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Opinion Article

Study on differences and similarities in the concept and origin of leprosy stigma in relation to other health-related stigma

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While the experienced or enacted stigma may be the same for all health related stigma, in terms of isolation, discrimination and social participation restrictions of the affected persons; the concept and origin of stigma varies from one disease to another. An understanding of the cause of stigma is, therefore, essential to formulate effective strategies for its reduction/elimination. This is especially imperative in the case of leprosy where the basis of stigma is significantly different from other health related stigma. In this paper, a comparison is made between the concept and origin of leprosy stigma with that of other stigmatised diseases.

Key words : Health-related stigma, Leprosy, Reduction/Elimination, India

Introduction

Stigma for any disease is a pernicious and an obnoxious complication which must be eliminated if we are to be successful in our efforts to take full advantage of the modern therapy (Lichtenstein 2003, Weiss et al 2006, van Olphen et al 2009). Due to prevailing high stigma in leprosy, many of the great developments in management of the disease and its complications such as MDT, corticosteroids and even reconstructive surgery are not availed of leading to continuing socio-medical problems in leprosy and further affecting the national efforts to eradicate leprosy (Dongre 2003, John et al 2005, WHO 2006, Rao et al 2008).

Of late, it has become fashionable to combine leprosy with other disease-related stigma and generate common platforms for its eradication (Scambler 2004, Fourth International Stigma Conference 2009). Stigma and discrimination for any disease are undesirable and sharing of experiences across several health events might have some benefits. However, since the origins of each disease related stigma are different, developing a common approach would be unrealistic and might even dilute the focus needed to have maximum effectiveness of programs for leprosy stigma reductions. In this brief paper, the uniqueness of leprosy stigma as compared with other health related stigma is made to highlight similarities and differences. Such distinctions form the foundation for apt strategies to reduce or eliminate stigma in leprosy.

Stigma is generally labelled as 'spoilt identity' (Goffman 1963) which will be true of any stigmatized health condition whether it be

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vitiligo, mental illness, AIDS or even smoking or drug addiction. Beyond this definition, when we seek to identify the causative and underlying factors for the stigma, major differences surface. Strategies and programmes for tackling the stigma will then depend on the critical reasons for the stigma.

Let us begin by understanding the origin and reasons for leprosy stigma.

Leprosy stigma

As early as 800 BC, it is clearly stated in Manu Sashtra that if there is leprosy in the family, do not give or take anyone in marriage, underlining the taboo against leprosy(Dongre 2000). There are many references in the Holy Bible that leprosy was caused by divine intervention and often a curse (Holy Bible: Numbers 12:10, Deuteronomy 24:8, 2 Kings 5:27, 2 Chr. 26:21; Matt. 8:2-3, Mark 1:40-42; Luke 5:12-13).

This belief still persists even after the discovery of the leprosy bacillus over 100 years ago. Many social restrictions stem from this notion, even when an individual presents no disabilities (Rao et al 2008).

The second common perception in leprosy is that it progressively disables and mutilates a person's limbs, despite medical therapy (Srinivasan 1993). The continuation of reactions and recurrent ulcers, despite successfully completing the multidrug therapy, adds strength to this belief.

Thirdly, leprosy is still associated with heredity, and transmission from parents to children is believed to be inevitable, although not visible in a given time (Bainson and Van den Borne 1998, Barkataki et al 2006). Fourthly, leprosy is associated with poverty, poor nutrition and unhygienic environment and those affected are considered to belong to that strata of society (Dongre 2003). Lastly, one cannot diagnose leprosy in its incubation period or in subclinical state and wait for its manifestation in any one of its clinical forms, varying signs and symptoms, often mistaken for some other disease (Bryceson and Pfaltzgraff 1990).

In the minds of many people, the cause-effect relationships might be confused or reversed and the wrong conclusions drawn which defies ordinary logic. Thus, a person of higher socio-economic status can also be infected and manifest leprosy which is possibly hidden till medical and social complications arise which degrades a person's economic status so that he appears poor.

Likewise, secondary deformities arise more due to lack of proper care of anaesthetic limbs and not a medical progression of the infection (Srinivasan 1993). Thus, leprosy stigma is deeply rooted in religious, social, economic and cultural domains with the medical aspects supporting their social theories. Any stigma reduction program must therefore take these factors as a package and develop suitable strategies for its success.

Other disease-related stigma

Many examples of disease related stigma abound in literature which include, tuberculosis, mental illness, epilesy, small pox and arthropod-borne infections.

Stigma associated with tuberculosis (TB) is often regarded as a barrier to health seeking and a cause of social suffering (Atre et al 2009, Berisha et al 2009, Dhingra and Khan 2010, Cramm et al 2010). In a sociological study of gender and community views of stigma in tuberculosis on 160 respondants from rural Maharashtra, India, Atre et al (2009) clarified features of TB-related stigma mainly on the fear of losing social status, marital problems and hurtful behaviour by the community largely due to poor knowledge of the disease. They found that the distinction between public health risks of infection and unjustified social isolation (stigma) was ambiguous. In a cross-cultural study of Bangladesh, India, Malawi and Colombia, Somma et al (2008) found the overall stigma index highest in India, lowest in Malawi and greater for women in Bangladesh due to its impact on marital prospects. Dodor et al (2008) identify ten causes of TB stigma from their

data: fear of infection, physical frailty, association with HIV/AIDS, outdated societal beliefs and practices about TB, health staff's own fear of TB, etc. Thus, the root cause for stigma is the fear and misconceptions regarding the infection, cause and spread (Jaggarajamma et al 2008) unlike in the case of leprosy where punishment and divine intervention are often referred to and less to life style such as drinking and smoking (Cramm et al 2010).

The latest in disease related stigma is against human immunodeficiency virus (HIV) infection and AIDS. Stigma in this case is primarily due to 2 major factors: one, this is predominantly a sexually transmitted disease and secondly, it is incurable (Kalichman and Simbayi 2004). Much of the preventive dimensions of this disease is quite clear unlike in leprosy (Porter 1993). There is a significant behavioural component in the prevention of infection and the social stigma (Parker and Aggleton 2003). There is very little ancient or historical evidences of AIDS or scriptural injunctions as in the case of leprosy, although one could cite admonitions of chastity, faithfulness to one's partner and good character in the religious books (Herek and Capitanio 1997).

Consider another stigmatized disease: schizophrenia. In a study across 27 countries, Thornicroft et al (2009) reported high anticipated and experienced discrimination. Stigma in this case is highly dependent on precise knowledge of the root cause of schizophrenia, generally vague or unknown and the attitudes built on limited experiences of dealing with affected people. (Weiss et al 2001, Kadri et al 2004, Sibitz et al 2009). Often, perceptions may be based on hypothetical situations. Links to heredity are commonly spoken of and there is a great deal of emotions and feelings in the experienced discrimination. Stigma is based on the fact that treatment may not be effective or the cure cannot be guaranteed. There is fear that the affected person will lose control. Unlike in the case of leprosy, there are strong reasons to suspect genetic factors in transmission and there have been developments in psychocial rehabilitation focussing on clinical and psychotherapeutic interventions (Karidi et al 2005). Thornicroft et al (2009) conclude that measures such as disability discrimination laws might, therefore, not be effective without interventions to improve self-esteem of people with mental illness. In a study of stigma associated with schizophrenia in Japan and China, Haraguchi et al (2009) recommend that anti-stigma programs be based on trans-cultural considerations.

Consider another stigmatized disease : vitiligo or leucoderma stigma in this case is due to incurability and progressive disfigurement. The cause is relatively unknown, although there are several theories and folk beliefs. A variety of treatment options are also now available to delay progression but the stigma remains. Although experienced discrimination and enacted stigma may be less, stigma nevertheless exists resulting in some cases, isolation and rejection (Ongenae et al 2005, 2006).

Concluding remarks

One should be careful in distinguishing between perceived and enacted stigma in considering any disease. Thus, while the enactment can be the same, as for example, in participation restrictions, discriminations, isolations, etc.; the perceptions will depend on the origin and societal attitudes prevailing in any community. Herein lies the difference between leprosy and other stigmatized diseases.

There are a few other aspects of stigma worth noting: One, stigma can be dynamic changing with time, availabilities of cures and even when changes occur socio-demographically or economically. Thus, stigma can change due to marriage or financial windfall or when there is a socio-political elevation. Stigma depends on the prevalence of the condition and once it is rare, many members of the society may not have sufficient knowledge to have any clue or perception to that disease. Unfortunately, health professionals themselves become stigmatizers due to their mind-set (Dodor et al 2009).

Thus, methods and strategies for stigma reduction must be constantly upgraded in the light of changing circumstances, resorting to powerful communication packages to make a dent. Coming back to the disease in question, leprosy, any rational method to reduce/eliminate stigma should focus on the tremendous developments taken place in understanding leprosy and its consequences, even though we still have a long way to go in unravelling the mysteries of reactions and nerve damages. Secondly, the curability of leprosy and the possibility of preventing nerve damage and hence, deformities is well documented in text-books but this should become common knowledge. Here, we must use the best communication strategy which are available but yet to be fully marshalled. Again, in the case of leprosy, one has several advantages as compared to other stigmatised diseases which must be fully exploited to reduce stigma.

Generalized health-related stigma reduction methods, appear as though they are more efficient but can become ineffectual if specific disease related factors are not fully utilized in the program. In many ways, leprosy is more a social rather than a medical condition.

Given the present strengths of medical knowhow, drugs, surgical interventions, protective gears, one hopes that the social (and sometimes the psychological) problems can be more easily solved. The reality at present is, however, different and often bordering on hopelessness of any solution. Thus, the reduction/elimination of leprosy stigma must depend on the correct mix of medical and social knowledge, varying the strategies according to the existing community/ cultural considerations. Often, the diagnosis of the cause of leprosy in any given community will have to take into consideration the special aspects, beliefs, etc. of that community in planning the leprosy stigma reduction strategy. Generalized methodologies may not work. Thus, strategies specific to one disease may not be effective in other diseases.

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