India, 2002

Background Characteristics***	Taken/Taking Treatment			N
	Rural	Urban	Total	
Sex				
Male	77.5	86.0	80.5	51387
Female	72.3	83.0	76.2	35358
Age				
<15	77.8	85.6	80.3	18724
15-59	76.0	85.8	79.5	47410
60+	71.8	81.8	75.4	20611
Caste				
ST/SC	70.4	80.8	73.3	24902
OBCs	77.4	85.4	80.1	33449
Others	78.2	86.4	81.8	28394
Marital status				
Never married	76.6	85.5	79.8	41533
Currently married	77.1	86.0	80.2	30945
Widowed/divorced/separated	68.1	80.0	72.4	14267
Living arrangements				
Alone	63.6	77.0	68.6	2426
With spouse and other members of family	77.1	86.0	80.2	29275
Without spouse but with members of family	75.0	84.5	78.4	55044
Educational status of principal earner of household				
Illiterate	71.1	79.8	73.1	32782
Up to middle	77.6	85.2	80.4	37318
Secondary & above	83.6	87.9	86.1	16645
MPCE quintiles				
Poorest	69.9	79.7	71.9	26391
Second	76.2	83.6	78.3	20085
Middle	78.9	84.6	81.0	13431
Fourth	80.0	86.8	83.1	13833
Richest	83.8	87.4	86.1	13005
Extent of disability				
Severe	78.8	89.1	82.7	12789
Moderate	84.3	88.9	86.0	13298
Mild	72.3	82.5	75.8	52627
Types of disability				
Mental	76.9	85.9	80.0	11282
Visual	73.1	82.7	76.1	10923
Hearing	62.5	73.2	66.1	12794
Speech	62.7	76.4	67.4	9958
Locomotor	83.0	89.9	85.6	41788
Total	74.9	84.5	78.4	86745

Note: Chi-square test (***1% level of significance)

Figure 3

Table 2: Parameter Estimation and Standard Errors of Multilevel Logistic Regression Analysis for Treatment Seeking Behaviour of Disabled Persons in India, 2002

Background Characteristics	Empty Model	Model-I	Model-II	Model-III
Intercept	1.188 (0.130)	1.031 (0.126)	0.682 (0.132)	-0.103 (1.169)
Place of residence				
Rural @				
Urban		0.520 (0.019)	0.356 (0.020)	0.358 (0.020)**
Sex				
Male @				
Female		-0.144 (0.018)	-0.142 (0.018)	-0.143 (0.018)*
Age				
<15 @				
15-59		-0.117 (0.025)	-0.126 (0.025)	-0.127 (0.026)
60+		-0.333 (0.036)	-0.375 (0.035)	-0.377 (0.036)*
Caste				
ST/SC @				
OBC		0.299 (0.021)	0.218 (0.021)	0.219 (0.022)*
Others		0.364 (0.022)	0.203 (0.023)	0.204 (0.023)*
Marital status				
Never married @				
Currently married		0.049 (0.024)	0.098 (0.024)	0.098 (0.024)
Widowed/divorced/separated		-0.228 (0.032)	-0.157 (0.032)	-0.158 (0.032)
Extent of disability				
Mild @				
Moderate		0.561 (0.028)	0.540 (0.027)	0.542 (0.028)**
Severe		0.400 (0.026)	0.385 (0.026)	0.388 (0.026)*
Types of disability				
Mental @				
Visual		-0.180 (0.035)	-0.141 (0.035)	-0.142 (0.036)*
Hearing		-0.600 (0.031)	-0.600 (0.031)	-0.604 (0.031)**
Speech		-0.701 (0.032)	-0.697 (0.032)	-0.701 (0.032)**
Locomotor		0.322 (0.028)	0.322 (0.028)	0.323 (0.028)*
Educational status of principal earner of household				
Illiterate @				
Up to middle			0.288 (0.019)	0.290 (0.020)*
Secondary and above			0.480 (0.028)	0.482 (0.029)*
MPCE quintiles				
Poorest @				
Second			0.201 (0.023)	0.202 (0.023)
Middle			0.303 (0.027)	0.305 (0.027)*
Fourth			0.371 (0.028)	0.373 (0.029)*
Richest			0.430 (0.033)	0.432 (0.033)*
Log(ppph)				-0.027 (0.118)*
Log(pppd)				0.122 (0.134)*
Variation (state)	0.581 (0.141)	0.509 (0.124)	0.558 (0.135)	0.508 (0.124)
Variation (household)	0.007 (0.002)	0.002 (0.001)	0.001 (0.001)	0.002 (0.002)
-2loglikelihood	89083.0	78605.8	76783.8	76323.8

Note: @ reference category. Figures in the parenthesis are standard errors of estimates
** (5% level of significance), * (10% level of significance)
ppph: population served per hospital, pppd: population served per doctor

The results of model-III suggest that place of residence, caste, extent of disability, educational status of principal earner of household, and MPCE quintiles and persons served per doctor have a significant positive association with treatment seeking behaviour of disabled persons. Whereas background variables such as sex, age, marital status, types of disability and persons served per hospital have a significant negative association with the treatment status of disabled persons. It is quite surprising to see that population served per doctor has a positive association with treatment seeking behaviour of disabled persons. It may be possible that better health care facilities and medical care are more important than the doctors for the treatment of disabled. The odds of urban disabled who have taken or taking treatment is significantly 43 percent higher than the rural disabled persons. Whereas chances of female disabled persons seeking treatment is 13 percent less compared to male disabled persons. The odds of older disabled persons going for treatment are less in comparison to younger disabled persons. However disabled person's marital status is not significantly associated with treatment seeking behaviour. The results also show that the chances of

widowed/divorced/separated disabled persons going for the treatment of disability is 15 percent less compared to the never married category and currently married disabled persons have 10 percent higher chances of treatment taking than the never married disabled.

The chances of going for treatment by the visual, hearing and speech disabled persons are quite low compared to mentally disabled persons. Whereas, the chance for seeking treatment is higher by 38 percent for locomotor disability compared to mental disability. Again, the odds of having taken or taking treatment for the moderately and severely disabled persons are 72 and 47 percent higher compared to the mild disabled persons. The probability of going for treatment after the onset of disability is quite high among disabled persons who belong to the highest economic quintile households in comparison to the poorest economic quintile. The chances are high for the disabled persons from middle class (34 percent) and, secondary and above (62 percent) educated and the principal earners of households compared to illiterate principal earners of household. Persons served per doctor is not showing the expected result. It may be due to the preference for quality of services rather than the availability of doctors. As the persons served per hospital among the states are increasing, the odds of going for disability treatment are decreasing. This implies that the state having uncrowded hospital have better medical facilities and treatment. In other words in uncrowded health facilities patients can spend more time with doctor and are confident of getting better treatment. In terms of variation in treatment seeking behaviour of disabled persons, the heterogeneity is more at the state level than at the household level.

SUMMARY AND DISCUSSION

It can be summarized from this study that most of the disabled persons from Punjab, Uttaranchal, Haryana, Rajasthan, Uttar Pradesh and Gujarat have already taken or currently taking some treatment after the onset of disability. On the other hand, most of the disabled persons from Arunachal Pradesh, Mizoram, Sikkim and Delhi have not taken or are taking any treatment after the onset of disability, which is a major concern. One fourth of disabled persons from Kerala are presently undergoing treatment. The treatment seeking behaviour of disabled persons reflects a wider differential according to different background characteristics in the rural areas, while the differentials in urban areas by background characteristics are marginal. The chances of male disabled persons going for treatment care

are more compared to female disabled persons. The probability of having taken or taking treatment by aged disabled persons widowed/divorced/separated, living alone, those who belong to ST/SC, and those who are from illiterate households and belong to poorest economic quintile households are quite low compared to their other better off counter parts. The disabled persons who are not getting treatment after the onset of disability are mainly residing in rural areas and can be considered as the most vulnerable group of the society. It may be due to their lack of awareness and knowledge about treatment seeking. The treatment and health care facilities are not reaching to them in an adequate manner and it may be also possible that the disabled persons are unable to move physically or afford the medical treatment available for the disability.

The chances of seeking treatment among severely and moderately disabled are highest compared to mildly disabled persons. For mental, locomotor and visual disabled persons the odds are high for seeking treatment after the onset of disability compared to other disabled in India. Among the different states, the quality of services and facilities of hospital is more important rather than the number of doctors. It can also be seen that the state having uncrowded hospital have better medical facilities and treatments. In other words, in uncrowded health facilities patients can spend more time with doctor and are confident of getting better treatment. In terms of variation in treatment seeking behaviour of disabled persons, the heterogeneity is more at the state level than at the household level. The state level influence is also there in treatment seeking behaviour of disabled persons. It depends on which geographical area, the disabled person belongs to. Moreover, this paper highlights certain issues regarding the treatment seeking behaviour of disabled persons so that better intervention programmes, awareness and medical care are made available at the state level as well as at the individual level for the betterment of disabled persons.

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