Risk factors of stigma related to leprosy- A Systematic Review

Abstract

The studies reviewed indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. The consequences of stigma can range from the psychosocial dysfunction to isolation, rejection and participation restriction. Despite the variation in prevalence of different types of stigma, its severity and nature, the risk factors associated with stigma are remarkably similar. They include visible impairments, disability, low socioeconomic status, low education and the various perceptions regarding leprosy. This suggests that risk factors contributing to the development of stigma are perhaps of a similar nature thus indicating that management of stigma in diverse culture is possible by implementing related stigma-reduction strategies to counteract the various risk factors in various settings. Nonetheless, establishing the particular risk factors that contribute to stigma in different settings can further aid the design of specific interventional programs to address the different determinants followed by the evaluation and monitoring of the stigma interventions at different levels and settings.

Key words: Stigma, Risk factor, Leprosy, Disability.

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Introduction

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English [1]. The most common notion of stigma however, still refers to people's fear of dealing with leprosy-affected people. This is in most cases due to a lack of scientific knowledge and suspicious ideas about the disease [2]. Considering the severity in terms of human suffering, the consequences of stigma in leprosy often outweigh the burden of physical afflictions, [3] different causes like fear, unattractiveness, unease of how to deal with leprosy affected person and the varying stereotypes of the societies [4].

Leprosy and its stigma have a pervading effect on a patient's life, affecting marriage, interpersonal relationships, employment, leisure activities as well as attendance at religious and social functions. In Nepal including other South Asian countries,a strong culture of belonging to one's family bears an essential value to an individual rather than the independent and individualized identity prevalent in west. For leprosy affected person to lose attachment to their family members potentially bears much grave psychosocial consequences than losing their fingers and toes [5].

The well-being and the self-esteem of a person are inextricably linked to their income generation and their ability to secure employment. In a culture where a person is valued by the ability to support their dependents, unemployment because of Leprosy can have an enduring effect not only economically but psychosocially too [6]. In severe cases, stigma may even lead to complete rejection or banishment by communities, insults and hate [7].

Risk Factors and Its Implications:

Risk factor has been defined as an environmental, behavioral or biological factor confirmed by temporal sequence which if present directly increases the probability of a disease occurring and if absent or removed reduces the probability [8]. Various risk factors contributing to the development of stigma in different cultural settings may bear diverse origin, however, understanding the differences and similarities of risk factors can have a significant contribution to direct the stigma reduction strategies and programs. The similarities in the existence of risk factors of stigma imply the possibilities of globally applicable psychosocial needs to leprosy affected persons. In a study conducted in South Africa, the needs that were similar to the rest of the world were the need for self-acceptance, need for social acceptance and the need for acceptance by the community [9].

Various studies intended to assess the impacts of interventions to reduce stigma have recommended possible ways in which stigma can be reduced. Social skills trainings along with counseling have been found to be effective in reducing self-perceived stigma in a study done in India [10]. Similarly, Ebenso et al found improved self-esteem, happiness and skills acquisition in leprosy affected persons with the aid of socio-economic rehabilitation (SER) [11].

Addressing stigma reduction interventions are challenging considering the diversity of risk factors, however, a literature review on stigma reduction strategies and interventions suggest that single-level and single-target group approaches are not enough. A patient centered approach targeting to reduce stigma in affected individuals, empowerment of affected persons and the involvement of affected persons in the development and implementations of stigma reduction programs at different levels were suggested to be the effective [12]. This further highlights the method of effective interventions and the need to assess the level of stigma and the pertinent risk factors.

There are various studies addressing the issues of stigma related to leprosy, however, rarely havesystematic reviews been done to extract the risk factors contributing to the development of stigma in leprosy. This article reviews all kinds of factors from socio-demographic to the clinical characteristics of the disease which have been associated with stigma in leprosy.

Definition of Terms

Impairment: Impairment is referred to as "a problem in body function or structure", such Range of factors that determine the outcome of the disease. This includes 1.The social and economic environment. 2. The physical environment 3.The person's individual characteristics and behaviors [14]. Participation restriction: Participation refers to the involvement in life situations. When an individual experiences problems in participation, it is referred to as participation restriction [15].Activity limitation: When an individual experiences difficulties in executing activities [Ibid]

Material and Methods

To review the articles related to the stigma of leprosy and its risk factors, a literature study was done. References were collected through a PubMed (Medline) search on the keywords "leprosy" combined with "stigma", "risk factors" "KAP" or "attitude." A total of 187 papers were displayed by the PubMed (Medline) search. 67 out of 187 papers were selected based on the issues of stigma addressed by them. Out of the 67 papers addressing issues of stigma, a thorough review of each article was done to select only those articles which dealt with the risk factors of stigma related to leprosy by original research. Seventeen articles were extensively reviewed to extract the types of stigma and the risk factors contributing to the development of stigma. We included articles that were published between 2000 and 18th July 2012.Both qualitative and quantitative studies were included into our review.

Results

Studies that involve the assessment of stigma can be broadly categorized into two groups: (i) studies that assess the effects of stigma on the person affected and (ii) studies that assess attitudes and/or practices towards people affected by leprosy. In addition, studies can be further categorized into different groups depending on the types of stigma that have been assessed. Most of the studies have assessed all kinds of stigma with or without specifying the particular stigma; however, our review has extracted the types of stigma from the studies.

ISSN: 2091-1041 | VOLUME 1 | ISSUE 2 |2013

There are three kinds of stigma, perceived stigma, enacted stigma and self- stigma.

1. Perceived stigma is also called anticipated stigma or felt stigma. It is the perception, expectation or fear of discrimination and the awareness of negative attitudes or practices in society [16, 17].
2. Enacted stigma is also called discrimination or experienced stigma. This occurs when any member of society, healthcare provider or person in the surrounding behaves negatively or discriminates by some means to the affected person [17-18].
3. Self-stigma is also called internalized stigma. This kind of stigmatization occurs when a person start believing what others think and say about him. This in turn, may lead to loss of self-esteem and dignity with consequent development of fear, shame as well as hopelessness and guilt [Ibid].

Encompassing all kinds of risk factors which have been associated with the stigma in leprosy, this review has categorized the stigma in three different types as 1.Perceived stigma, 2.Enacted stigma and3.Mixed stigma. Mixed stigma in this review refers to more than one type of stigma.

Perceived Stigma

Among a total of 7 studies that focused on perceived stigma, a study conducted in Indonesia found 35.5 % of perceived stigma in 1,358 leprosy affected persons. In the same study, perceived stigma in the community towards leprosy affected persons were assessed, and found the level of perceived stigma ranging from 18 to 50 %.Eighteen percent of them perceived that leprosy causes problem to family and 50% perceived that leprosy causes shame and embarrassment [19]. In a study conducted by Corline Browers et al in eastern Nepal 100 leprosy disabled and 100 community controls were selected for the study which found that perceived stigma was higher in disability group II than disability group I [20]. In a study conducted at 3 different sites in India, 12-17% (n = 599) of perceived stigma was found in leprosy affected persons and likewise 40-80% (n = 2399) of perceived stigma was found in community members [21]. In Bangladesh, a study conducted in 189 leprosy affected persons found 50 % of perceived stigma [22]. Similarly, in a study at eastern Nepal, stigma towards leprosy in 300 community members were assessed where overall community stigma was found to be 52% [7].

There were two qualitative studies conducted for perceived stigma in India and Nepal. In Nepal, 19 in-depth interviews were conducted where perception, beliefs and behavior were assessed [23]. Similarly in a study conducted in India where the difference in self-stigma and community stigma was assessed between the communities with integrated and the communities with vertical health program approach was implemented. Integrated health approach refers to the health approach which was commonly implemented for all health conditions including leprosy while vertical health approach refers to the approach basically focused for leprosy control activities, carried out by trained personnel and with minimal participation of community members. Both self-stigma and community stigma were two times higher in the vertical approach health care system than integrated health care system [24].

Enacted Stigma

There were two studies that focused on enacted stigma. Lustosa et al conducted a study in 107 leprosy affected persons in Brazil where experienced discrimination was found to be 27.1% [25]. while experienced discrimination was found to be 2.1% in a study conducted in Bangladesh where social problems and stigmatization acts were reported within a month of diagnosis [26].

Mixed Stigma

Mixed stigma in our review includes more than one type of stigma. 223 leprosy affected persons were studied in Brazil where 35.4% of them were found to have participation restriction [27]. In a study conducted in India, 52% of the leprosy patients, belonged to lower socio-economic status and were associated with the stigma [28]. Similarly, a study in the Philippines found that lower (34%) General Self Efficacy (GSE) scale and higher (63%) Screening of Activity Limitation and Safety Awareness(SALSA) were associated with leprosy affected persons (n = 108) [29]. The mixed method study on the

impact of socio-economic rehabilitation (SER) in 20 leprosy affected persons was conducted where positive impact of SER was found [11]. A study in China revealed that 73 % (n = 73) of ex-leprosy patients had experiences of stigma [30]. Zodpey et al in India found that enacted stigma was prevalent in 23-49 % where the total numbers of leprosy affected persons were 486 [31]. The other study conducted in Bangladesh, in fact assessed the depression and stigma in 140 leprosy affected persons where 87.9% had felt isolation from their family, 67.9 % from relatives or friends and 68.5 % from society and 85 % patients had an experience of being hurt by the family's negative attitude against leprosy [32]. In a qualitative study performed in Nepal, 76 leprosy affected persons were assessed to understand the dynamics of stigma [33].

Discussion

The most influential definition of stigma to date was introduced by Goffman in 1963 as "the attribute that is deeply discrediting" and that "leads to a spoiled identity". An attribute in itself is neither creditable nor discreditable but only relative to our stereotypes thus implying the stigma to be a relative interpretation of an attribute in terms of stereotypes [34]. However, the conventional use of stigma by researchers considers stigma to be a social process which exists when elements of labeling, stereotyping, separation, status loss and discrimination occur in a differential power situation which can involve the personal experience or reasonable anticipation [16, 35].

The experience of stigmatization or the enacted stigma exist when there are actual experiences of discrimination by any member of society, family or friend while perceived stigma refers to the anticipation or fear of discrimination and negative attitudes, not necessarily by the presence of enacted stigma. Self or internalized stigma is in fact a long term impact of continuous socialization about stigmatization which leads to the development of loss of self-esteem and dignity along with the consequent development of fear, shame, hopelessness and guilt [36]. Mixed stigma in this review refers to the stigma which includes more than one type of stigma.

whole. The experience of social discrimination, fear, shame and hesitation to participate in society ultimately can lead to isolation, anxiety and depression, which further results into consequent economic burden. On the other hand, fear of social exclusion and social hesitation to participate in society can lead to disease concealment ultimately resulting into the development of disability, poor treatment adherence and the persistence of the negative stereotypes [5].

Considering the effects of stigma in leprosy, it is important to:

1. Understand the different factors associated with stigma in different set-ups and different regions.
2. Understand Similarities and differences of risk factors pertaining to leprosy which can effectively direct both culture specific and culture free interventions or programs to reduce the level of stigma.

Furthermore, our literature review concludes that there is a significant level of similarities in risk factors which calls for universal control strategies and programs that can be implemented throughout the globe.

Risk Factors of Perceived Stigma

There were 7 studies which particularly focused on perceived stigma. In both studies conducted in Indonesia and Nepal, the major risk factors of perceived stigma were visible impairments, disability and activity limitations in leprosy affected persons [19,20]. while unemployment in the community was found to be the risk factor for the negative attitude towards leprosy affected persons [19].

In a qualitative study done in Nepal, Leonie Try conducted an in-depth interview to assess the level of perceived stigma in leprosy affected persons where she found that perceptions and beliefs about leprosy along with the acts of stigmatized behavior were the determinants of stigma [23].

In a study conducted by Rao et al., both community perceptions and perceptions of the affected

ISSN: 2091-1041 | VOLUME 1 | ISSUE 2 |2013

persons in terms of leprosy-related stigma were assessed in a 5-point scale of strongly agree, agree, neutral, strongly disagree and disagree. It was assessed at family, society and at the workplace. The major domains where perceived stigma was highest were participation at religious rituals where the risk factors were low education, backward classes and deformity. Furthermore, the occupation which involved selling food-items was found to be the major risk factor for high amount of community stigma[21].

Community attitudes towards leprosy affected persons have also been found to be influenced by the integration of the affected persons into the leprosy control programs in society where community stigma in integrated were 50% lesser than those who were not integrated [24].

In a study conducted by de Stiger et al. in community members of Nepal, attitudes towards leprosy affected persons were categorized in different activities namely; 1.Eating limitation 2.Individual negative behavior 3.Social-public limitations 4.Segregation and 5.Usual behavior. Four sets of negative behavior interestingly were shown to be decreasing from 83% before 20 years to 52% in recent years where the major risk factors have been elicited as deformity, fear of infection by germs, fear of curse by god and both [7].

Table 1: Risk factors associated with the different types of leprosy stigma

Author and year	Location	No. and type of subjects	% affected with stigma	Measurement methods/scales	Risk factors
PERCEIVED STIGMA					
Van Brakel et al 2012[19]	Indonesia	1,358 affected by leprosy and 931 community members	35.5% in affected and 18 -50% in unaffected	EMIC, P-scale, Jacoby stigma scale, Discrimination Questionnaires	Participation restriction, disability, unemployed community
Corline Brouwers et al 2011[20]		100 leprosy disabled persons and 100 community controls	NA§ (Jacoby scores were higher in DG* II group than DG I group)	WHOQOL, Jacoby Scale, Participation Scale, GPAS	Visible impairments, activity limitations, participation restrictions, female sex, low WHOQOL scores
PSS Rao et al 2008[21]	3 different sites in India	599 leprosy affected and 2399 Community members	12-17% in affected and community stigma 40- 80 % 50%	Different domain questionnaires	Older patients, low education, low SE-class, deformity, touch-full activities
Atsuro Tsutsumi et al 2007[22]	Bangladesh	189 leprosy affected persons	perceived stigma	PSQ	Low quality of life, deformities, low income.
Leonie try et al 2006[23]	Nepal	19 leprosy affected people	Perception, beliefs and behavior	Qualitative study	Perceptions and beliefs about leprosy and stigmatized behavior
S. Arole et al 2002[24]	India	24 affected persons and 24 unaffected community	Self stigma(vertical = 40% vs Integrated = 15% Community stigma(vertical = 42% vs integrated = 21%	Questionnaire assessment and FGD**	Lack of community participation at leprosy control program

D.H. de Stigter et al 2000[7]	Nepal	300 community members	52%	4 sets of negative behavior assessment	Deformity, fear of infection by germs, fear of curse by god, and both
ENACTED STIGMA					
Lustosa et al 2011[25]	Brazil	107 leprosy affected persons	Experienced discrimination 27.1%	SF-36 Reported by respondents	Grade II disability, reaction episodes
S.G. Withington et al 2003[26]	Bangladesh	2364 leprosy affected persons	2.1% Enacted stigma	Social problems and stigmatization act	Positive skin smear, female sex, presence of dependents
MIXED STIGMA					
Nardi et al 2011[27]	Brazil	223 leprosy affected persons	35.4% participation restriction	P-scale disability assessment	Disabilities, co-morbidities, low income and recent hospitalization
V Nagaraja et al 2011[28]	India	NR leprosy affected persons	52%	MKS	Low socio-economic status, deformities, belief as cause to be sin, ignorance.
Noriko Boku et al 2010[29]	Philippines	108 leprosy affected persons	High SALSA-63% Low GSE 34 %	P-scale, GSE score, SALSA scale	Visible impairments,
Bassey Ebenso et al 2007[11]	Nigeria	20 leprosy affected people for SER	All kinds of stigma	Mixed-methods study assessing impact of SER on stigma	Deformity, participation restriction, unemployment, lack of financial contribution, belief of cause of leprosy
Shumin Chen et al 200530	China	49 ex-leprosy patients	73%	FGD with questionnaires (All kinds of stigma included)	Fear of infection
Zodpey et al 200031	India	486 leprosy affected persons	23-49% enacted, attitude and impact	MKS, enacted stigma, attitude and impact	Females were affected more than males in all the domains
Atsuro Tsutsumi et al 2004[32]	Bangladesh	107 leprosy affected persons	Experienced discrimination 27.1%	SF-36 Reported by respondents	Grade II disability, reaction episodes
S.G. Withington et al 2003[26]	Bangladesh	140 leprosy affected persons	68.5-87.9%	CES-D and questionnaires	Isolation from family members, relatives, friends, society
Heijnders et al 2004[33]		76 leprosy affected persons	NR	Qualitative study	Visible signs, wet wounds, visible reactions, low income

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Risk Factors of Enacted Stigma

In a study conducted by Lustosa et al in Brazil where the level of experienced discrimination was correlated with the medical condition of the affected persons, Grade II disability and the episodes of reactions were found to be major determinants of the experienced discrimination in leprosy affected persons [25].

In one study in Bangladesh which explored the level of experienced discrimination or enacted stigma in leprosy affected persons, positive skin smear, presence of dependents and female sex were found to be the major risk factors. The reported discrimination was assessed within a month of diagnosis. The deterioration in family behavior towards them after the diagnosis was reported by 0.6%, deterioration in local community cooperation was reported by 1.1% and a specific changein social status due to the diagnosis, such as loss of job, restriction to religious, educational and medical facilities were experienced by 1.1 % [26].

Risk Factors of Mixed Stigma

Most of the studies in leprosy stigma have assessed the impact of leprosy on daily life ranging from the participation restriction to the development of depression [27, 29, 31,32]. The impact assessment and the associated risk factors were analyzed in all these three studies [27, 29,32]. Visible impairments, disabilities, co-morbidities, low income and recent hospitalization were the risk factors of negative impact in leprosy [27].

Low socio-economic status measured by Modified Kupuswamy Scale(MKS), deformities, belief as sin and ignorance were the risk factors of stigma in a study done in India.[28] In the study conducted in Bangladesh, isolation from family members, relatives, friends and society were the other factors that implicated the development of depression in leprosy affected persons in Bangladesh [32].

The mixed-methods study in Nigeria showed that deformity, participation restriction, lack of economic contribution and belief of the causes of leprosy were the risk factors of stigma in leprosy[11] while a qualitative study in Nepal showed that visible signs, wet wounds, visible reactions and low income were prominent risk factors of stigma[33].

Gender difference was studied by Zodpey et al in leprosy affected persons where they found the effects of the disease (isolation and rejection from the society) significantly more in females than in males [31]. In a qualitative assessment of ex-leprosy patients living in a leprosy village in China, fear of infection was the major risk factor preventing them to go back to their family members. In addition, the fear of getting stigmatized in the community was the other factor of isolation of these ex-leprosy persons [30].In this literature review, the majority of the risk factors of stigma shows similarities despite that the studies have been done in different settings, time periods and with different instruments. This shows that stigma is a global phenomenon regardless of endemicity of the disease, therefore issues of stigmawill continue to persist until and unless we realize that stigma is not cured along with the disease but it remains to afflict even after the completion of the treatment. Leprosy is often diagnosed late, when permanent impairment has already occurred. Even after completion of treatment a significant proportion of patients sustain disabilities; resulting in the double burden of disability and disability induced stigma [36].This in turn has accumulated the stigma burden in society despite leprosy elimination in countries like Nepal. This psycho-social process of stigma has rendered stigma a cyclic process of complex phenomenon which does not only necessitate the disease treatment but the meticulous interventions to reduce stigma, disability prevention and rehabilitation. Psychosocial burdens of leprosy are related to widely held beliefs and deep rooted prejudices concerning leprosy and its underlying causes, and not merely to the disabilities.[13]Therefore, the reduction in leprosy burden needs to be accompanied by a reduction of the socio-economic challenges related to the disease [37].

Conclusion

The risk factors of leprosy-related stigma are remarkably similar in different cultural settings. From our literature review, the basis of stigma appears to be the visibility of the disfigurements and disability augmented by the stereotypes of the society, knowledge, and the status of the person in terms of economy, education and ability to participate in society. This cross-cultural similarity in risk factors contributing to stigma suggests that the

management of stigma in diverse cultures may be achieved through implementing related strategies to counteract the risk factors in various settings. Nonetheless, knowing the particular risk factors contributing to stigma in different settings will facilitate the design of context-specific interventional programs including advocacy and/or health education to counteract the different determinants followed by the evaluation and monitoring of the stigma interventions at different levels and settings.

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