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A Study On Aging With Hansen's Disease Overcoming Social Exclusion And Discrimination.

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Abstract
Background- Hansen's disease or Leprosy is a disease, which still strikes fear in the societies as a mutilating, disfiguring, contagious and incurable disease. Because of the horrifying nature of the enigmatic physical disfigurement and the stigma attached to it, the affected elderly individuals suffer from exclusion from society, non-fulfilment of the special care required by them causing physical and emotional stress and decreased quality of life.
Purpose- To analyse the degree of awareness about leprosy, how the affected elderly population is treated, knowledge about its available treatment and role of rehabilitative services among the persons affected with leprosy.
Methodology- A total of 150 leprosy affected elderly individuals were selected from the community. Participants were interviewed based on a self-devised questionnaire which assess their awareness about the disease and the behaviour of society towards them.
Result- The result of above survey shows that awareness about disease is still at low level and the stigma is reduced but not up to significant level. The affected individuals suffer from marked segregation from the society and ageing related special needs and care are not fulfilled.
Conclusion- There is need of reconceptualizing the stigma associated with leprosy. The society should be more empathetic towards the leprosy affected elderly persons. Better steps should be taken towards their acceptance and taking proper care with timely accomplishing medical treatment and improving their quality of life with the help of physiotherapeutic approach.
Keywords: Leprosy, Hansen's Disease, Rehabilitation, Stigma and Discrimination.

INTRODUCTION

Longevity brings with it opportunities, not only for older people and their families, but also for society as a whole. Older people can also contribute in many ways to their families and community. Yet the extent of these opportunities and contributions depend heavily on one factor: Health. If these added years are dominated by decline in physical and mental capacity, the implications for older people and society are more negative. There are many challenges faced by elderly population in context with their health. One such disease or challenge is leprosy which can cause multiple consequences in elderly people.Leprosy is a bacterial disease caused by *Mycobacterium leprae* and also known as Hansen's disease. *Mycobacterium leprae* is the causative agent of leprosy. Ramanathan, Malviya, Jain, & Husain, (1991) stated that an inferiority complex is generated by its own because of some social restrictions imposed by the community on the affected individual and this restriction acts like a force which pull out the individual from the society by its own. Kaur & Brakel, (2002) revealed that the loss of former place in society or social role, causing loss of dignity, cause mental and physical stress and some of leprosy elderly individuals end up as beggars, often living in leprosy colonies with other leprosy affected individuals. Arole, Premkumar, Arole, Maury, Saunderson, (2002) reported a very important negative impact of stigma is delayed presentation of new cases of leprosy; due to this stigma patient conceal the early symptoms of disease which may lead to disability. For the affected persons stigma leads to shame, anxiety and lack of self confidence. Leprosy is one of the most stigmatized diseases known today. Social stigma is associated mainly due to prevalent myths like its hereditary and contagious nature, divine curse along with the physical deformities. Rao, Raju, Barkataki, Nanda, Sandeep, (2008) in a study showed that the Leprosy is popular from decades because of its social stigma and disfigurement of body parts. Rensen, Bandyopadhyay, Gopal & Brakel, (2010) had found that this leprosy affected elderly individuals face psychosocial difficulties due to prevalent social stigma and physical impairments associated with leprosy following with these impairments' individuals experience limitation in daily activities of life.As a result of

such limitations or because of visible deformity, community restricted the participation of these affected individuals in social and religious functions and these restrictions in long term cause self and social devaluation of affected individuals and social rejection of some of them. Rensen et al. (2010) had reported that their families and community may reject them or they themselves leave their home due to social rejection. People have left their families and even spouses and children, fearing the repercussions of the fact that they had Hansen's disease. The fear of social ostracism prevented the disclosure of disease to the community.

Singh (2012), had revealed that the affected people not only face physical impairments but also suffer psychosocial repercussions due to the community's attitude, had also reported that the attitude of community toward leprosy affected individual was not good and community was still attached with stigma and did not want to engage them in any social activities.

As far as the relationship with the community was concerned, communities of some affected individuals were aware of their diseased condition and communities of some individuals were not allowed to use common community places . The negative behaviour of community create psychological stress that's leads to social rejection and isolation of leprosy affected individual. The knowledge of leprosy in general population is inadequate, the cause of disease was known to only small part of population and few of them believed it to be the consequence of the individual's past misdeeds. Hegde, Shenoy, Pinto, & Amin, (2015) had reported that despite the various advances in the field of leprosy management; it is still referred to as "living death".

Present study has been conducted in rural as well in urban areas of Shahjahanpur in U.P. to rule out the awareness about the disease in community by the aspect of leprosy affected elderly individual.

Epidemiology

National Leprosy Eradication Programme

(Communicable disease programmes, n.d.). Government of India launched the National leprosy control programme in 1955 with following goals: To reduce the incidence of disease by interrupting is transmission so that the disease does not remain as a public health problem; to treat the patient to achieve the cure and completely rehabilitate if possible and also to prevent the development of deformity. Status of health at the time of independence was grim and leprosy was no exception. In the absence of proper treatment for leprosy disease was generally mistaken or the outcome of misdeeds by the people as the curse of God. There occurred a steady increase in the number of cases through successive decades starting with 1.37 million in 1951 and reaching 4.0 million estimated cases in 1981. The prevalence of disease was 57/10000 in 1981. By the March 1997 there were 5.41 lac patients in the country and the prevalence rate is 5.75 per 10000. India today ranks foremost among the countries saddled with leprosy sufferers, 58 per cent of the global recorded case load and 52 per cent of estimated cases are contributed by India. High numbers of patients are present mainly in the state of U.P., Bihar, Orissa, West Bengal, and Madhya Pradesh.

Objectives of the Programme

National Leprosy Control Programme had been in operation since 1955. Initially it started as centrally aided scheme with primary focus on rural areas of high and moderate endemicity. It was converted into 100 percent centrally sponsored scheme since 1969. The main objective that time was to control leprosy through Dapsone Monotherapy. In view of scientific advancement and availability of highly effective treatment of leprosy the programme was redesignated as a National Leprosy Eradication Programme in 1983 with an aim to achieve arrest of the disease activity in all the known leprosy cases in the country by the year 2000 A.D. After the World Health Assembly Resolution in the year 1991 the objective of the programme was defined to achieve the elimination of leprosy by the end of century in the country thereby reducing the caseload to 1 or less/l0000 population.Annual Report of "National Leprosy Eradication Programme (NLEP)" 2016-2017 reveled that during 2016-17, Leprosy Case Detection Campaign (LCDC) was carried out in 163 districts of 20 states, wherein 34,672 cases were detected and were put on treatment. This activity was aimed at early case detection and timely treatment. The success of the Campaign can be estimated by the fact that a drastic decline in the trend of the cases present with visible deformity was achieved. Moreover, prevention of deformity in new cases due to timely detection and treatment could be made possible and another innovation introduced during the year was Sparsh Leposy Awareness Campaign (SLAC) through Gram Sabhas, carried out with the help of Panchayat and Village Health and Sanitation Community and this report also stated that the expected outcome of SLAC was to generate awareness, reduce stigma and improve self-reporting by the affected cases, the activity

was carried out in 60% of the total villages across India and this year is started with 0.86 lakh leprosy cases on record as on 1st April 2016, with PR 0.66/10,000. Till then 34 States/ UTs had attained the level of leprosy elimination. 554 districts (81.23%) out of total 682 districts also achieved elimination by March 2017.

Aims and Objectives

To analyze the degree of awareness of leprosy among the elderly leprosed individuals.

To analyze the behaviour of society towards the leprosy affected elderly individuals.

Materials and Methods

A survey study was conducted in the 15 rural blocks of District Shahjahanpur having population of approximate 3585769 located in Uttar Pradesh for working with the prevalence rate of 1.12. Leprosy affected individuals were treated at block level community health centre. The individuals who included in study were leprosy affected individuals. An uniform questionnaire is designed for leprosy affected elderly individuals to find out their perception on disease and impact of stigma at family level, in the society and at the work place on them. An uniform questionnaire of 20 questions were asked with the affected individuals based on disease information, participation restrictions, social interactions and other discrimination having the answers with the option of Yes or No. Details of each respondent in terms of socio economic characteristics, the necessary data is collected in depth by us with the help of Para Medical Worker appointed at the community health centre of concerned block while taking interview and data were entered on excel sheets checked and analyse on the basis of answers given by the leprosy affected elderly individuals. This study enrolled all 150 men and women affected with leprosy of elderly age group of 60 years and above who had been diagnosed with Paucibacilliary or Multibacillary completed their Multi Drug Therapy regime and released from treatment before the interview was conducted. Individuals affected with leprosy that met the above criteria but unable to respond to a question and giving irrelevant respond ,refuse to being part of interview and creating nuisance are excluded from the study. The eligible 150 individuals identified out of which 150 were interviewed in which 36 individuals were female and 114 are males in the median age of 67 years they were confirmed by their treatment records present at concerned community health centre of related leprosy affected elderly individuals and study is still in progress. Iinterviews had conducted by approaching the affected individual at their place and after providing a peaceful environment with no external element present by respondent side who can affect the interview. The questionnaire consisting of 20 questions some of which are inspired by basic knowledge of disease, rehabilitation services, community behaviour towards leprosy, Government initiatives and economical dependency and categorised under three main category as Basic Disease Information, Socioeconomic condition and Government Initiatives for treatment and rehabilitation of leprosy affected elderly individuals.

For better analysis of questionnaire we divided it into three main aspects

Basic Disease Information: General information of leprosy, Medicines distribution from community health centre, complication of disease due to delay case reporting and this section contains 6 questions.

Socioeconomic condition and Stigma: Marital relationship, Social acceptance, Impact of stigma, behaviour of family members towards them and economical dependency and this section having 9 questions related with community behaviour.

Government Initiatives: Health Visits and Rehabilitation services and contain 5 questions of general initiative of government towards elimination of disease.

Results

Total 150 leprosy affected elderly individuals were listed in which 36 individuals are female and 114 are male individuals. We had interviewed all the 150 individuals till now in regards with questionnaire of 20 questions divided in 3 sections.

Table 1.1 Frequency distribution of leprosy affected in 60 individuals present over district Shahjahanpur

Sr.No.	QUESTION	Frequency in %	
		YES%	NO%
1	Do you know about Leprosy?	90	10
2	Is this a contagious disease?	18.3	81.6
3	Is this disease caused by sins of previous birth?	36.6	63.3
4	Is your family member discriminating in living and eating together?	41.6	58.3

5	Do you know about symptoms of leprosy?	93.3	6.6
6	Do you know that medicine of leprosy is distributed at free of cost in all government hospital?	100	0
7	Can marital relationship with leprosy affected individual is done?	51.6	48.3
8	Do you have the information about leprosy from hospital?	100	0
9	Is ASHA (Health Worker) of your village is came to your place for health examination?	91.6	8.3
10	Do the person of your village or community invited you in the wedding ceremony or in the religious function?	33.3	66.6
11	Do you know that congenital body marks, patch with itching on skin is not leprosy symptoms?	53.3	46.6
12	Do you that leprosy is also a bacterial disease like other bacterial disease?	50	50
13	Do you know that never conceal the symptoms of leprosy because delay detection can complicate the disease and disability may occur?	100	0
14	Do you know that deformity caused by leprosy can be corrected by Reconstructive surgery?	70	30
15	Are villagers of your community discriminating in keeping social relationship with you?	45	55
16	Do you know that Uttar Pradesh Government started the Leprosy Case Detection campaign (LCDC) in which early case detection is done?	76.6	23.3
17	Do you know that if affected individual completed the full treatment then the individual will not be a leprosy patient?	86.6	13.3
18	Do you ever being involve in begging or depending on others for essential things of livelihood?	68.3	31.6
19	Do you know that if affected individual completed his treatment with in time duration then he will continue his life as a normal person?	85	15
20	Do you know that self care practice and exercise as elaborated and demonstrated by physiotherapist can minimize or correct the deformity?	88.3	11.6

General disease information: All leprosy affected elderly individuals were aware about the disease and its symptoms and distribution of multi drug therapy is distributed at free of cost in all government hospital. 46.6 % of leprosy affected individuals were correlating the disease symptoms with other dermatological disease. 50 % of leprosy affected individuals were worried that they were not affected with a general disease and the maximum population are aware about the demerits of delayed presentation and its severe harms to human body. Socioeconomic condition and stigma: 81.6 % individuals had believed that this disease is not spreading with touch but still 18.3% individuals are disagreeing with this statement. A large population of approximate 36.6% were still in believe that this disease was the result of sins of previous birth but 63.3 % are believed it's have nothing to do with previous birth. A population of 41.6 % leprosy affected individuals were treated in bad manner and keep separate their kitchen wares by their own families but 58.3 % were still treated good by their families. About 48.3 % individual had believed that leprosy affected individual are not fit for marital relationship and 51.6 % affected individual believe that marriage can be done because it will not spread the disease to spouse. An approximate 45 % of leprosy affected individuals face social rejection and 55 % population did not feel this type of rejection but if the individual present with visible deformity have to face more rejection. Community had still maintain a social distance by not inviting affected individual at wedding or other religious functions, an approximate 66.6% of affected individual feel socially isolated but 33.3 % get the chance of being a part of social gathering in the society. 86.6 % of affected individuals had believed that they are cured after completion of multi drug therapy but 13.3 % still believe that disease is not cured because of anaesthesia present over patches and disfigurement of limbs. An approximate 68.3 % leprosy affected individuals were completely dependent on others or they end up their lives as a beggar but 31.6% affected

population are did not involve in begging. Approximate 85 % of the individuals believe that if someone completed their multi drug therapy course with in time duration than they will leads a healthy life and 15 % affected individual did not feel the same.Government Efforts: Toward eradication of leprosy, Government appointed the Accredited Social Health Activists (ASHA) at village level on the community health centre who plays important role in doing healthy contacts and 91.6 % affected elderly individual are in contacts of ASHA but 8.3 % refuse to have any visit of ASHA in terms of health. Almost all leprosy affected individual were told that they got the information regarding leprosy from government hospital. 70 % of affected individual were believed that after reconstruction surgery the deformity is minimized or corrected but 30 % which was also a huge population still did not believe that surgery could not bring any changes in the deformity. A large population of affected individual near about 76.6 % were in contact with health team who had gone for early case detection campaign started by the National Health Mission but 23.3 % population did not aware about such type of any campaign. A huge number of leprosy affected individuals near about 88.3 % informed that self care practice as explained and demonstrated by Leprosy health staff of the concerned area could effectively stop the disfigurement and harm to body and exercises demonstrated by the Physiotherapist would benefit their muscle strength and range of movement of stiffed joints but 11.6 % of affected individuals had reported NO for any benefit with such type of exercises and practices.

DISCUSSION

The word leprosy brings a thunderstorm in the brain of society due to prevalence stigma and disfigurement of body parts. The individual who are affected with leprosy feel psychological condition which disturb them in some extent of social appearance. Leprosy has been found to affect infected individuals specially elderly ones that they cannot carry out their life further smoothly due to physical deformities and socially segregated because of stigma attached to it.

The combination of leprosy, physical deformity and stigma caused dehabilitation, anxiety, fear and depression. Physical impairments limit the activity and ability of a person to carry out duties or task that was previously possible. Affected Individuals experience many disadvantages in living in society and individual present with permanent impairments have to experience more social isolation because of which they are unable to play roles normally expected of them. These disadvantages are called participation restrictions, the participation restriction experience by the individuals in the study includes unemployment, poverty, loss of social status and self esteem.

When affected individuals experience problems in social participation or participation restriction for a long time, they feel devalued and gradually pushed out of normal society. They are forced to leave their families and communities due to rejection they experienced. Ultimately, they go and live with other affected individuals who also devalued like themselves, mostly in leprosy colonies and some of them end up as beggars.

Present study features two main causative factors for segregation of affected individuals namely prevalence stigma causing participation restriction, social rejection and second is physical impairments causing limitation of activities.

To prevent the segregation of affected elderly individuals it is important to work on prevalent stigma and social rejection of physically impaired individuals. Prevention of impairment and disability is possible with early detection of a new case and providing rehabilitation interventions like physiotherapy, occupational therapy, reconstructive surgery and temporary socio-economic assistance and most important factor for preventing segregation of leprosy affected elderly individuals is educate and aware the society about leprosy. It would help in acceptance of leprosy affected elderly individuals and it will reduce the prevalent stigma. Many individuals still believed that this disease is due to sins of previous birth that shows the society's negative attitude towards leprosy compel them to feel ashamed but in fact this is also a normal bacterial infection so we have to educate the society about leprosy. The family members, community and society should be gentler and kinder with affected elderly individuals and should not be socially rejected because this will keep them out of anxiety and psychological stress. Social participation will bring change in the perception of affected individuals about leprosy. Rehabilitation programme should be developed for the leprosy affected beggars. Self-care practice will continue for the prevention of deterioration of disabilities and other leprosy related problems. Counselling and efforts to motivate the affected individuals to live a socially responsible life because a large population of affected individuals ends up their life as beggar. Affected individuals are believe that if someone complete their treatment, he/she is recovered from disease but some of them are not sure because of permanent damage caused

by the leprosy. Recently the initiatives started by the government is being effectively implemented viz. rehabilitative services provided for leprosy affected individuals are benefited the many of them but some of them still not satisfied or got effective change in their conditions. Psychological rehabilitation of these individuals is dependent on the interpersonal relationship between the patient and healthcare worker. The healthcare worker dealing with these affected individuals is the primary link between the patient and their normal existence. This link needs to be strengthened and the patient should be respected as a person and brought to the mainstream of society. The family relationships of these patients need to be preserved by every possible means. The focus of psychosocial rehabilitation lies with the family and family protection and other measures should be adopted in a dignified way. Thus, holistic approach including education of community on leprosy, early detection of new cases and treatment and rehabilitation can help in the elimination of curse of leprosy.

Social rejection and isolation is caused by physical impairments and social stigma.

Future Strategies

Although large information has available in public domain on leprosy and success achieved by many countries but the main problem of stigma is still maintained. This seems that the complete eradication of Hansen's disease from the universe is very difficult and it need some more years because of long term activity. The role of mental health professionals and Physiotherapist is important in tackling psychosocial issues and physical disability issues related to Hansen's disease. Psychosocial assistance and support to the affected population of this disease will be helpful in eradication of this disease. This requires a national-level mass campaign of health education for the general public. The general public should be made aware that Hansen's disease is not a genetic disorder, it is 100% curable, and the patients need social support. A better coordination between all healthcare partners like dermatologists, psychiatrists, physiotherapist and other healthcare workers will settle all the issues and help in achieving the eradication goals.

CONCLUSION

There is the need of reconceptualising the stigma associated with leprosy. Older leprosed individuals are often assumed to be dependent and burden to society. The society should be more empathetic towards the leprosy affected elderly individuals. Better steps should be taken towards their acceptance and taking proper care with timely accomplishing treatment and rehabilitative services and improving their quality of life with the help of physiotherapeutic approach.

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AUTHOR'S CONTRIBUTION

Mohammad Hassan (Author 1) conceptualized the study, conducted the literature review, designed the methodology, and carried out primary data collection and analysis. He was also responsible for drafting the initial manuscript and interpreting the findings in the socio-cultural context of Hansen's disease and aging.

Prof. (Dr.) Shahiduz Zafar (Author 2)* served as the principal investigator and research supervisor. He provided critical guidance in refining the research objectives and ensuring methodological rigor. He reviewed and revised the manuscript for intellectual content, contributed to the discussion and conclusion sections, and approved the final version for submission.

Both authors have read and approved the final manuscript.

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