# Providing Care to Persons with Stigmatised Illnesses: Implications for Participatory Communication

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*Public health challenges such as AIDS, tuberculosis, plague, and leprosy have implicitly assumed stigmatisation of patients. This article is about stigmatised illnesses, a disease where patients face medical and social challenges. Today, diseases such as leprosy, TB are curable if detected early. However, the social problem of stigma still persists. Why is it that despite the availability of treatment, persons with diseases continue to be ostracised by the community? What is the role of the health-workers? Should they be effective distributor of medicines and methods of cure or should they also empower the community to examine and reflect upon this medical cum sociological phenomenon and help the community to devise methods of providing cure as well as providing care? What are the best practices the community can follow to deal with leprosy and its social ramifications? Importantly, what are the implications for participatory communication and for effective interventions in the future? This article discusses several core themes that suggest some answers to these questions.*

Public health challenges such as AIDS, tuberculosis, plague, and leprosy have implicitly assumed stigmatisation of patients. A frequent response has been the isolation of patients (Krishnatray and Melkote 1998). Thus, for persons infected with these diseases it is both a medical and a social problem. The publicity given to HIV/AIDS patients in the last 15 years has had the positive effect of systematically examining stigmatisation of the disease and persons affected by it. Public communication campaigns have addressed issues of stigmatisation and discrimination and ways to destigmatise affected individuals (Pryor and Reeder 1993). This article is about stigmatised diseases (such as leprosy, HIV/AIDS, TB, cancer, etc.) where patients face medical and social challenges. Leprosy and TB are amongst the oldest diseases known to humankind. Like AIDS, TB involves physical disfigurement and negative

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social consequences. Both leprosy and AIDS are manifestly visible, progressively deforming, chronic, and of unusually long duration. Persons suffering from it have been usually neglected, avoided, segregated, and ostracised (Skinsnes 1964). Today, leprosy and TB are curable if detected early. And HIV/AIDS is treatable. However, despite their health status, the social problem of stigma still persists. That is, even though the illness may disappear, it is not necessary for its social pathology to disappear. The disfigurement often associated with such diseases only serves to increase stigmatisation of the infected person.

Why is it that despite the availability of medicines to cure diseases such as leprosy, persons with leprosy continue to be ostracised by the community? What is the role of the health-worker? Should he/she be an effective distributor of medicines and methods of cure, or should he/she also empower the community to examine and reflect upon this medical cum sociological phenomenon and help the community to devise methods of providing cure as well as providing care to persons suffering from leprosy? What are the best practices the community can follow to deal with leprosy and its social ramifications? Importantly, what are the implications for participatory communication and for effective interventions in the future? This article discusses several core themes that suggest some answers to these questions:

- The dominant framework used in health as well as general development areas and the inherent biases associated with it. An alternative framework anchored on the principle of empowerment is provided as a contrast to the dominant framework.
- The best communication model that should be employed. An important objective here is to examine the effectiveness of the organisational value of communication as opposed to the transmission value of communication.
- The value of participation in health-related activities and the positive impact of *creating experiences of cure.*
- The empowerment of the community to deal with leprosy, which is both a health and a social problem, and
- The role of health-worker and health-care system in the treatment/eradication of disease and its stigma.

## Dominant and Alternative Frameworks Used

It will be useful to describe and then discuss the overall framework used by change agencies and governments in their development and health-related

activities. We will present the dominant approaches and contrast them with alternative approaches that will need to be seriously examined and incorporated in eradication and/or treatment of persons with leprosy or AIDS, diseases that involve both medical as well as social dimensions.

The *goal* in the dominant framework has been to promote community improvement or people development through the eradication of debilitating diseases or by provision of specific development programmes. This is good but not sufficient. In the alternative framework, the goal is building social justice, capacity and equity in the community. The underlying *belief* in the dominant framework has been that the present conditions are mostly due to cultural and individual inadequacies and that there is a universal standard available for development. This standard is usually articulated by the experts and is non-negotiable. On the other hand, in the alternative framework, the belief is that the present conditions are usually due to a general lack of power and control of the people, especially their lack of power and control to access resources that are important for their survival or betterment. Additionally, there is a diversity of standards that may be set up by the community as opposed to the single standard of the experts.

The combined effect of the above mentioned goals and beliefs has led to a distinct *bias* in the dominant framework. In general, there is insensitivity to the local cultures and their practice, the change directed is always by the sources external to the community, the process is deterministic and is usually toward a pre-determined end dictated by an external agency. The individual is the locus of change and blame and any anomalies are attributed to the inadequacies of individuals. In other words, there is a 'victim-blame' hypothesis. On the other hand, in the alternative framework, the process and the solutions are culturally proximate to the community, the change directed is influenced by local ideas and sources, the process itself is open-ended and on-going, and the locus of control is the local community.

The *context* is also important. In the dominant framework, there is little interest in the power relationships and structural constraints in the host community but in the alternative framework these factors become very important. The *role of the health-worker* or the change-agent in the dominant framework has been to consider him/her as an expert, a benefactor, and a disinterested non-participant. In the alternative framework, the change-agent plays the role of a collaborator, facilitator, participant, an advocate for the people, a risk taker or even an activist.

The *best examples* of work in the dominant framework have included the prevention of underdevelopment, remedy through/by experts, and use of mass media to diffuse standard messages that are usually prescriptive.

In the alternative framework, the best examples include the activation of social support systems, social networks, mutual help and self help activities; facilitate critical awareness; facilitate community and organisational power and importantly, use communication to build and strengthen interpersonal relationships between members of the community. Finally, in the dominant framework the outcomes desired have been modernisation, infrastructure development, and change in people's attitudes and behaviour toward modernising objectives. In the alternative framework, the outcomes have included an increased access of all community members to material, psychological, cultural and informational resources; the honing of individual and group competence, leadership skills and critical awareness skills and, the building of empowered organisations and communities (Jacobson and Kolluri 1999; Servaes 1999; Tehranian 1994).

## Transmission vs. Organisational Communication Models

A discussion of the overarching frameworks brings into sharp focus the communication models used by change agencies including health-care agencies. Communication models have traditionally looked at communication as a process of moving a message through some channel with the hope that it will reach the receiver and that there will be an effect. The process is usually linear, top-down (from a health expert down to a receiver), and the message itself is prescriptive, preachy, and quite often very technical in nature. The intention in most communication situations related to health matters is to provide an effective mechanism of providing medical cure. However, this communication model that is so widespread is not true to the real intention of communication. The root of the word 'communication' is 'communicare' or to build commonness and closeness between participants. Especially, in health-care situations such as eradication/treatment of leprosy or AIDS, communication should involve the objectives of building understanding, empathy, and partnerships between the members of a community and between the health-care system and the community. This calls for a different model of communication.

The transmission value of communication must be extended to include its organisational value. Empowerment requires more than just information delivery and diffusion of technical innovations. The objective of health professionals and other change agents is to work with individuals and communities at the grassroots so that they may eventually enter and participate meaningfully in the political, cultural, and economic processes in their

societies. This calls for grassroots organising (Kaye 1990) and communicative social action on the part of the individuals suffering from debilitating diseases, the poor, women and others who have been marginalised in the process of social change. The implication then is a reconceptualisation of the role of health communication. Greater importance will need to be directed to the organisational value of communication and the role of communicative efforts in empowering people.

## Participatory Approaches to Communication and Cure

In a participatory approach to communication and cure, the individuals in the community are active in all the programmes and processes; they contribute ideas, take initiatives, articulate their needs and problems, and assert their autonomy (Ascroft and Masilela 1989). There is great diversity in participatory research methodologies. The following description brings together many of its tenets (Servaes 1989; Kronenburg 1986):

- It rests on the assumption that human beings have an innate ability to create knowledge and that this is not the prerogative of experts or professionals.
- It is an educational process for the participants as well as the health-workers. It involves the identification of community needs, awareness regarding constraints, an analysis of the causes of glitches and the designing and execution of solutions.
- There is a conscious commitment of the health and community worker to work for the cause of the community. Thus, the traditional scientific principle of neutrality is rejected.
- It is based on a dialectical process of dialogue between the worker and the community.
- It is a problem-solving approach. The objective is to discover the causes of problems and mobilise the creative human potential to solve social problems by clarifying the underlying conditions to those problems, and
- Its major asset is its heuristic value. The close cooperation between the health/community worker and the community fosters an atmosphere in which all participants analyse the social environment and formulate plans of action.

In a related study, Krishnatray and Melkote (1998) directly compared the participatory approach to cure with the diffusion of Information Education

and Communication (IEC) approach in the context of leprosy. This study found several strengths with the participatory approach. The immediate positive outcome of the participatory approach was dialogue between the health-worker and the members of the community. A dialogue involves the group in a serious engagement on issues of concept, cause and cure of leprosy. The health-workers abet the participatory process by refraining from directing attention to themselves: questions are deflected to the group, answers are avoided, clarifications are withheld, and conclusions are discouraged; instead, questions are raised to keep the dialogue going. Their main arguments tend to be based not on logic and reason but on analogy. The purpose of the dialogue is threefold:

1. to remove the health-worker from occupying a position of centrality;
2. to energise the group to collectively analyse multiple conceptualisations of leprosy by a process of cognitive agitation (Patankar 1992) and,
3. to create redundancies in the communication situation so that an open and free environment built by this process reinforces the action component (Krishnatray and Melkote 1998).

The action component of the participatory strategy rests on 'hydro-oleo-physio-therapy' (HOPE), an inexpensive water-oil massage of ulcers and wounds that patients undertake three times daily. The purpose of HOPE is also to let the group see for itself that ulcers, perceived to be sources of infection, gradually heal. However, the latent function of the therapy is more powerful. The act of seeing the health-worker scrubbing and applying medication on ulcers raises doubts and questions on infectivity and patient-avoidance behaviour. Additionally, the live case demonstration where the patients display their wounds and skin patches and narrate their trial and tribulation not only in dealing with the disease but also its social consequences create strong emotional bonds between the community and the patients. An obvious implication for health communication campaigns is de-emphasising technical content and contextualising information in the personal and social experiences of the group.

## Empowering the Community through Participation

Earlier a question was raised: Why is it that despite the availability of treatment for diseases such as cancer, TB, leprosy, etc persons affected by them continue to be ostracised by the community? There are two dimensions to these health conditions. One lies in the domain of medical cure and the

other lies squarely in the socio-cultural domain wherein such diseases are considered as a social disease. The stigmatisation attached to them is a community phenomenon and is independent of the medical cure. And, it is the community that must achieve destigmatisation.

So, what are the best practices the community can follow to deal with stigmatised illnesses and its social ramifications? We have already pointed to practices such as the activation of social support systems, social networks, mutual help and self help activities; facilitating critical awareness; facilitating community and organisational power and importantly, using communication to build and strengthen interpersonal relationships between members in the community. Thus, it is important that with the active use of practices such as the ones listed above, the community members need to be empowered to deal with the social stigma issue on their own even as the health-care system aggressively attacks the issue as a medical problem and provides methods of cure. Additionally, there are other ways in which communities may achieve empowerment in general. First, empowerment is achieved through organisational effectiveness (Speer and Hughey 1995). Communities need effective organisations of their own that work for their self-interest, network with similar organisations, and compete effectively for resources. This provides a niche for community workers. They may be used to help local leaders in forming or strengthening local organisations, develop communication and problem-solving skills, and help in information gathering and networking. Second, effective organisations are sustained by strong interpersonal relationships (Speer and Hughey 1995). Participatory approaches described earlier help in creating viable and self-sustaining organisations that are built through interactions with people based on shared values. The third tenet relates to individual empowerment and involves the concept of action-reflection. Individuals must activate their critical consciousness (Freire 1970); however they need to go beyond reflection to social action as part of an organised group. Organised groups provide a context and process for cognitive and emotional insights, for challenging new ideas and for testing and evaluating actions and behaviours. Over time, increased participation and reflection on the part of individuals are associated with their empowerment (Speer and Hughey 1995).

## Role of the Health/Community Workers in Eradicating Disease and Its Stigma

In terms of general recommendations from communication research, there are several factors that contribute to an effective intervention on the part of

the workers. The role of the health-worker would be as a facilitator. It requires the practical commitment of the external facilitator to the goal of social transformation. This may be achieved by the immersion of the worker in the praxis adopted by the community and by the rejection of an asymmetrical relationship between the health-worker and the community members, that is, the subject/object relationship and its replacement by a subject/subject relationship. These steps are hard to achieve. Hence, some have argued that individual personality and motives are crucial in this type of work, and that only a selected few may be capable of sufficient sensitivity, humility, and self-reflexivity to do this work (Fals-Borda 1991).

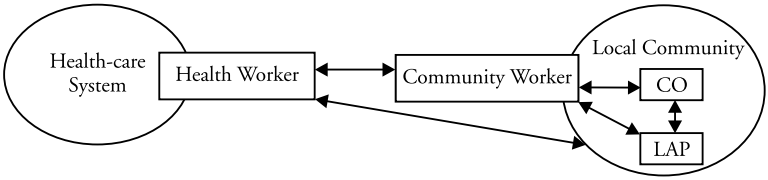
However, in the end, the health-workers role will become redundant. Successful campaigns will mean that social change process moves forward with the momentum created by community dynamism and without the presence of the worker. Thus, the locus of control in this process rests with the community leaders, groups or individuals involved and not with the health-worker, doctors, experts, or the sponsoring external organisations. While the professionals may have an important role to play in designing intervention strategies, they are not the key players. The key players are the people of the community, handling their problems in local settings and honing their competencies in the concrete experiences of their existential realities.

The community worker plays a very important role in the empowerment process. This person may be employed to help the community and its members to:

- Perceive and articulate their social, cultural, historical, economic, and political realities.
- Operationalise their needs.
- Identify resources they need.
- Identify, articulate, and operationalise possible solution alternatives.
- Identify and gain access to individuals, agencies or organisations that are crucial to meeting their needs or solving their problems.
- Build communication skills such as presenting issues cogently, resolving conflicts, negotiate and arbitrate.
- To help the community members to organise and lead.

The model shown in Figure 1 may be used to illustrate the role of the important actors in the cure and destigmatisation process. It suggests a *trialogue* with the health-care system, the community, and persons with

Figure 1
Relevant Actors in Leprosy Cure and Its Destigmatisation




CO = Community Organisations and Community Leaders.
LAP = Leprosy-Affected Person.

leprosy constituting the three vectors. The health-care system through a cadre of health-workers and health-clinics forms the first vector. The health-worker is in contact with the community through a dedicated community-worker (or workers). Meanwhile, the health-worker is in direct contact with persons with leprosy to provide the medical advice and cure. However, destigmatisation takes place within the community. The second vector represents the local community with the community-worker, community organisations, and leaders constituting the important actors. This highlights the community-orientedness. Destigmatisation and rehabilitation of the cured persons will occur within the community and individual families. The health-workers and the community workers are the most important catalysts in the process. Sometimes, the health-worker and the community-worker could be the same person or persons. The health/community-workers can assist local groups and organisations and persons with leprosy in identifying and articulating possible solution alternatives, identifying resources that may solve their security problems, and identifying and gaining access to relevant authorities external to the system that are crucial to meeting their needs or solving their problems.

## Implications for Communication Campaigns

While the medical cure of disease may be a relatively straightforward process, destigmatisation of disease is not. The fact that both leprosy (perhaps the oldest stigmatised disease known) and HIV/AIDS (a recent communicable disease) are stigmatised points to the irreducibility of stigma. This article has juxtaposed dominant communication and participatory paradigms that have informed much of health communication practices. Table 1 contrasts

Table 1
Types of Communication Campaigns

| | *Types of communication campaign* | | |
|---|---|---|---|
| | *Inform (IEC)* | *Behaviour change (BCC)* | *Participatory* |
| Paradigm | Dominant-diffusion | Dominant-behaviouristic | Alternative-communicative social action |
| Value/model | Transmission | Transmission | Organisational |
| Belief | Lack of correct knowledge, attitude and behaviour on part of receiver of communication | Lack of correct knowledge, attitude and behaviour on both source and receiver of communication | Lack of access to and availability of resources |
| Bias | Project goal | Project goals | Community empowerment |
| Main issues addressed | Low awareness<br>Low exposure<br>Low recognition<br>Low priority | Myths, misconceptions, stereotypes,<br>Indifference, inaction, negative attitude towards doctors, hospitals, drugs, patients, care-takers | Critical enquiry, collection action-reflection, *trialogue* (3-way interaction), emphasis on interpersonal contact, and cultural interpretations of disease |
| Objective | Create Awareness-Dissemination/Education | Change attitude and behaviour | Empowerment and integration |
| Audience | Stakeholders, general public | Care-takers, patients, doctors, paramedical staff | Local community, families, care-takers doctors, paramedics, social support network, traditional healers |

(*Table 1 contd.*)

(*Table 1 contd.*)

| | *Types of communication campaign* | | |
|---|---|---|---|
| | *Inform (IEC)* | *Behaviour change (BCC)* | *Participatory* |
| Message | Intent: | Intent: | Intent: |
| | Disseminate, 'expert' information | Clear myths and misconceptions, convert sympathy into empathy, advocacy | Skill acquisition and enhancement, capacity building, integration of stakeholders, redefine medical illness. |
| | Content: | Action: | Action: |
| | Scientific information about disease, types of disease, treatment/ curability, whom to consult and when | Identify gatekeepers, promote interaction with community, create opportunities for activities, portray the 'other side', propagate success stories, and stigma coping strategies | Create experiences of cure, build self-esteem, identify and train change agents, mobilise community groups, NGOs, media, etc., train for case detection and advocacy |
| Media | Mass-media | Rural media, rallies, meetings, etc. | Groups, volunteers, persons who have conquered disease, and champions |
| Health worker | Central figure, health system-faced | Central figure, health system-faced | Co-learner and community-faced |
| Spokesperson | Specialists, experts, celebrities, leading writers, artists and journalists | Celebrities, religious leaders, cured persons, care-takers leading writers, artists and journalists | Community leaders, cured persons, care-takers, researchers/NGOs, etc |

the types of communication campaigns that can be categorised as dominant and participatory. Two types of dominant campaigns—Information, Education and Communication (IEC) and Behaviour Change Communication (BCC), are compared with participatory communication campaign.

This article posits that participatory communication method is more appropriate to the task of destigmatisation. It provides individuals, communities, and organisations involved with the necessary skills, confidence, and countervailing power to deal effectively with the problem. Empowering processes privilege multiple voices and perspectives and truly facilitate effective sharing of knowledge and solution alternatives among all relevant actors involved in the process.

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