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Why Do Leprosy Patients Default Treatment? Evidence from Sri Lanka

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Abstract

Introduction

Leprosy is a major health issue in the Western Province despite Sri Lanka achieving the national elimination target and the Western province records the highest number of cases. Considerable number of Leprosy patients default treatment. There are many socio-economic factors, needs and gaps and identification of these factors and reasons for defaulting will be important to develop and change strategies to address the gaps in service provision for defaulters.

Objective

The research was carried out with the objective of identifying the reasons for defaulting among adult leprosy patients in the Western Province, Sri Lanka.

Methods

A qualitative study using in-depth interviews was conducted to identify the underlying reasons for defaulting among a group of treatment defaulters and patients on regular treatments. Selection of subjects was done using purposive sampling method. In depth interviews were conducted at the household level for defaulters and clinic level for patients on regular treatment.

Results

The underlying reasons for defaulting identified in the in-depth interviews included; poor knowledge, stigma, low income, side effects of the drugs, substance abuse, early disappearance of skin patches, work commitments, change in the residence, long waiting time and poor care giver support.

Conclusions

There are many socio-economic reasons which should be addressed by the government at least for patients who have defaulted. The public health system which is well established at the grass root level should be more utilized to tract the defaulters and support them to re-start treatment. From the onset, patients should be well educated to continue treatment. Further studies should be carried out to explore the association of substance abuse and defaulting.

Keywords – Leprosy, Defaulting, Stigma, Service provision,

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I. Introduction

In contrary to its popular belief, Leprosy is not a very contagious disease. Often Leprosy patients experience stigma and discrimination due to poor awareness and fear for the disease. Stigma is considered as one of the main causes for delayed diagnosis that facilitates transmission of the infection within families and communities (Nunzi, 2012). There are two main types of leprosy, Pausibacillary (PB) and Multibacillary (MB) as per the WHO classification. The treatment regime for leprosy is Multi Drug Therapy (MDT) (World Health Organization, 2016a).

The global registered prevalence of leprosy at the end of 2015 was 176,176 cases (0.2 cases per 10,000 people). These statistics show that 94% of new leprosy cases (199,992) were reported from 14 countries, each country accounting for more than 1000 new cases. From the rest of the world only 6% of new cases were reported. Degree of continued transmission of infection is indicated by the number of new cases (World Health Organization, 2015).

Organized leprosy control activities In Sri Lanka date back to Dutch colonial era. This includes the establishment of Leper's Asylum in Hendala and Leper's Ordinance enacted in 1901 which made isolation of leprosy patients compulsory. A Public Health Inspector (PHI) was appointed for each district in 1954 and was the key person responsible for coordination of clinics, village surveys, contact tracings, defaulter follow-ups and community awareness programmes. In 1980, Sri Lanka was one of the first countries in Asia to bring in MDT for all patients and a full coverage was achieved in the same year (Pathmeswaran, 2008).

A social marketing strategy was initiated in early 1990s, which resulted in 150% increase in case detection and even more was the huge increase in self-reporting. This was the outcome of a professional, authoritative and broad-based advertising campaign launched by the Ministry of Health, assisted by a Swiss charity organization and the Novartis Foundation for Sustainable Development in 1990's. This huge public awareness campaign in Sri-Lanka encouraged people who earlier hid their symptom out of fear to come out, enabling early diagnosis and cure and almost eliminated the stigma attached to leprosy and (World Health Organization, 2006).

During the last two decades Nearly 2000 Leprosy cases were reported annually in Sri-Lanka. Leprosy elimination target of WHO (less than 01 case per 10,000 population) was achieved by Sri Lanka in 1995. In Sri Lanka The new case detection rate was around 10 per 100,000 population during past 10 years (Dabrera, 2013). In 2012 the prevalence and incidence of leprosy in Sri-Lanka were 0.77 per 10,000 population and 10.38 per 100,000 population respectively (World Health Organization, 2012). In 2013, Leprosy became a notifiable disease and contact tracing was commenced in 2014. The highest percentage (38%) of Leprosy cases was reported from the Western province in 2015. Of the screened cases, 1.3% was positive for Leprosy. The highest number of new Leprosy cases (332) was detected in the Colombo district in 2015 (Anti Leprosy Campaign, 2015).

In 2001/2002 leprosy services were integrated to general health services and leprosy patients are managed at skin clinics conducted in base hospitals and the above with a consultant dermatologist. With the above change, the case detection programs are centered around consultant dermatologists. Despite Sri-Lanka achieved the national elimination targets, it has been difficult to reach sub- national targets. There are pockets of leprosy endemic areas in Sri-Lanka.

Health seeking behaviors of people has a positive link with perception and culture of people. Socio-cultural, economic and beliefs regarding leprosy have a great influence. In case of leprosy, surrounding community can influence on what type of treatment they take. A significant impact on one's health seeking behavior is caused by limited knowledge, confusion about cure, wrong believes about

diseases and lower economic conditions (Alt et al 2015; Manker et al, 2011).

Stigma associated with leprosy originates from socio-cultural beliefs often lacking scientific rationale. These can hinder all aspects of leprosy control. Due to the fear of social rejection, patients affected by leprosy are more likely to hide their condition from their spouses and from other family members and tend to not seek or adhere to treatment. Due to this early case detection and initiation of treatment at an early stage is hindered. This can result in permanent disabilities (Kar, 2010).

Certain patients discontinue the treatment course after some time or do not initiate their treatment following the diagnosis of their disease condition. Such patients are defaulters. A defaulter is an individual, who was unable to complete treatment within the maximum allowed time frame. In the PB Leprosy treatment regime, it is nine months and in MB Leprosy, it is eighteen months. Thus, when a PB patient has missed treatment for more than three months and MB patient for more than six months, such patients cannot complete their treatment within the recommended period (World Health Organization, 2018).

There are two categories of defaulters. Those are "True defaulters" and "Defaulters who have restarted treatment". The true defaulter category includes patients who have interrupted treatment for a total of three or more months (if PB) or a total of six or more months (if MB) and their follow up (contact numbers, place of residence) details are missing from the health system. Defaulters who have restarted treatment category include patients diagnosed with leprosy who have abandoned treatment before its completion and return to the health care facility to complete treatment beyond three months period for pauci-bacillary (PB) cases and beyond six months period for multibacillary (MB) cases (World Health Organization, 2016b). Statistics on default adult leprosy patients who restarted the treatments in Sri-Lanka and in the Western province are outlined in table 1 and 2 respectively.

Table 1: Distribution of Default Leprosy Patients Who Have Restarted Treatment Sri Lanka

Description	2012	2013	2014	2015
Number of default leprosy patients who have restarted treatment	12	82	53	81

Source- Annual Report 2015, (Anti Leprosy Campaign,2015)

Table 2: Distribution of Adult Leprosy Defaulters Restarted Treatment in the Western Province

District	2013	2014	2015	2016
Colombo RDHS area	14	12	04	09
Colombo CMC area	12	11	01	02
Gampaha	07	07	02	06
Kalutara	03	05	00	05
Total	36	35	07	22

Source: Fairmed Foundation (2017)

Healthcare teams take effort to trace and persuade the defaulters to return for treatment. When a PB patient has missed treatment for more than three months and a MB patient for more than six months, it is not possible for them to complete the treatment regime within the maximum time allocated. Therefore, the full course of treatment should be restarted after clinical examination and confirmation of the classification which is done at the clinic (World Health Organization, 2018).

II. Methods

A qualitative study with in-depth interviews was carried out at the household level among true defaulters and at clinics for "default who have restarted treatment" and non-defaulters. The study participants were male and female leprosy patients age 15 years and above who have been residing in the Western Province during past last one year. The sample size was determined while conducting the

interviews. Patient recruitment and interviews were conducted until researcher was satisfied that the theoretical saturation point was reached. Purposive sampling method was applied to select the sample which represents a cross section of the study population

In-depth interviews were carried out in the main thematic areas of personal factors, healthcare related factors and social factors which were identified as factors for defaulting in the literature. In-depth interviews were conducted in participant's residences and in the clinic setting. In-depth interviews were conducted as semi structured interviews with time ranging from 45 minutes to one hour. To ensure the participant's privacy a quiet place with minimum interruption was selected to conduct the interview. In order to build a rapport before the initiation of interviews, interviewer had a casual conversation with participants. The interviewer informed the confidentiality of the study to the participants. All interviews were recorded digitally (audio) with the consent of the participant and as short notes.

The analysis of qualitative data was aimed at developing some form of explanation, understanding or interpretation of the people and situations that were investigated. It is a cyclical and ongoing process throughout the data collection phase (Braun and Clarke, 2006). In this study thematic analysis method was used as the method of analysis.

III. Results

The following areas were identified as major reason for defaulting by adult Leprosy patients.

Poor income -A majority of leprosy patients are people who live with poverty and have very poor socioeconomic conditions. Since they were unable to find work every day, patients are doing multiple jobs to earn money. Defaulted patients were not having adequate money to cover their basic needs such as food, cloths, shelter and education. The poor educational background also leads to poverty.

Substance abuse- Most of the Leprosy patients in poverty live in overcrowded slum areas. Of them most are addicted to substances like heroin, cannabis and illicit liquor. Poor educational background also contribute to this and considerable proportion of the income is spent on substances. There are places freely available to purchase substances.

Change of the residence -Many defaulters have changed their residences due to work, marriage, going overseas. If the patient has not informed the clinic there can be discontinuation of treatment.

Disappearance of skin patches – The skin patches disappear within few months of treatment and symptoms are relived. Some patients interpret this as cure of the disease condition and stop treatment.

Work commitments – Due to work commitments especially daily wage earners find it difficult to attend the clinics on weekdays. Some are unable to attend the clinics due to the nature of their job which involves travelling to distance places.

Lack of knowledge – Most of the patients are with poor socioeconomic and educational level. Their knowledge on the disease is poor and do not understand the importance of completing the full treatment course.

Side effects of the drugs- Dapsone hypersensitivity syndrome occurs due to Dapsone in the MDT regime. Patients complain of darkness of the body, passing red color urine and sometimes rising sugar levels. The patients consider them as serious side effects and stop treatment.

Waiting time at clinics – Patients do not like long waiting times in clinics. This has affected patients who are employed and unable to spend a long time in the clinics.

Stigma- In the society especially in persons with low socio-economic conditions Leprosy is associated with stigma. Patients are reluctant to reveal their disease condition due to stigma. This leads to non-attending clinic and treatment default. There are instances where patients are discriminated even by their own family members.

Lack of care giver support – Patients with poor socio-economic conditions, unmarried persons without parents, persons who have lost their spouse and persons who are addicted to substance receive poor caregiver support. This has led to discontinuation of treatment.

IV. Discussion

In order to explore the underlying reasons for defaulting in-depth interviews were conducted among defaulted and non-default leprosy patients. Effort was made to identify and broadly discuss the underlying reasons for defaulting among adult leprosy patients.

Although detailed data that can be obtained through a quantitative study is limited, qualitative study can act as a rich source of information about a particular factor. This study used the qualitative methods to study individuals in their natural settings and to explore their perceptions of certain phenomena in relation to the exploring the reasons for defaulting. Individual interviews were conducted since the interviewees may not feel comfortable enough to share their personal feelings within a group such as a focus group. Hence, in-depth interview method was adopted.

In most of the defaulters unfavorable living conditions were present in most. Some were stigmatized by the society and family members due to substance abuse. Financial problems were one of the key reasons for defaulting. Patients were very poor and were unable to cover their basic needs such as shelter, food, and children's education. The social and financial problems act as obstacles for clinic attendance and getting treatment for leprosy. Many patients preferred a doctor visiting to their houses and explain the disease and complications.

V. Conclusion

Main reasons for defaulting were identified as personal factors, health care related factors and social factors following the in-depth interviews conducted with defaulters and non-defaulters. Reasons identified in subthemes under each theme are; Personal factors (low income, substance abuse, early disappearance of skin patches, work commitments, change in the residence and poor knowledge) Health care related factors (experience of side effects of the drugs, long waiting time), Social factors (poor care giver support, stigma).

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