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Original Research Article

Health care needs of persons affected by leprosy in Kurnool division of Kurnool district

Visweswara Rao Guthi[1]*, A. Sreedevi[2]

Department of Community Medicine, [1]Assistant Professor, Kamineni Institute of Medical Sciences, Narketpally, Nalgonda, Telangana, [2]Professor and HOD, Kurnool Medical College, Kurnool, Andhra Pradesh, India

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***Correspondence:**
Dr. Visweswara Rao Guthi,
E-mail: vissumbbs@gmail.com

ABSTRACT

Background: One of the challenges in NLEP-3 is need assessment as well as establishment of well-coordinated services with capacity building for prevention and care of disabilities due to leprosy at primary, secondary and tertiary levels in the country. There is very little data on the types of problems faced by people with leprosy-related disabilities (PLD) and the resulting needs. Aim of the study is to assess the health care needs of study subjects.

Methods: This is a community based cross–sectional study conducted in Kurnool district. There were 296 registered persons affected by leprosy between May 2012 to October 2013 out of which 276 registered persons affected by leprosy were available for the study. Information collected was place of registration for availing MDT, treatment status, mode of detection, health care provider consulted first etc.

Results: 48.55% of all the registered cases reported voluntarily. (36/276) 13.05% of cases were detected during consultation for other general ailments and 8.69% were detected by health worker during routine field visit. Health worker provided MDT to the persons affected by leprosy at their houses in 14.49% of the cases, 85.51% of the persons obtained MDT from the treatment centre themselves.

Conclusions: This study concluded that there was encouraging to note that public health system was the predominant health system for seeking health care. Most of the cases reported voluntarily to the health care facility. Majority was aware that leprosy causes deformities but did not know that deformities can be prevented.

Keywords: Leprosy, Health care needs, Detection delay, Treatment regularity, MDT

INTRODUCTION

Leprosy is an important cause of preventable disability. Physical impairment associated with leprosy is usually secondary to nerve damage. Impairments may give rise to disabilities, such as limitations of activities involving the use of hands, feet and eyes, and restrictions in social participation. Multi-drug treatment (MDT) can cure leprosy and if instituted early can prevent disability. However, leprosy is still often diagnosed too late, when permanent impairment has already occurred. Even after completion of treatment, a significant proportion of patients sustain disability from nerve damage, requiring continued self-care to limit further secondary damage.[1]

Future projections of the global leprosy burden show that 5 million new cases would arise between 2000 and 2020, and that in 2020 there would be an estimated 1 million people with WHO Grade 2 disabilities.[2] Though introduction of MDT has reduced the incidence of disability drastically, the total disability load in the world is estimated to be about 3 million.[3] A total of 5256 Grade 2 disability detected amongst the new leprosy cases during 2013-14, indicating the Grade 2 disability rate of 4.13/million population.[4]

Health needs assessment is the systematic approach to ensure that the health service uses its resources to improve the health of the population in the most efficient way. It involves epidemiological, qualitative, and comparative methods to describe health problems of population, identify inequalities in health and access to services, and determine priorities for the most effective use of resources.[5]

One of the challenges in NLEP 3 is need assessment as well as establishment of well-coordinated services with capacity building for prevention and care of disabilities due to leprosy at primary, secondary and tertiary levels in the country.[6] There is very little data on the types of problems faced by people with leprosy-related disabilities (PLD) and the resulting needs.[7] Though much progress has been made in reducing the number of leprosy patients registered for MDT globally, relatively little is known about disability after release from treatment. Therefore there is an urgent need for data on leprosy-related disability to assess the need for prevention of disabilities (POD) and rehabilitation services. Such data is also needed for programme monitoring, evaluation and for advocacy.[8] The aim of present study was to study the health care needs of persons affected by leprosy.

METHODS

This is a community based cross–sectional study conducted in administrative limits of Kurnool division of Kurnool district from November 2013 to May 2014. Kurnool district is divided into Kurnool, Adoni and Nandyal revenue divisions. Among these Kurnool division was selected by simple random sampling.

Inclusion criteria

All persons affected by leprosy who were registered between 1st May 2012 to 31st October 2013 and utilized/utilizing the services from the leprosy treatment units. (As per the data available at the District Leprosy Office, Kurnool) and patients should have completed at least two months of treatment.

Exclusion criteria

Those who were not residing in the study area and who were not willing to participate in the study. There were 296 registered persons affected by leprosy between May 2012 to October 2013 out of which 276 registered persons affected by leprosy were available for the study (20 cases were not available due to migration for work, not able to contact, left area permanently). The study was taken up after the approval of the Ethical committee of the Kurnool medical college, Kurnool.

During the study, purpose of the study was explained to all study subjects in his/her own language and informed verbal consent was taken. A pilot study was conducted in Kallur PHC area with the objective of standardizing the questionnaire and to know the feasibility of study. Permission was obtained from the District Leprosy Officer, Kurnool district to carry out the study. The District Leprosy Office maintains a register of all leprosy patients in the district. For the study purpose, information and address of all registered patients between 1st May 2012 to 31st October 2013 was obtained from the register. Each of the available registered case was contacted in person by the investigator and interviewed using a pretested, semi structured questionnaire. In case of patients living in hilly and remote areas and those missed during visit to their houses, the medical officers of the respective PHCs were contacted and requested to pool the cases in their administrative limits and intimate the same to the investigator for the study purpose.

Information was collected from these patients by interview method using a pre tested, semi structured questionnaire. Information collected was to assess the health care needs of the registered cases by obtaining information about the following parameters: Place of registration for availing MDT, treatment status, mode of detection, health care provider consulted first, time between the patch was first noticed and consultation with health system, difficulties encountered during availing MDT, information provided by health staff about MDT, reactions and prevention of deformity and self-care, mode of obtaining MDT from treatment centre, accessibility to MDT, regularity in treatment with MDT, reasons for irregular treatment, reactions during or after MDT (as inferred by investigator). To assess the information given to the patient by health staff about MDT and reactions, a structured scale with yes/no response was developed. The patients were asked whether they had been informed about each item in the scale by the health staff and their response was recorded. Each item in this scale was adapted from guidelines in the National Leprosy Eradication programme regarding the basic facts to be educated to a patient while starting MDT. The grading ranged from highly satisfactory to highly not satisfactory depending on the number of affirmative responses. Data was entered in Microsoft excel and analyzed using SPSS 20th version statistical software with descriptive statistics and chi square test.

RESULTS

It was observed from the Table 1 that maximum number of patients in the study population was in the 15-59 years of age group. Adults comprised of 92.03% (254), children and geriatric individuals affected with leprosy constituted 7.97% (22) and 11.23% (31) respectively. Among MB cases, majority of study subjects (67.33%) were $\geq$30 years of age and among PB cases, majority of study subjects (54.77%) were less than 30 years of age. In the study population 63.04% (174) of them were males and 36.96% (102) were females. More than one third of the study population (42.03%) were illiterates followed by educated up to primary school (29.35%), 11.23% were educated up to high school, 7.98% were studied up to upper primary school, 6.15% had received education up to intermediate and 3.26% were graduates. Among MB and PB cases, majority of study subjects were illiterates and who studied up to primary class (76% and 65.86% respectively). 46.01% (127) were unskilled workers, 18.48% (51) were unemployed including homemakers, 11.60% (32) were semiskilled workers, 9.78% (27) were students, 8.69% (24) were skilled workers, 4.71% (13) were clerical/shop owner/farm owners and 0.73% (2) was semiprofessional. Among MB cases majority of study subjects were unskilled workers (53.33%) and among PB cases majority were other than unskilled workers (62.70%). More than half the study population 183 (66.31%) were Hindus, 51 (18.47%) were Christians and 42 (15.22%) were Muslims.

Table 1: Distribution of study population according to socio demographic factors.

Demographic factors	Type of leprosy		Total no (%)
	MB no (%)	**PB no (%)**	
Age group (years)			
≤14	5 (3.33)	17 (13.50)	22 (7.97)
15-29	44 (29.34)	52 (41.27)	96 (34.78)
30-44	46 (30.66)	29 (23.02)	75 (27.17)
45-59	37 (24.67)	15 (11.90)	52 (18.85)
≥60	18 (12)	13 (10.31)	31 (11.23)
Gender			
Male	96 (64)	78 (61.90)	74 (63.04)
Female	54 (36)	48 (38.10)	102 (36.96)
Education			
Illiterate	67 (44.67)	49 (38.88)	116 (42.03)
Primary	47 (31.33)	34 (26.98)	81 (29.35)
Middle	11 (7.33)	11 (8.74)	22 (7.98)
High school	12 (8)	19 (15.08)	31 (11.23)
Intermediate	9 (6)	8 (6.35)	17 (6.15)
Graduate	4 (2.67)	5 (3.97)	9 (3.26)
Occupation			
Unemployed (including home maker)	29 (19.33)	22 (17.46)	51 (18.48)
Unskilled	80 (53.33)	47 (37.31)	127 (46.01)
Semiskilled	19 (12.67)	13 (10.32)	32 (11.60)
Skilled	12 (8)	12 (9.53)	24 (8.69)
Clerical/shop owner/farm owner	4 (2.67)	9 (7.13)	13 (4.71)
Semi professional	0 (0)	2 (1.59)	2 (0.73)
Students	6 (4)	21 (16.66)	27 (9.78)
Religion			
Hindu	93 (62)	90 (71.43)	183 (66.31)
Muslim	26 (17.34)	16 (12.70)	42 (15.22)
Christian	31 (20.66)	20 (15.87)	51 (18.47)

Among 276 study subjects in the study 76 (27.53%) of the study subjects were under treatment and 200 (72.47%) were released from treatment. In the study it was identified that 41/276 (14.86%) faced difficulty in seeking health care for leprosy and 15/276 (5.43%) reported that they had experienced difficulty in getting treatment for other general ailments because of leprosy. Among those who faced difficulty in seeking health care for leprosy (n=41), they had to wait too long at the health centre was one of the main reasons (56.09%), followed by doctor being on leave when asked to come (24.39%) and 19.52% felt that negative attitude of the health staff was the difficulty. 16/276 (5.79%) of the study population had reactions in leprosy. 11/16 sought timely medical care during reactions and 5/16 did not receive timely medical care during reactions. Among 16 study subjects who had reactions, 6 persons had reactions during treatment and 10 had after treatment of leprosy. 4/276 (1.44%) of the study population had new skin patches after completion of treatment (Relapse). 59/276 (21.37%) had difficulty in activities of daily living. 8.70% (24/276) had only one thickened nerve, 14.86% (41/276) had two thickened nerves, 6.88% (19/276) had three thickened nerves and 0.72% (2/276) had four thickened nerves and 68.84% (190/276) had no thickened nerves.

It was observed from table 2 that (134/276) 48.55% of all the registered cases reported voluntarily. (36/276)

13.05% of cases were detected during consultation for other general ailments and 8.69% were detected by health worker during routine field visit. 67.03% (185 / 276) of the persons affected by leprosy approached public health system first (50.36% approached PHC medical officer and 16.67% approached CHC/DH/GGH), 15.94% (44 / 276) approached quack and 14.85% (41 / 276) had self-treatment and only 2.18% (6 / 276) of study subjects approached private practitioner.

Table 2: Distribution of study population according to health care needs.

Health care needs	Number	Percentage (%)
Detection of leprosy		
Self-suspicious silent patch, then consulted doctor	134	48.54
Detected during consultation for other reasons	36	13.05
By health worker during routine filed visits	24	8.68
Detected by friends/relatives	50	18.15
By other leprosy patient	32	11.58
Health care provider consulted first		
Self-treatment	41	14.85
Quack	44	15.94
PHC doctor	139	50.36
CHC/district hospital/GGH	46	16.67
Private practitioner	6	2.18
Knowledge regarding Cause of leprosy		
Curse of the god	23	8.33
Past sins	16	5.80
Bad luck/Ill fate	16	5.80
Infection/germs	63	22.83
Don’t know	155	56.16
Others*	3	1.08

Table 3: Distribution of study population according to health care needs related to MDT.

Health care needs related to MDT	Number	Percentage (%)
Mode of availing MDT (2nd dose onwards)		
Self-collection from treatment centre	236	85.51
Provided by health worker during home visits	40	14.49
Accompanied MDT	0	0
Difficulties encountered during collection of MDT (n =65)		
Distance to collection centre	38	58.46
Fear of losing wages	33	50.76
No money	17	26.15
Attitude of health staff	4	6.15
Disability	7	10.78
Reasons for irregular treatment (n =50)		
Fear of reactions	11	22
Difficulties to collect drugs	41	82
Felt it was not effective	9	18
Habits like alcohol	10	20
Out of town	2	4
Others	3	6
Knowledge regarding prevention of deformities		
Yes	78	28.26
No	57	20.66
Don’t know	141	51.08

Table 4: Distribution of study population according to detection delay# and type of leprosy.

Detection delay (in months)	Type of leprosy		
	MB no (%)	PB no (%)	Total no (%)
1- 6	53 (35.33)	91 (72.23)	144 (52.18)
7-12	64 (42.67)	30 (23.80)	94 (34.05)
13-18	18 (12)	4 (3.18)	22 (7.97)
19-24	10 (6.66)	1 (0.79)	11 (3.98)
≥25	5 (3.34)	0 (0)	5 (1.82)
Total	150 (54.34)	126 (45.66)	276 (100)

#Detection delay is the time between onset of symptoms to consultation. Chi-square value with 1 degree of freedom is 37.344, p=0.000

Table 5: Categorization with respect to patient's perception about information given by health staff about MDT & reactions.

Category	MDT no (%)	Reactions no (%)
Highly satisfactory	165 (59.78)	15 (5.43)
Satisfactory	70 (25.36)	54 (19.56)
Not satisfactory	32 (11.59)	59 (21.37)
Highly not satisfactory	9 (3.27)	148 (53.64)
Total	276 (100)	276 (100)

Prior to coming in contact with health system, 56.16% did not know the cause of leprosy and 22.83% of the leprosy affected persons knew that leprosy was an infection. 8.33% said that the reason was curse of gods, 5.80% said that past sins and bad luck/ill fate were the reason for leprosy respectively. It was subsequently observed in the study that even after being diagnosed only 129/276 (46.73%) of the persons affected by leprosy responded in affirmative that they were explained by health staff that leprosy is bacterial infection.

It was observed from the table-3 that health worker provided MDT to the persons affected by leprosy at their houses in 14.49% of the cases, 85.51% of the persons obtained MDT from the treatment centre themselves. Accompanied MDT is not practiced in this area. It was observed in the study population that 65/276 (23.56%) reported that they faced difficulties to collect MDT. Among them (n =65) the predominant reasons were distance to collection centre (58.46%), fear of losing wages (50.76%) and no money (26.15%).

In the study it was observed that predominantly 226/276 (81.88%) of the study subjects reported that they were taking treatment regularly without discontinuation. Among those irregular in treatment N=50 (18.12% of study population) it was observed that the predominant reasons for irregular treatment were difficulties to collect drugs (82%), fear of reactions (22%), habits like alcohol (20%) and felt it was not effective (18%) and out of town (4%). These factors affecting the compliance to treatment have to be addressed and are the needs of persons affected by leprosy. Thus while designing an educational intervention to address these needs; greater thrust is required in these areas.

It was observed in the study that 208/276 (75.36%) reported that leprosy caused deformities and 78/276 (28.26%) of patients knew that deformities in leprosy can be prevented. It can be inferred that in the study population though majority were aware that leprosy causes deformities many did not know that deformities can be prevented and this information need which is unmet should form the thrust areas for necessary intervention.

It was observed from the table-4 that 52.18% of the cases had detection delay of ≤6 months and 47.82% of the cases had detection delay of more than 6 months. More than half (52.18%) of study population had detection delay 1-6 months, 34.05% had 7-12 months delay, 7.97% had 13-18 months delay, 3.98% had 19-24 months delay and 1.82% had ≥25 months delay. Mean detection delay was 6.88 months. Among MB cases, majority of study subjects 64.67% had detection delay of >6 months and among PB cases, majority of study subjects 72.23% had detection delay of ≤6 months. This difference was statistically significant.

It was observed from the Table 5 that the knowledge about MDT based on information provided by health staff is highly satisfactory in 59.78% of the persons affected by leprosy and in 25.36% it was satisfactory. Thus it can be concluded that the ability of the health staff to provide MDT information is sufficient in more than three fourths of study population to meet the information needs as recommended in NLEP to persons affected by leprosy.

It was observed from the Table 5 that knowledge about reactions based on information provided by health staff was highly not satisfactory in 53.64%, in 21.37% it was not satisfactory and in 19.56% it was satisfactory and in 5.43% it was highly satisfactory. Reactions lead to neuritis leading to deformity. Among study population only 25% patients had satisfactory knowledge about reactions. It is a need of the patients to recognize symptoms of reactions and seek immediate medical care. It can be inferred that knowledge of persons affected by leprosy about reactions is not sufficient and this information need has to be addressed in nearly 75% of the study subjects.

DISCUSSION

This is a community based cross–sectional study conducted to assess the health care needs of persons affected by leprosy. This study shows that that 67.03% of the persons affected by leprosy approached public health system first, 15.94% approached quack and 14.85% had self-treatment and only 2.18% of study subjects approached private practitioner.

In a study done by Samraj et al showed that among 86 newly diagnosed leprosy patients, 3.5% had self-treatment, 8.1% had traditional therapies, 9.3% consulted Government health care provider, 15.1% consulted private practitioner and 62.8% did not seek any medical help after their first symptom. [9]

This study shows that prior to coming in contact with health system, 56.16% did not know the cause of leprosy and 22.83% of the leprosy affected persons knew that leprosy was an infection. 8.33% said that the reason was curse of gods, 5.80% said that past sins and bad luck / ill fate were the reason for leprosy respectively. It was subsequently observed in the study that even after being diagnosed only 46.73% of the persons affected by leprosy responded in affirmative that they were explained by health staff that leprosy is bacterial infection.

In a study done by Grewal et al reported that only 33.3% knew that leprosy is caused by infectious agent and some believed that leprosy can occur spontaneously (16.6%), due to past sins (15%), curse of God (5%) and 28.3% respondents didn't know the cause.[10] In a study done by Nicholls et al, it was seen that only 12.3% of the persons affected by leprosy told that cause of leprosy was infection, 42.2% told that they did not know the cause of leprosy.[11]

In this study Health worker provided MDT to the persons affected by leprosy at their houses in 14.49% of the cases, 85.51% of the persons obtained MDT from the treatment centre themselves. Accompanied MDT is not practised in this area.

This findings contrast in a study done by Gautham et al reported that Health workers provided MDT to the patients by delivery to their houses in 54·4% cases, as accompanied MDT in 12% cases and personally at treatment centres to 33·6% cases.[12] In a study conducted by Sahu et al among registered leprosy cases in Orissa it was seen that 43% collected MDT self from treatment centre and 40% received it at home given by the health worker.[13]

It was observed in the study population that 23.56% reported that they faced difficulties to collect MDT. Among them the predominant reasons were distance to collection centre (58.46%), fear of losing wages (50.76%) and no money (26.15%).

In a study done by Gautham et al reported that 30 subjects (11.6%) reported that they faced difficulties in obtaining MDT, including non-availability of MDT at the centre (60%), fear of loss of wages (46.6%) and the distance to the collection centre (40%).[12] In a study conducted by Sahu et al among registered leprosy cases in Orissa it was seen that 21.5% of cases reported that distance was the main difficulty to collect MDT.[13]

In the study it was observed that predominantly, 81.88% of the study subjects reported that they were taking treatment regularly without discontinuation. Among those irregular in treatment, it was observed that the predominant reasons for irregular treatment were difficulties to collect drugs (82%), fear of reactions (22%), habits like alcohol (20%) and felt it was not effective (18%) and out of town (4%). These factors affecting the compliance to treatment have to be addressed and are the needs of persons affected by leprosy. Thus while designing an educational intervention to address these needs; greater thrust is required in these areas.

In a study done by Gautham et al reported that 86 patients (33.2%) were irregular in taking their MDT; reasons for this included being out of town (54·6%), MDT not available at the centre (33·7%) and habits like alcohol consumption (26.7%).[12]

It was observed that 52.18% of the cases had detection delay of ≤6 months and 47.82% of the cases had detection delay of more than 6 months. More than half (52.18%) of study population had detection delay 1-6 months, 34.05% had 7-12 months delay, 7.97% had 13-18 months delay, 3.98% had 19-24 months delay and 1.82% had ≥25 months delay. Mean detection delay was 6.88 months. Among MB cases, majority of study subjects 64.67% had detection delay of >6 months and among PB cases, majority of study subjects 72.23% had detection delay of ≤6 months. This difference was statistically significant.

Similar results were observed in a study done by Sarkar J et al showed that 43.2% had detection delay ≤ 6 months, 41.2% had 7-12 months delay, 11.9% had 13-23 months delay and 3.7% had ≥24 months delay.[14] In a study conducted by Kumar et al in Agra in 2013 it was observed that 38.57% had delay of 13-36 months followed by 36.34% had delay of >36 months and

25.09% had delay of <12 months.[15] In a study conducted by Gautham et al, among 259 LAPs in Chamrajnagar district reported that the mean detection delay among all patients was found to be 8.25 months. Mean detection delay was lower in MB (7.93 months) when compared to PB (8.42 months) cases. In 14.1% of Pauci bacillary cases and 6·7% of Multi bacillary cases there was a detection delay of more than a year.[12]

It was observed that the knowledge about MDT based on information provided by health staff is highly satisfactory in 59.78% of the persons affected by leprosy and in 25.36% it was satisfactory. Thus it can be concluded that the ability of the health staff to provide MDT information is sufficient in more than three fourths of study population to meet the information needs as recommended in NLEP to persons affected by leprosy. It was observed that knowledge about reactions based on information provided by health staff was highly not satisfactory in 53.64%, in 21.37% it was not satisfactory and in 19.56% it was satisfactory and in 5.43% it was highly satisfactory. Reactions lead to neuritis leading to deformity. Among study population only 25% patients had satisfactory knowledge about reactions. It is a need of the patients to recognize symptoms of reactions and seek immediate medical care. It can be inferred that knowledge of persons affected by leprosy about reactions is not sufficient and this information need has to be addressed in nearly 75% of the study subjects.

In a study done by Gautham et al reported that the knowledge regarding MDT provided by health staff is satisfactory in 44.4% of cases but information regarding reactions is satisfactory in only 6·6% and highly unsatisfactory in 86.5%. Thus for nearly 87% of the study subjects such information needs have to be addressed as reactions lead to neuritis and deformity.[12] In a study conducted by Sahu et al among registered leprosy cases in Orissa it was seen that 90.7% of cases had satisfactory knowledge regarding MDT.[13]

CONCLUSION

This study concluded that there was encouraging to note that public health system was the predominant health system for seeking health care. Most of the cases reported voluntarily to the health care facility. Most of the cases were educated regarding MDT adequately but majority were not satisfactorily informed about reactions in leprosy, disabilities in leprosy and self-care in leprosy. These neglected areas in the study population are the needs of these patients. It was revealed that majority were aware that leprosy causes deformities but did not know that deformities can be prevented.

Recommendations

It is recommended to counsel patients at the beginning of MDT about certain basic facts about leprosy and to plan, organise and conduct health education campaigns periodically to all registered cases. Mass media tools need to be adequately utilized. It is recommended to step up targeted, need based behavioural change communication strategies which will reduce detection delay, promote early recognition and management of reactions, early reporting and self-care practice in the community. Majority of patients did not know that deformities in leprosy can be prevented. So it is recommended to plan, organize and conduct a field based disability care and prevention programme to improve their awareness regarding prevention of deformities in leprosy.

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