

Stigmatizing neglected tropical diseases: a systematic review

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Abstract

Background: The Neglected Tropical Diseases (NTDs) are the most common infections of poor people in developing countries, where they cause severe and permanent disabilities and a high disease burden. The stigma associated with disfiguring NTDs such as Buruli ulcer, leprosy, onchocerciasis, lymphatic filariasis and cutaneous leishmaniasis, have important psycho-social effects in affected communities and has only been partly analyzed in the literature.

Objective: The present article will review literature on stigma associated with cutaneous NTDs, explore the public health implications of stigma, and suggest a comprehensive approach to this cluster of diseases.

Methodology/Principal findings: A literature review was done using the following datasets: PUBMED, Google Scholar, SCIELO, LILACS, and MEDLINE. Furthermore, a web search was conducted on the WHO website. Eighty three articles were found on our topic of interest. Eighty of them were related to cutaneous disfiguring NTDs; twenty had a qualitative approach. Our findings show that stigma is associated with all five cutaneous NTDs and causes remarkable psychological and public health consequences. Gender differences with regard to stigma are also considered.

Conclusions: Stigma associated with disfiguring NTDs has been shown to be a major factor influencing access to health services and treatment adherence. If effective programs are to be successfully implemented, appropriate interventions are needed to prevent stigma and eliminate its negative effects. Although lymphatic filariasis and leprosy tend to show a broader research coverage of socio-cultural and psychological aspects of the disease, further research on other cutaneous stigmatizing neglected tropical is urgently needed. The literature suggests that stigma should be addressed in joint interventions rather than one disease at a time.

Introduction

Neglected tropical diseases

The neglected tropical diseases (NTDs) are among the most common infectious diseases of poor people in developing countries where they cause a high disease burden that rivals HIV/AIDS, tuberculosis, and malaria.¹ Globally they affect more than one billion people and put at least two billion at risk. The World Health Organization (WHO) has identified 14 diseases in this group, which include most “tropical” diseases in the poorest countries, such as Chagas disease, leishmaniasis, leprosy, lymphatic filariasis, onchocerciasis and schistosomiasis, among others.² NTDs inhibit the capacity of poor and neglected communities to achieve sustainable development.³ More than 70% of countries and territories affected by NTDs are low-income and lower middle-income countries, and 100% of low-income countries are affected by at least five NTDs.⁴

In aggregate, the NTDs cause approximately 534,000 deaths annually and 56.6 million disability adjusted life years (DALYs) lost. If considered together, these NTDs would, therefore, represent the fourth most important group of communicable diseases in humans, after lower respiratory tract infections, HIV/AIDS, and diarrheal diseases.⁵ The impact of NTDs extends far beyond visible human disease into the spheres of chronic non-perceived “unwellness,” socio-economic losses, and missed development opportunities.⁵

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International attention for the NTDs is now growing. It is widely perceived that the real burden is more important than the current figures show, and that new opportunities exist to effectively eradicate or control this burden.^{6,7}

Over the last decade, several key papers have emerged that illustrate how the stigma resulting from specific NTDs contributes substantially to disease burden and even poverty. A common mechanism is the exacerbation of disease and suffering that result from significant delays in seeking medical attention.¹ In terms of human suffering, the consequences of stigma often outweigh the burden of physical afflictions. The social stigma associated with many NTDs, particularly highly disfiguring diseases, such as Buruli ulcer, leprosy, onchocerciasis, lymphatic filariasis, and cutaneous leishmaniasis, have important psychological and social effects in affected communities.

Stigma

The concept of stigma has historically undergone a dynamic process of redefinition. According to Goffman's early (1984) conceptualization, the term stigma "would be used to refer to an attribute that is deeply discrediting."⁸

Leprosy has traditionally been used as an example of the stigmatization process and its consequences on society.^{9,10,11} Based on data from the Carville leprosarium in southern USA, Gussow & Tracy (1977) drew attention to the importance of stigmatized leprosy patients, not only as victims, but also as agents who may struggle towards destigmatization.⁹

A current approach to the concept of stigma would define it as a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or a group.¹² Stigma marks the possessor as socially unacceptable or as an inferior being and often leads to a spoiled identity.¹³

Stigma is referred to as health-related stigma when this judgment is based on an enduring feature of identity conferred by a health problem or health-related condition¹⁴ and contributes to a hidden burden of illness. The emotional impact of social disqualification contributes to the physical, psychological, and social burden of any illness in various ways; for example, stigma may delay help-seeking or terminate treatment for treatable health problems.¹⁵

Measuring stigma and its consequences as a guide for policy is increasingly becoming a priority,

although its magnitude and intensity is still difficult to quantify. Nevertheless, some authors like van Brakel (2006) argue that the consequences of stigma are remarkably similar in different health conditions, cultures, and public health programs.¹⁶

Until now stigma has mostly been addressed in the literature for one disease at a time. The present article will review literature on stigma associated with disfiguring NTDs with cutaneous manifestations (Buruli ulcer, cutaneous leishmaniasis, leprosy, lymphatic filariasis, and onchocerciasis), explore the public health implications of stigma, and suggest a comprehensive approach to this cluster of diseases.

Methodology

A literature review was done during which references were collected from the following datasets: PUBMED, Google Scholar, SCIELO, LILACS, and MEDLINE. Furthermore, a web search was conducted on the WHO website. Different search words were used in varying combinations to identify primary and secondary studies (reviews). The search terms were: neglected tropical disease(s), stigma, health education, psychological impact, social consequences, and the five diseases in question (Buruli ulcer, cutaneous leishmaniasis, leprosy, lymphatic filariasis, and onchocerciasis). In addition, a manual literature search was conducted among the references quoted in the articles obtained above. In addition relevant references were harvested from the articles identified in the search as well as from other literature available to the authors.

Articles were included if they were quantitative or qualitative studies related to the topic of interest published between 1983 and 2009. The full text (not just the abstract) needed to be available and be written in English, Spanish or Portuguese to allow a proper evaluation of the papers.

Findings

Sixty-six articles were found on our topic of interest. Fifty nine of them were directly or indirectly related to cutaneous disfiguring neglected tropical diseases. Twenty four of them were literature reviews on different social, psychological, and cultural aspects of the main five analyzed NTDs. Seventeen were quantitative studies, most of them cross-sectional. Eighteen were qualitative studies, most of which included a quantitative approach. Two interventional studies and different editorials were also included.

Buruli ulcer

Buruli ulcer (BU) is the third most common mycobacterial disease in humans after tuberculosis and leprosy. Its causative agent, *Mycobacterium ulcerans*, is restricted to foci throughout the tropics and directly related to stagnant or slow-flowing water. According to the WHO clinical case definition, the pre-ulcerative stage of BU includes nodules, plaques, or edema; in the ulcerative stage skin ulcers with typically undermined edges are common. Occasionally, osteomyelitis complicates the course of illness. Recent studies show that the burden of disease associated with BU reaches 100,000 DALYs.¹⁷ Despite the dramatic increase in incidence rates in West Africa during the last decade, the disease remains largely neglected.¹⁸

Children are predominantly affected by BU. The immediate and long-term impact of BU on this group is two-fold. First, the prolonged morbidity and hospitalization can seriously disrupt schooling. Second, complications such as amputations and contracture deformities are frequent, and children disabled by the disease will not be able to work.¹⁹

Few studies have evaluated the perceptions and attitudes towards BU among affected individuals in endemic countries.^{20,21} A study by Stienstra (2002) found that patients were hindered by their disease in functioning as a leader, they feel ashamed or embarrassed because of BU, and think less of themselves. Frequently, patients said they were avoided by others and expressed more problems in getting married. Fear of acquiring the disease was on the basis of many stigmatizing aspects. The same study showed that different causes were attributed to BU. Most respondents attributed the disease to magico-religious factors and witchcraft.²⁰

Similar results were found in a study in Ghana by Renzaho et al. (2007) in which 53% of participants did not know the cause of BU, and only 5.5% identified swimming or wading in ponds as a risk factor.²¹ Nevertheless, this study revealed a high level of acceptance and sympathy towards BU patients in the community; this differs markedly from other published reports, like the previous one by Stienstra et al. (2002)

The psycho-social aspects of health seeking behaviors of patients with BU in southern Benin were studied by Aujoulat et al. (2003) Much concern was expressed about the social consequences of scarring and disabilities associated with BU which can reduce a person's opportunities for marriage and employment.²² No studies focusing on the psychological im-

part of BU on affected individuals were identified.

Cutaneous leishmaniasis

Leishmaniasis is generally seen as one of the most neglected tropical diseases and has strong links with poverty.²³ It is a complex vector-borne disease caused by more than 20 species of the protozoan genus *Leishmania* and ranging from localized skin ulcers to lethal systemic illness.²⁴ The disease is endemic in 88 countries with 350 million people at risk. It has an estimated yearly incidence of 1-1.5 million cases of cutaneous leishmaniasis (CL) and 500,000 of visceral leishmaniasis (VL). It is the third most important vector-borne disease with an estimated 2.35 million DALYs lost.²⁵

Some forms of CL are generally characterized by large and/or multiple cutaneous lesions with a variable tendency to self-cure. Most lesions occur on the face, often leading to severe stigmatization in affected persons; women with lesions are often deemed unsuitable for marriage or raising children.²⁶ The disfigurement and resulting social stigmatization related to CL may cause or precipitate psychological disorders, as well as restrict social participation of the individual affected by the disease.²⁷

The stigmatizing effect of CL was studied in five districts of Kabul (Afghanistan) in 2002. It was shown that many local perceptions about CL are closely related to stigma and also concluded that "affected people are excluded from communal life."²⁸ The level of exclusion varied from "minor domestic restrictions" to "severe physical and emotional isolation." In the same study, it was shown that affected children felt disfigured because of lesions or scars, because of painful treatment, or because they were excluded from play with other children. During adolescence and childhood, parents tend to isolate affected children with active lesions. About 22% of the respondents said that a woman with a leishmaniasis lesion or scar would have difficulty finding a husband. These results highlight that stigmatization can occur in all age groups.

The psychological impact of CL, which is also closely related to stigma, has not been as deeply considered in the literature as other skin diseases. A study by Yanik et al. (2004) in Turkey showed that depression and anxiety symptoms were higher in CL patients. Body satisfaction was also impaired in the groups with active CL and healed scars. Culturally, older people were more accustomed to the CL scar, but younger generations had less acceptance of any lifelong stigma and disfigurement on the face.²⁹

Leprosy

Leprosy or Hansen's disease, is a chronic disease caused by the bacteria *Mycobacterium leprae*. Left untreated, leprosy can be progressive, causing permanent damage to the skin, nerves, limbs, and eyes. According to official WHO reports from 118 countries, the registered prevalence at the beginning of 2010 was 211,903. Some countries such as India, Brazil, Nepal, Mozambique, and Democratic Republic of Congo still have an incidence of leprosy above the elimination goal.³⁰ In terms of burden of disease, leprosy is responsible for 198,000 DALYs.¹⁷

Leprosy poses a great risk of permanent and progressive physical disability. Disabled persons affected by leprosy may experience many disadvantages that limit or prevent them from fulfilling their normal role in society. They may lose their jobs and consequently their economic independence. Eventually, the leprosy sufferer loses social status and becomes progressively isolated from society, family and friends.³¹

Generally, the attitude of the general public towards individuals with leprosy has been shown to be negative. The repulsion of leprosy patients by society is primarily attributable to the visible disfigurement and disabilities seen in untreated patients and to the traditional stigmatic and detrimental connotations attached to the disease.³³ In fact, different authors argue that stigma against leprosy is partly due to local perceptions about the causes and transmission of leprosy; these perceptions have differed over time and between places.³⁴ Generally, all the perceptions described are negative and usually imply that the sufferer has done wrong and brought the disease upon him or herself.³⁵ Some perceptions on the causes of leprosy include consideration of the disease as punishments for sins or immoral conduct, bad/unclean blood, evil spirits, God's will, hereditary, caused by natural force or food, related to under-nourishment, or marrying a leprosy patient.³⁶ In some studies, even school teachers and health workers lacked knowledge about the cause of leprosy, furthering unreasonable negative attitudes.³⁴ It appears that the element of fear is more likely to lead to rejection than any other affective dimension.³³

Undoubtedly, the stigma attached to leprosy may imply important psychological consequences for affected individuals. The psychological impact of leprosy stigma was studied by Tsutsumi et al. (2007), who analysed the quality of life, mental health and perceived stigma of leprosy patients in Bangladesh. It was found that fifty per cent of pa-

tients suffered perceived stigma, and this was associated with decreased quality of life and general mental health status.³²

People affected by leprosy employ a variety of coping strategies to manage stigma. These strategies depend very much on the expected and experienced reactions of others towards them as the impact of stigma is related to the individuals' position in family and community hierarchies.¹³

Lymphatic filariasis

Lymphatic filariasis (LF) is a tropical disease which affects 120 million people in 80 countries with about 14 million suffering from lymphedema or elephantiasis.³⁷ LF is a mosquito-borne disease caused by the filarial nematode. *Wuchereria bancrofti* accounts for approximately 90% of all LF cases, followed by *Brugia malayi* and *Brugia timori*.³⁸ LF causes a wide spectrum of clinical and subclinical disease. Approximately two-thirds of infected individuals show no overt evidence of disease. The remaining third suffer from chronic manifestations of LF: chronic lymphedema, elephantiasis, and hydrocele.³⁹

According to WHO, LF is the second most common cause of long-term disability after mental illness.³⁹ The current estimated burden of LF is estimated to be 5.77 million DALYs lost.¹⁷ The chronic disabling manifestations of this disease, including lymphedema of the limbs, breasts and external genitalia, have a profoundly detrimental effect on the quality of life of affected individuals.

The degree of stigmatization in LF appears to be directly correlated with the severity of visible disease. People with higher grades of lymphedema and hydrocele tend to have more severe psychosocial problems than physical ones; different studies have demonstrated how this interferes with the social life of the individual.⁴⁰ Individuals with gross deformity are dejected, avoid all social activities, and lead an isolated life within the family. Some patients have reported feelings of depression; some even have suicidal thoughts. Sexual or marital problems are also common, although more females than males report them. This is not surprising as males are generally reluctant to admit and discuss these problems.³⁷

Sexual dissatisfaction is more clearly expressed when LF manifests as hydrocele in men. Results from a recent study in India reveal that hydrocele is always considered a burden to the patient and his family. In a focus group discussion with men, they all mentioned that they would never allow their daughters to marry men who have hydrocele. In this study, 94% of women reported dissatisfaction

with their sexual life.³⁸ Gyapong et al. (1996) found similar results in a study in Northern Ghana.⁴¹ Furthermore, several studies have found that hydrocele has an immense impact on economic activities and productivity.³⁸

Only a few studies have examined the impact of stigma on LF patients and the different responses seen in affected individuals. Person et al. (2009) studied health-related stigma among women with LF from the Dominican Republic and Ghana. The consequences of enacted stigma redefined the women's occupational roles and resulted in a loss of income, a loss of social identity, decreased social interactions and access to resources, and labeling with further stigmatization. Women from Ghana reported greater suffering than Dominican women sensing a loss of purpose in their lives and reporting decreased self-esteem.⁴²

Perceptions and practices related to LF are closely related to the appearance and perpetuation of stigma. Different authors have shown that knowledge of certain aspects of filariasis is poor, and it is correlated with level of education.^{37,41,43,45} A widespread belief is that LF has a supernatural etiology; specifically, it is thought to arise from accidentally stepping on a magical substance.

Onchocerciasis

Onchocerciasis or River Blindness is a chronic infectious disease caused by the filarial nematode *Onchocerca volvulus* and transmitted by *Simulium* blackflies. It occurs in 38 countries in Africa, Latin America, and the Arabian Peninsula. The infection primarily causes skin disease, visual impairment, and blindness.⁴⁶ In 1990, onchocerciasis was estimated to be responsible for the loss of an estimated 1 million DALYs annually globally, with visual impairment and blindness accounting for 40% of this figure and severe itching 60%.⁴⁷ Taking into account the effectiveness of control programs, the current estimated burden of disease for onchocerciasis is 484,000 DALYs.¹⁷

Beyond the visual and cutaneous effects, onchocerciasis has other severe socio-economic and psychological consequences. The stigma associated with the disease may reduce marital prospects among affected individuals, disrupt social relationships, and cause loss of self-confidence. Among agricultural workers, onchocerciasis has been associated with increased time away from work and reduced productivity, leading to lower income.⁴⁸

Studies on the stigmatizing effect of onchocercal skin disease (OSD) are few, but the evidence indicates that OSD poses a more serious social problem than previously appreciated.^{49,50} In a formal attempt to document the problem, The Pan-

African Study Group on Onchocercal Skin Disease (1995) of the UNDP/World Bank/WHO Special Program of Research and Training in Tropical Diseases (TDR) conducted a multi-country study at eight sites. Approximately one-third of those with OSD reported low self-esteem and difficulties in attaining marriage. It was also shown that some affected persons think less of themselves or think they are worthless and that 1-2% consider suicide. Embarrassment, sleeplessness, and reduced concentration have also been associated with onchocerciasis.⁵¹ The level of stigmatization increased with the level of education of study subjects.⁴⁹

Ovugas et al. (1995) studied the psycho-social aspects of OSD in Uganda by analyzing the reaction of non-affected individuals. The results revealed that people stigmatize, fear, and avoid affected subjects, though selectively, depending on the nature of relationships. The affected individual tended to be considered dull, weak, dirty, dangerous, and emotionally cold. People would not elect them for positions of leadership.⁵²

Traditional perceptions about onchocerciasis have a strong link to stigma. The perceptions linking the disease and infertility/impotence are perhaps the most damaging aspects of stigma as borne out in individual case histories. Research evidence indicates that people affected with OSD believe it affects reproductive capacity and birth outcomes, leading to infertility, abortion, and stillbirth among women and impotence among men.^{53,54}

Discussion

Public health implications of NTD related stigma

Control programs for NTDs in developing countries often fail to fully meet their objectives for multiple reasons. Many studies have highlighted the importance of factors such as lack of awareness of early symptoms of the disease; traditional perceptions about the disease and its treatment; availability, accessibility, affordability and quality of health care; and previous unsatisfactory interactions with health services. In this discussion the focus will be on the ways in which stigma based on disfiguring cutaneous symptoms may negatively affect health service provision (access to diagnosis and treatment and adherence) for the NTDs in question.

In order to improve our understanding of stigma and its psycho-social and public health impact, it is of paramount importance to situate stigma in relation to other factors and to contextualize it in a broader conceptual framework (see Figure).

Decreased access to diagnosis and treatment

Behavioral trends in disease prevention and health care are influenced by overall local percep-

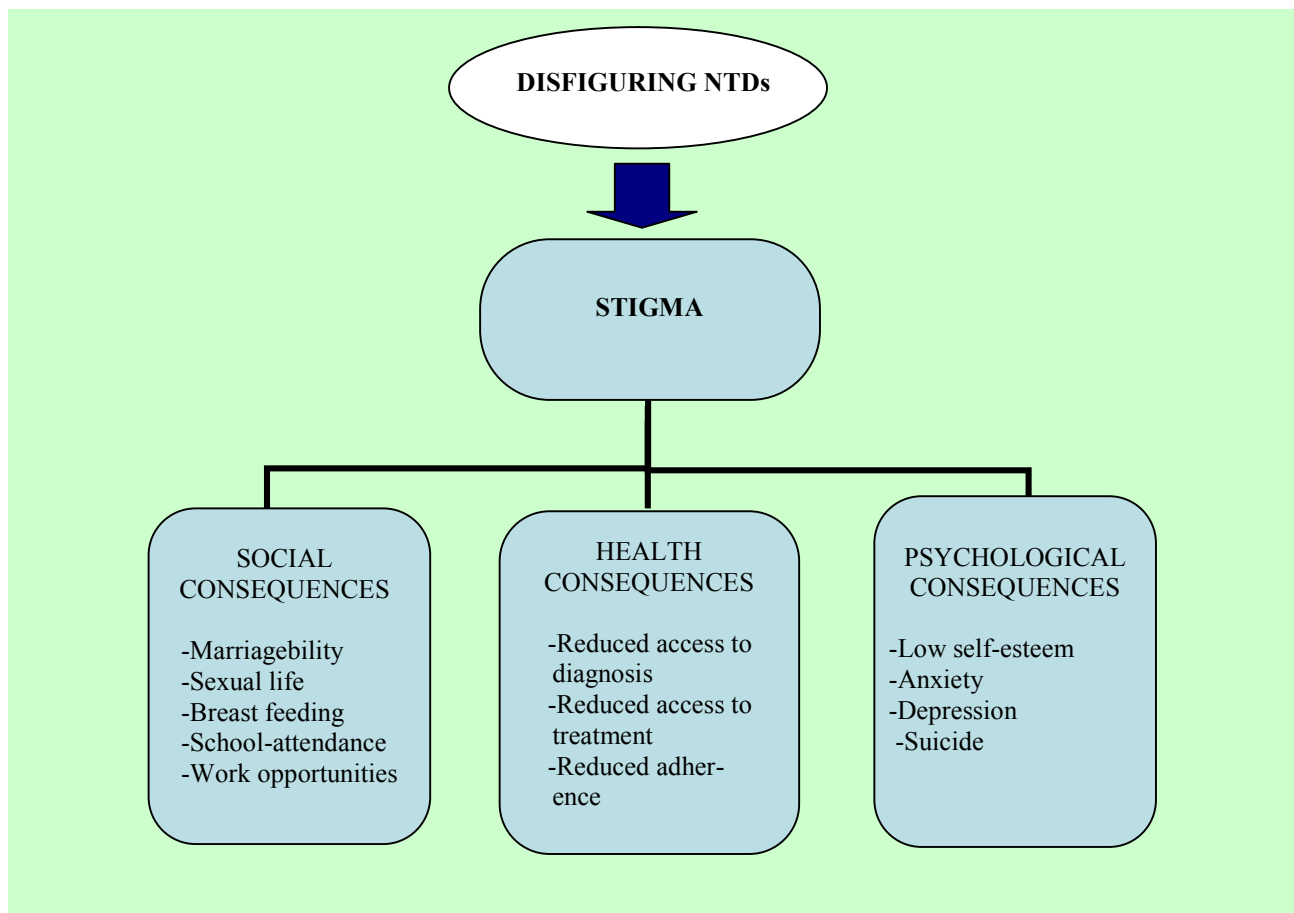


Figure: Conceptual framework for stigma associated with disfiguring NTDs. Stigma has important public health consequences, such as reduced access to diagnosis and treatment and low adherence. Psycho-social effects on affected populations are also relevant.

tions and complex psycho-social factors, such as the extent to which the individual feels in control of his or her health; the perceived seriousness of a disease and one's vulnerability to it; the perceived costs and benefits of a proposed treatment; and a sense of one's ability to cope with the disease. All these factors are part of a complex social cognition models which aim at explaining and/or predicting the occurrence of health behaviors.²⁴

Stigma has been found to be a major factor leading to delay in patients seeking access to health care services. As we have already analyzed, some studies show that patients affected by BU tend to present late for treatment at a stage when the surgical treatment as well as the disease itself has devastating consequences.²² A study by Aujoulat (2003) found that people who have had the disease are ashamed of their scars and try to hide them.

Different studies suggest that patients with leprosy would rather conceal their illness than suffer the social rejection which may accompany revelation of the diagnosis.^{55,13,56,59} Where patients present late, sometimes because of stigma, transmission of the disease in a community increases and

consequently, hinders control efforts. Finally, patients who report late may suffer deformities and disabilities.³¹ This is much more evident with female leprosy patients, who tend to have a longer period between the first symptoms and the diagnosis when compared to men.⁵⁷

Similar conclusions with regards to LF are drawn from a qualitative study by Perera et al. (2007) in Sri Lanka. Stigma associated to LF resulted in emotional distress, social isolation, and delayed diagnosis and treatment. Free treatment services at government clinics were avoided because the participant's condition would then be identifiable in public. Local private practices were favored, because their condition could be more easily hidden. The consequence of this behavior is that patients received less effective and even ineffective treatment from private practitioners.⁵⁸

Low adherence to treatment

Stigma is a major factor influencing adherence; this has been demonstrated in leprosy studies. Often, to prevent discrimination, leprosy patients try to hide their disease by not immediately seeking

medical care at the first signs of leprosy. This, in turn, worsens the stigma and perpetuates the cycle. Once treatment has commenced, patients may stop going to clinics or taking their medication because of fear of rejection by their community or a lack of acceptance of their condition.³⁵

Furthermore, adherence to treatment is highly dependent on community knowledge and perceptions about the disease itself. These are also closely related to stigma. Health education is crucial for community adherence and for the success of most control programs. The lack of community information about the disease and about the side effects of administered drugs can negatively affect adherence to mass drug administration (MDA) and the success of control programs. A study by Krentel et al. (2006) about the use of knowledge, attitudes, and practice (KAP) surveys on LF to prepare a health promotion campaign for MDA in Indonesia indicated that knowledge about symptoms of LF, its transmission and its control has a positive impact on compliance with MDA.⁶⁰

Other relevant factors may also be responsible for the late presentation of cases in health services and non-adherence to treatment. These include geographic access, attribution of the illness to superstition, and failure to make the diagnosis at an early stage.¹⁹

Finally, some gender differences have been found to influence adherence and completion of treatment. Kumar et al. (2004) analyzed gender differences in epidemiological factors associated with treatment completion among leprosy patients in Nepal. Male patients were significantly more likely to be adherent than female patients. This may be due to fear of social consequences among other factors.⁶¹

Implications for health education

Health education must play a central role in disseminating knowledge and addressing attitudes in the community at large, among the medical profession, and among people affected by NTDs. In cases where stigma is an obstacle to seeking adequate preventive or curative care, public health programs should combat it through health education campaigns.⁶² Appropriate information, education and communication (IEC) approaches will therefore have to be developed for all concerned if success is to be achieved. This would not only help to reduce the stigma and social isolation suffered by affected patients but would also possibly increase adherence to treatments and motivate target communities to keep a clean environment, and participate actively in control activities.

Education must be easily understandable and address real concerns. It is not enough to educate only patients; their communities need to be educated as well. Sometimes targeting information at a particular group may help, for example, village leaders or young people.³⁵ Interventions may focus on support for affected persons, changing behaviour among people who stigmatize in the general population (or particular groups), and eliminating or controlling the stigmatized condition. For many conditions, various combinations of these approaches may be appropriate.⁶³

Community health education programs focused on reducing stigma and increasing acceptance of leprosy patients have been shown to be effective in promoting more favorable attitudes towards leprosy patients.^{64,65,66} Croft's study (1999) in Bangladesh found markedly lower levels (18-28%) of prejudice in a rural community which had received community education as compared with another rural community that had not received health education.⁶⁵ A culture-specific health education program in Malaysia that incorporated local beliefs and considered community sensitivities, social structure, and values has also been found to increase the acceptance of leprosy messages and improve knowledge and attitudes towards leprosy.⁶⁴

Study limitations

Most of the articles related to NTDs and stigma are either cross-sectional/qualitative studies or literature reviews. Measuring stigma and its consequences is still challenging and available data are scarce.

One important limitation of the data is its limited geographic coverage. For instance, most leprosy and LF studies were conducted in Asia, while most onchocerciasis studies took place in Nigeria or other West African countries. Thus, these findings may not be representative of all endemic areas affected by these diseases.

One onchocerciasis study which was more representative geographically of the entire (non-OCP) African region was the one conducted by The Pan African Study Group (WHO, 1995). This spanned a total of eight study sites across West, Central and East Africa. Varkevisser et al. (2009) also conducted a multi-country study (Indonesia, Nigeria, Nepal, Brazil) on gender and leprosy.

Sample sizes tended to be small in many of the studies, and selection/observation bias was not taken into account properly. Therefore, it is necessary to be cautious with generalizing the results. For instance, Tsutsumi's et al. study (2007) to determine the quality of life and general mental health

of leprosy patients, includes a sample size of 189 patients.

Selection bias can arise in different forms. Some leprosy studies are conducted among patients attending a leprosy institute or tertiary specialized hospital (Peters & Eshiet, 2002; Tsutsumi, Izutsu, Islam et al., 2007). This may not be representative of the entire affected population, most of which live in remote rural areas with a limited access to health services. Moreover, to analyze stigma associated with OSD, Brieger et al. (1998) used the following inclusion criteria: adults aged 20 or older, employed, not pregnant, and not having a serious illness. Bearing in mind that individuals with severe OSD have a higher rate of absenteeism from work it is easy to see how these results may be biased. Besides, the more stigmatized individuals may be less likely to participate in the study because they feel embarrassed.

Conclusions

Most NTDs have been the subject of vertical control programs since at least the 1950s through the 1980s. Most of them were based on detection and treatment of cases and did not consider cultural, social, and psychological factors strongly linked to affected communities

Some of these control programs in developing countries have not always been successful or sustainable because the strategies pursued are inappropriate for the community or incompatible with traditional perceptions of etiology, transmission, treatment, and prevention.

If effective interventions are to be successfully implemented, a greater understanding is required of the psychosocial consequences of the disease for individuals and their families, the barriers they face to accessing the care they need, and their coping strategies.

Appropriate interventions are needed to prevent stigma and eliminate its negative effects. Intervening with these social, cultural and moral processes requires multifaceted, ecologically tailored interventions for those who experience perceived and internalized stigma. Many current interventions to reduce stigma remain obdurately biomedical and individualistic. No cross-cultural or “universal” theory of stigma or deviance is just around the corner, but adequacy at the level of theory might lead to a useful contextualization for predictions of efficacious stigma reduction programs.¹³

Finally, it is necessary to highlight that stigmatizing NTDs must be addressed as a group. Most of them share particular cultural phenomena (perceptions and practices). A horizontally inte-

grated intervention to reduce stigma associated with this group of poverty-related diseases is desirable and would add a new perspective to current control programs. Further research to address socio-cultural aspects of stigmatizing NTDs is also needed.

Abbreviations

ACL: Anthroponotic cutaneous leishmaniasis
BU: Buruli ulcer
CL: Cutaneous leishmaniasis
DALY: Disability adjusted life year
IEC: Information, education, communication
KAP: Knowledge, attitudes, practices
LF: Lymphatic filariasis
MDA: Mass Drug Administration
NTD: Neglected Tropical Disease
OCP: Onchocerciasis Control Programme
OSD: Onchocercal skin disease
TDR: UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases
VL: Visceral leishmaniasis. WHO: World Health Organization

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