Can social marketing approaches change community attitudes towards leprosy?

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Summary
This essay explores how the concept of social marketing can be employed to change attitudes towards leprosy. Firstly, the concept of social marketing is discussed, then the attitudes that people have about leprosy, the stigma that people with leprosy and their families may face, and the detrimental effects that this can have on their lives. The effect of knowledge and education on attitudes towards leprosy is discussed, as this can be a key component of social marketing campaigns. Various methods of social marketing used to change attitudes and reduce stigma are examined, such as mass media campaigns, school based education, methods which involve community leaders, and the integration and improvement of leprosy services. Principles of social marketing which can lead to the success of campaigns such as incorporating local beliefs are emphasized. The success of the social marketing campaign in Sri Lanka is described, which aimed to remove the fear of leprosy, and to encourage patients to seek and comply with treatment. Finally, it is argued that social marketing, used correctly, can be highly effective at changing community attitudes towards leprosy, reducing stigma and improving the lives of patients, who become able to seek treatment sooner as they lose their fear of stigmatization.

What is social marketing?

Social marketing is ‘the planning and implementation of programs designed to bring about social change using concepts from commercial marketing’.\(^1\) For every marketing programme, a ‘marketing mix’ of the ‘4P’s’ must be planned.\(^1,2\)

- Price: the tangible and intangible costs of engaging in action.
- Product: the package of benefits associated with the proposed programme or action.
- Place: making the product available to the consumers in the correct places.
- Promotion: promoting the product and informing consumers in order to maximize the desired response.

Additionally, in social marketing, there are two further ‘Ps’ which are not usually seen as a major part of conventional marketing – politics and publics.\(^2\) There must be a clear
understanding of the political drivers and constraints on any social marketing initiative, and strategies need to be developed to inform and persuade the political players who can influence the marketing programme. Most social marketing initiatives need to satisfy more than one group of people, so these groups must be identified and strategies developed for identifying and satisfying their needs. As the marketplace is constantly evolving, programme effects must be regularly monitored and management must be prepared to rapidly alter strategies and tactics. A strategy for social marketing might include: advertising (TV, print, internet); communications and public relations (e.g. media relations); and strategic alliances (e.g. with NGOs, Health Professional Associations (e.g. the BMA) and/or private industry).

Examples of social marketing in healthcare include anti-smoking, drug abuse, drinking and driving and HIV/AIDS campaigns. For example, social marketing strategies have been employed to attempt to decrease the prevalence of smoking, which have increased the rate of decline of cigarette consumption. Media campaigns have been run, often particularly targeting youths (therefore preventing young people from starting smoking) and pregnant women, and clean indoor air policies have been implemented. Anti-smoking media campaigns have been shown to be more effective when they are used as part of a multi-faceted approach to reduce smoking, including community programmes, higher taxes, and school based programmes. Additionally, social group interactions, through family, peer or cultural contexts, can play an important role in reinforcing, denying, or neutralising potential effects of antismoking advertising.

Attitudes to leprosy

Leprosy is still a problem worldwide; although registered cases have fallen from 5.4 million worldwide in 1985 to less than 1 million in 1998, around 685,000 new cases are recorded each year, a number which has remained largely unchanged. Leprosy stigma remains a problem in both endemic and non-endemic countries, with the prevalence of stigmatizing attitudes towards leprosy as high as 80% in some countries. Many people ‘mistakenly view leprosy as a punishment from a god or evil spirit’, which may come from biblical references to leprosy which suggest that patients with leprosy should be pronounced as unclean. However, many believe that the word ‘Tsara’ath’ was mistranslated and more recent translations do not refer to ‘leprous disease’, instead preferring the terms ‘terrible skin disease’ or ‘an infectious skin disease’. Hindus believe that deformity resulting from leprosy is a divine punishment, and the Chinese believed that leprosy was sexually transmitted by contact with a prostitute, and therefore a punishment for immoral behaviour.

In terms of human suffering, the consequences of stigma often outweigh those of physical afflictions. Many people can live happily with physical impairments, provided that they are ‘accepted, respected and loved by those around them and are able to function and participate meaningfully in the society in which they live.’ The stigma of leprosy can have far reaching effects on a person’s mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious functions. Patients have reported their family leaving them, exclusion from school, and other forms of stigmatization, upon receiving a diagnosis of leprosy.

Although enacted stigma (when the person actually faces the effects of stigma, e.g. discrimination, rejection and divorce) is not as widespread as it has been, it is still common.
Enacted stigma may affect people’s dignity, social status, employment, family relationships and friendships. Additionally, fear of enacted stigma can lead to emotional stress, anxiety, depression, suicide, parasuicide, isolation and relationship problems.

Misconceptions and poor attitudes towards leprosy are common even among healthcare professionals. For example, in a study of Nigerian physiotherapy students, 87% felt that leprosy patients should be isolated, 62% would not agree to work in a leprosy hospital, only 8% of students said that they would eat with a person affected by leprosy, and only one student would marry somebody who had leprosy.

How attitudes towards leprosy can affect its management

Stigma and a fear of enacted stigma can lead to delay in presentation, leading to an increased risk of nerve damage and disability and prolonged infectivity in the community, and discontinuation and refusal of treatment. Women generally have a longer time to presentation than men, and this may be because stigma can be particularly damaging to a woman, for example being deserted by her husband. In a comparison of two communities, patients from the community where the local radio station had given regular airtime to the leprosy hospital to talk about leprosy had a lower mean time to presentation.

Patients sometimes refuse treatment, because of the stigma attached to the diagnosis. Sometimes stigma can lead to discontinuation of treatment, particularly if patients find it hard to hide their disease. Monthly visits to a health post, leprosy medications, and increased pigmentation from clofazimine may be difficult for patients to conceal. However, many perceive leprosy medication as a way of preventing their disease from becoming worse and more visible, thereby preventing further stigmatization.

Patients sometimes deny the diagnosis of leprosy; many for fear of stigma, although this is now rare. Some deny that they have leprosy because they have not been in contact with ‘dirty people’. Delay in presentation can also result from ignorance (particularly about treatment and recognition), the absence of pain, being unconcerned, and because natural healers may stop patients from seeking medical attention. Patients most at risk of stigmatizing attitudes live in isolated areas with limited communications, where natural healers have the power to forbid contact with health services.

Can education improve attitudes towards leprosy?

Many people know that leprosy is curable and that the risk of transmission is slight, but this knowledge does not always lead to positive attitudes towards leprosy patients. In fact, in one study, after a health education session about leprosy at school, the attitudes of some children towards leprosy actually worsened, although this may have been due to the short duration of intervention (one session). It has been suggested that because leprosy is feared, no one will listen to attempts to educate the public on facts of the disease. Some community leaders suggest that changing attitudes is a huge task because ‘leprosy remains a taboo subject. It is a disease of society, not of people’.

However, many studies have demonstrated that education can improve attitudes towards people with leprosy. In one instance, when a group who had received health education
about leprosy was compared with a group who had not received it, 78% of the latter group would not buy goods from a shopkeeper known to have leprosy, compared with 25% of the group who had received health education. More prolonged health education may have more of an impact upon the attitudes of children, with 38% of children after a 7-year health education programme in an area of Tanzania willing to share a meal with someone with leprosy, compared with 21% in an area where the health education had not been implemented.

How can social marketing be used in the field of leprosy?

It is very expensive for health services to actively seek patients with leprosy, so the challenge is to motivate people affected by the disease to undergo diagnosis and treatment on their own initiative. This is often the primary aim of social marketing campaigns in the field of leprosy, but in order to achieve this, many forms of action may be undertaken, one of which is usually to try to change negative attitudes towards leprosy. Although there are many different ways in which the ‘product’ can be marketed, such as mass media campaigns, school based education and improving leprosy services, it is important to emphasize that these are rarely effective alone; it is usually necessary to use a variety of marketing methods for maximum effect.

Media campaigns

Media campaigns can both improve knowledge about leprosy, thereby having the potential to bring about positive changes in people’s attitudes towards leprosy, and also directly change attitudes towards leprosy. Health education should be culture-specific to increase positive attitudes and acceptance of leprosy patients, considering people’s sensitivities, social structure, values and beliefs, emphasizing the ‘public’ ‘P’ of social marketing. The existing knowledge, attitudes, beliefs and practices of the target population should therefore be explored and researched if appropriate programmes and campaigns are to be designed and implemented. Community health education campaigns should provide accurate knowledge about leprosy by working their way around the local community’s cultural beliefs and misconceptions, rather than denouncing them outright. In one highly successful campaign, in Malaysia, health education packages were developed on the basis of anthropological studies to produce newspaper articles, cartoon tape-slides, cartoon story books and posters, for a number of different groups which are known to have different attitudes and beliefs about leprosy, and different cultures as a whole; Chinese, Malays, Ibans and Kayans. Campaigns are less effective in some groups than in others, such as the socially and economically disadvantaged who may need to be targeted specifically. Groups which are thought to have more potential to bring about change, such as young people, can also be targeted.

People affected by leprosy can sometimes be used in campaigns aiming to disseminate positive messages about leprosy; instead of showing a patient with facial deformities, a healthy, normal happy patient with no deformity as result of seeking early treatment is depicted. To add to the success of a campaign, celebrities can be involved.
Often, TV and radio are the largest mediums used, employing shows, dramas, and chat shows. Again, it is important to incorporate local cultural beliefs. National broadcasters in the country where the campaign is to be undertaken should be used as much as possible. In some areas, TV and radio are not accessible, but campaigns can still be undertaken, using different methods such as drama, street theatre, music and song, dance, discussion groups, posters, flip charts, video van screenings and puppet shows. This emphasizes the ‘place’ ‘P’ of social marketing. Although TV is a highly effective medium, radio is much cheaper and more accessible in many countries. Although health messages often receive free airtime, this is usually not in prime time, so often paid for advertising is required to ensure it is broadcast when most people are watching TV or listening to the radio. In addition to posters, leaflets, T-shirts, caps, badges and key rings, make the message more continuously visible and can give information about where people can seek diagnosis or treatment. Campaigns must be sustained, as the social marketing theory incorporates the stages of behaviour change (Fig. 1), allowing intervention at different stages.

However, sometimes the media are unable to educate people effectively about leprosy, and reduce stigma so other strategies must be employed. For example, in one study, when two communities were compared, one which received an intensive health education programme, and one which simply had leaflets distributed, although both communities had a similar level of knowledge of leprosy, those which had the intensive health education programme had developed more accepting attitudes towards leprosy and its diagnosis and their confidence in a cure was enhanced. High involvement decisions, which challenge the ideas of people going back through many generations, have significant emotional and social consequences so a complex approach will be require in order to tackle negative attitudes towards leprosy. The ‘participatory’ communication model, which de-emphasises the role of knowledge in the destigmatization process and underlines the need to promote interaction between the community and patients, is seen as more successful than the ‘diffusion’ approach. An example of the participatory communication model in action was used by the Danish Leprosy (DANLEP) unit-trained government health workers in Madhya Pradesh,

Figure 1. The stages of change.
when they brought together community members, patients, doctors and healthcare professionals in mixed-group residential camps to share experiences, discuss, build capabilities, and remove attendant stigma. 34 A mix of various different approaches, not just mass media campaigns, is therefore usually employed. 29

School based education

Education of pupils within the classroom generally increases knowledge of leprosy, but it does not always positively impact upon peoples’ attitudes towards leprosy. 24,27 It has been suggested that continued programmes may be more successful than single sessions. 24,27 Combining education in schools with other methods that involve other members of the community may improve attitudes about leprosy. 26 However, school based education may, in fact be of more use in improving attitudes, as school children may be more willing to change their attitudes following education than the general public. 36 In addition, educated children may transfer health information to their family, although this may not necessarily lead to a more positive attitude about leprosy. 10,24–25

Involving community leaders

It is important in all social marketing campaigns to involve community leaders. Village heads, women’s organizations or volunteers can sometimes be persuaded to address the topic of leprosy at their meetings, which often helps to give the message a greater immediacy as well as a deeper credibility with the audience. 28 In one study, 71% of community leaders were willing to participate in health education about leprosy. 39 Although they had some negative reactions and incomplete awareness about leprosy, it was believed that they had the potential to be educated and could then be used effectively in health education campaigns. 39

One group that are particularly important to target in marketing campaigns about leprosy are folk healers. Although they may report positive attitudes about modern medicine for leprosy, their knowledge of causation is often poor, attributing the disease to witchcraft, and they rarely refer patients to medical services, which delays treatment. 15,22,42 Although their treatments are ineffective, they maintain a status within the community, and patients usually visit them before seeking medical attention. 15,40–41 Fortunately, knowledge, attitudes and behaviour of traditional healers can be changed through education. 42

Integrating and improving leprosy services

Generally, when leprosy health care services are integrated in to general health services, patients face less stigma within the community. 43 One study compared villages in which leprosy control activities were integrated with primary health care services with villages using the traditional vertical approach. 10,43 In the former, the patients, all of whom had visible deformities, experienced less discrimination and stigma in areas such as employment, receiving economic support from service providers, receiving invitations to social functions, and access to local services. 10,43
Patients prefer to attend general medical services rather than specialist leprosy services.\textsuperscript{44} However, some health care professionals still have negative attitudes towards leprosy patients.\textsuperscript{15,44–46} Many do not think that leprosy services should be integrated, feel that they do not have adequate knowledge to be able to integrate services, or see leprosy as a low priority and so do not feel committed to integration.\textsuperscript{15,44–46} Changing the attitudes of healthcare professionals is therefore a challenge of great importance. Attempts at integration have demonstrated the need for better supplies of leprosy medicines and ongoing training, in addition to careful preparation and initial training of all local health workers and intensive education of the public on leprosy.\textsuperscript{47,48} The WHO campaign to eliminate leprosy as a public health problem has raised commitment for integration, and many countries have realized that elimination can only be achieved if the leprosy services are expanded, which can only be achieved if they are integrated into general health services.\textsuperscript{46} A problem with integration of leprosy services (and therefore making them available locally), once they are running well, is that occasionally patients prefer to travel long distances to services to achieve anonymity, particularly when the stigma of leprosy in their community is high.\textsuperscript{49}

Laws

If community attitudes about leprosy are to be changed, it is important that laws reflect a positive attitude about people with leprosy. Social marketing can be used to convince governments that leprosy is not a disease caused by punishment from God or an evil spirit, and educate them about its causation. This may cause them to change their attitudes towards, and their laws about, leprosy patients. Until recently, stigmatization of people with leprosy existed at a legal level in India, for example. The Indian Christian Marriage Act, the Muslim Marriage Act and the Hindu Marriage Act all granted divorce on the grounds of leprosy.\textsuperscript{38} The Motor Vehicles Act (1939) prohibited them from obtaining a driver’s licence even though only a small proportion suffer from sensory loss of the limbs, and provisions in the legal manuals of public transport companies imposed travel restrictions.\textsuperscript{38}

In an attempt to combat stigma, non-discriminatory terms are sometimes used. For example, leprosy may be called Hansen’s disease, but people are often aware that leprosy and Hansen’s disease are the same thing.\textsuperscript{10,50} In Brazil, the word ‘lepra’ which means dog mange, is discouraged by law.\textsuperscript{10} By contrast, in Botswana, leprosy is referred to as ‘lepero’, implying an association with ‘bad blood’ and as ‘qumtina’ in Ethiopia, denoting the ‘state of amputation or mutilation’.\textsuperscript{33}

The leprosy social marketing campaign in Sri Lanka

An example of social marketing being used in the field of leprosy is the campaign in Sri Lanka, launched in 1990, which attempted to get as many leprosy patients as possible to receive MDT, by employing social marketing.\textsuperscript{28,51} It was a campaign run by the Sri Lankan Ministry of Health, Leprosy Relief Emmaus Switzerland, and the then Ciba-Geigy Leprosy fund.\textsuperscript{28} The campaign marketed two ‘products’: an attitude not to fear leprosy, and a behaviour to seek and comply with leprosy treatment.\textsuperscript{28} A ‘marketing mix’ of the other ‘P’s was planned – price (free drugs), place (location of clinics and marketing the campaign differently in different places) and promotion (media and message).\textsuperscript{29}
Initially, the market was researched using community-based surveys on knowledge, attitudes and practices on leprosy, and focus groups to explore perceptions of leprosy. They found that leprosy was perceived as an extremely infectious, incurable and dreaded disease in which the fingers fell off.

Advertising, using all forms of media, was employed to create awareness of the ‘product’, with particular emphasis on television and radio. A famous local actor was used in the television campaign to challenge misconceptions about leprosy and to explain that it was curable without any deformity if treatment was sought early. In the past, TV soap operas had portrayed people with leprosy as tragic incurables, but in the new social marketing campaign, these same actors were used in advertisements and dramas with positive messages and happy endings. The logo for the campaign depicted a perfect hand holding a flower. In remote areas without access to TV and radio, week-long education sessions were held along with ‘skin camps’, which combined leprosy detection activities with free treatment for skin problems. Young adults were targeted, as they were mostly literate and amenable to change and could then go on to influence their parents or elders. The message stressed the curability of leprosy and linked the benefits of seeking early treatment and cure with what they valued most, such as getting married, being accepted and having a family.

Health education was offered to 5000 opinion leaders, teachers and village women. Letters and health education materials were sent to the nation’s clergy, school teachers were provided with explanatory flip charts, and traditional healers were contacted with information about leprosy and MDT. Access to treatment was improved by increasing the number of treatment centres and improving collaboration with general health care services. All treatment was provided free of charge, and reimbursement for travel costs and compensation for lost pay was sometimes provided. Primary care staff and hospital outpatient doctors received training to improve their ability to diagnose and treat leprosy.

Regular 6-monthly cross sectional surveys were used to evaluate the programme, and focus groups regularly tracked acceptability of the message. Changes were made accordingly to improve programme activities. The results of the social marketing campaign in Sri Lanka were tremendous, with case detection up by 150% after less than a year and an increase in self-reporting. The backlog of leprosy patients in Sri Lanka has now largely been cleared. The change was brought about by a social marketing strategy that promoted two products; the attitude not to fear leprosy, and the behaviour to seek and comply with treatment.

Successful social marketing strategies have been employed elsewhere. For example in the five states of India where leprosy is endemic. Uttar Pradesh, Madhya Pradesh, Orissa, Bihar and West Bengal, a 16-month project was started in September 1999 using TV, radio, live drama shows, video-van screenings and public events. The proportion of people who would not sit next to a leprosy patient fell (44% to 27%), as did the proportion who would not eat food prepared by a leprosy patient (68% down to 50%) and the proportion who believed that leprosy was caused by bad deeds in a previous life (37% down to 12%).

Conclusion

Social marketing can be used effectively to have a positive impact upon community attitudes towards leprosy, if used correctly. Stigma and incorrect beliefs about leprosy are still held worldwide, having highly detrimental effects on the lives of those affected by leprosy, impacting upon areas such as relationships, employment and attendance at social and
religious meetings. The potential for campaigns which positively impact upon community attitudes to improve the lives of those affected is therefore clearly enormous.

A mixture of approaches, such as mass media campaigns, school based education, initiatives involving community leaders, improving and integrating leprosy services and seeking changes in the law should be used as no single approach is likely to be as effective on its own. The mass media can use TV and radio effectively, but it is important to remember that these are not accessible to everyone and it is vital that different tools, such as street theatre, video van screenings and posters are employed for communities where TV and radio are less accessible. It is important to use positive messages, showing people free from disease and deformity because they sought early treatment, as opposed to scare tactics. Leprosy services should be integrated in to general medical services, as this makes them available locally for patients, and reduces stigma.

It is important that all aspects of the campaign are adequately researched before any action is taken. The campaign should be on-going and recognize that different people are at different stages in the process of change. The campaign should ensure that local cultural beliefs are incorporated and should consider peoples’ sensitivities, social structure and beliefs. The campaign should be continually monitored and changed if need be.

References
