Engaging, Mobilizing and sustaining community involvement in health care. Evidence - based strategies of synergizing interventionists and stakeholders with special reference to infectious diseases.

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I Introduction:

Community involves certain levels of interaction amongst people through shared identity or common experience. A sense of community belonging is desirable, as it is one of the most effective ways of internalizing norms and initiating change in behavioral pattern. The conceptual base of this paper is that the desirable norms can be introduced through appropriate community intervention. The focus is on using well-established community networks and community based organizations to aid intervention effectiveness. It looks at synergizing the interventionists and the stakeholders along with the significant others. Research has indicated that people’s participation in the process of change and development is imperative.

The present research work is in the field of social development; sub field of community development and the specific area is community health. It examines the role of community based organizations (KNSS) and community networks in motivating the community in the quest for eradication of leprosy, a contagious disease; which is a pointer to adoption of the similar strategy to fight infectious diseases. The findings of this research paper are based on the evidence-based approach to social development using the case study method.

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The present paper is based on her Ph.D work.
II Research Methodology

The present research work attempts to explore the significance of people’s participation in public and social policy by resorting to the case-study method. This is due to the belief that the case-study method can contribute to a better understanding of how people’s participation evolves and ultimately translates into attitudinal change and health seeking behaviors. It also relates to how communities respond to social change and become contributory factors in sustaining social change. This will encourage policy makers to consider the dynamic and interpersonal dimensions of the experience of voluntary action in the development of support and partnership between the community, stakeholders and the interventionists.

The case study method can confront and explore difference and complexity in ways, which move beyond normative description. It accepts uncertainty and incompleteness, but thereby opens up the possibility that policy makers and practitioners can be helped to better understand community behavior and its implications on health care.

The endeavor of the present project is to reveal through case-study analysis the real experience of those involved within it. Through greater understanding of these experiences, others can also learn about the strengths and weaknesses of involving people in social action.

For this purpose, Shantivan a relatively successful voluntary organization, working in the field of community health was selected. The researcher had established contacts with the organization, its management, workers and the beneficiaries in course of her doctoral studies. In depth, analysis of Shantivan was carried out in December 2004 onwards. The data was collected from the printed records of the voluntary organization and unstructured interviews with the key-persons, volunteers, full-time paid workers and beneficiaries. Insights of this kind have consequences for any discussion concerning the strategy to be adopted for the promotion of community health.

For relating theory to practice, the researcher resorted to the Evidence based approach to Social Development.

III Research theme

The present research paper is in the subfield of community health and the role of community networks, community based organizations and people’s participation in promoting community health. Their role has briefly elaborated as under:

1. Networking: Networking is the key to forming the in groups, which would facilitate social change. Networking sustains a rich well-integrated and dynamic environment from which emerge familiar patters of social interaction; self help initiatives and citizens organizations. Networking has been a natural aspect of human life, which is about formation and maintenance of relationships. This is truer
with relatively simple communities like the semi urban and village community. In India, one observes the linkage between the families; certain ethnic and religious groups and caste communities are extremely well networked. These linkages eventually lead to bigger groups like the village community. Such well-established networks could enable us to transmit socially relevant information and develop collective problem solving strategies. Community is essentially made up of these informal networks; which could be brought to use for initiating process of change and most importantly sustaining change. However, the community networks should be evaluated in terms of the quality and quantity of their connections and the degree to which they are able to generate innovative and sustainable solutions to common problems. The Complexity theory emphasizes on the role of connectors who are the catalysts that progress change along with the task of putting people together.

The key feature to network type structures is their capacity to communicate across organizational boundaries gathering, checking and constantly updating information from a range of sources. Community networks provide a tool for collective learning and parallel information processing. The well connectedness of the community arises from the acceptance of diversity, flexibility and its internal bonds and external bond, which are major factors in the empowerment of its members and its ability to achieve change through interaction with the environment.

Networking can be seen as a constellation of several functions. These include mapping of networks, making contacts and maintaining interpersonal relationships, managing and monitoring the overall network. It also includes merging networks, providing mediator, motivating and mobilizing people to participate in the consultation exercise, community activity and campaigns.

The purpose of networking is to establish, extend and replenish the set of connections through which people learn from one another, exchange information, share ideas and resources and develop cooperative strategies for accomplishing collective and individual goals. Community networks support constant dialogue and reflection from which is generated collective intelligence, shared expertise and a sense of solidarity. Further more these networks allow pooling of resources and dissemination of information is faster.

2. Communication within community
Communication is an art of transmitting information, ideas and attitudes from one person to the other. Communication is instrumental in both conformity and initiating change. An important part of the process of communication is the communicator i.e. one who communicates. In social groups, we find peer leaders and influential people who can make attitudinal changes happen. While interacting with the community it is almost impossible to have one to one dialogue with the stakeholders, thus the peer leaders are an important aid to information transfer. These interpersonal channels allow clarification and additional information regarding a particular health issue. The interpersonal channels have more accessibility to stakeholders and they can help overcome social and psychological barriers of selective
exposure, perception and retention. We have seen that despite the systematic efforts of the mass media, the community is unable to translate the information into reduction of risk health behaviors. Affective ties, adaptability and multiple channels characterize communication between communities. Every society has its own communication system, which is both interactional and informal. No communication can be effective unless the local channels are favorably activated. This is particularly true in Indian society where bonds of family, kinship and castes are strong.

It is clear that health workers cannot achieve the related health goals and thus it is important for communities to get involved and increase the sustainability of intervention strategy. It is however necessary to note that the intervention program should always start with an understanding of local health traditions, customary beliefs and well rooted behavioral aspects including health behaviors that lead to prevention and curative aspects of the disease. Besides this an intervention module should consider the mechanisms of interactions, the natural social networks, nodes of community interaction, identify the peer leaders from within the community. This is to utilize natural networks in instilling health related behavior and attitudinal change. This networking needs to be done at all levels be it caste, class, ethnic groups or even smaller groups. Information transfer should be through both hierarchical or vertical and horizontal networks. Hierarchical networks involve the professional team of health care workers and horizontal networks involve the stakeholders and the significant others. These significant others include family members, relatives and even neighbors who would influence health decisions of the affected.

3. **Behavior change and communities**

Behavior change is a process rather than a single event. Behavior change in a community begins with pre – contemplation where the community may not realize that change is possible, desirable or relevant to them. This is followed by the contemplation stage where an action or event may trigger people to think about risk behavior change. The next stage is a stage when preparation is made to accept change, where the community equips itself to undertake change through gathering information about change and finding appropriated means to achieve change. Eventually the change occurs when community’s act on their previous decisions, experience, information, skills and motivations for making the change and a new behavior is adopted.

The main barriers to a community health are the obstacles to improving a community’s health are cultural, social and interpersonal expectations and behaviors. Even the best of medical interventions may not bring about the expected change due to the attitudinal barriers within the members of a community. The continuing spread of infectious disease, including HIV and Tuberculosis despite the widespread knowledge about how to prevent disease transmission, owes its prevalence at least to certain degree to social and behavioral processes.

To enable communities gain capacities in addressing their problems, it is essential to develop capacities in context with the existing socio – economic and cultural milieu of the community. In India, especially behavior and beliefs are a part of a wider belief system, which includes culture, religion and traditional systems of medicine. For e.g. there are erroneous beliefs about condom usage,
which leads to selective avoidance of safe sex message and leads to risky behaviors. Thus to bring about the required change health messages have to be built on local resources and practices which find acceptability with a given community and not lead to attitudinal reactance.

4. **Role of Community organizations, community nodes and community peer leaders**

A health promotion program should be built on existing organization and the peer leaders can play a role in transfer of information in culture specific acceptable ways. The natural groups may be varied in nature and their specific goals; however they can be involved in rooting healthcare behaviors in the particular community.

**People’s participation**

Balwantrai Mehta Committee (1957) observed, “Rural development and rural welfare are possible only with local initiative and local direction. In the ultimate analysis it must be an instrument of expression of local peoples will taking in view the local development”.

Participation denotes the involvement of a significant number of people in situations or actions, which enhance their well-being. In the context of health intervention, it refers to an active process whereby people influence the direction and execution of health projects rather than merely receiving benefits. People are not just recipients but they are also mechanisms of propagation of health care behaviors and play a role in health intervention activities. People’s participation is a collaborative involvement of beneficiaries with that of health care workers. The forms of participation can vary from passive participation where people are merely being informed about the project to decision-making and self-mobilization where people take initiative independent of external control.

5. **Need for peoples participation**

It had been observed that non-participation of people results in uniform and stereotype schemes, which are not suited to local needs or resources. Besides there are deficiencies in collection of information and these are reflected in inappropriate planning. It has been observed that once the stakeholders get involved in intervention activities they are also more likely to comply with the health care activities including reducing risk behaviors.

6. **Groups, networks and information transfer**

The entire community can be visualized as a collection of groups or of people each of who shares certain relationship with other. Each of these units is connected and interdependent on other. This codependence facilitates information transfer, attitudinal change behavioral concordance and compliance.

*Attitude change and informational social influence:* Other people’s actions and opinions define social reality for us and we use these as a guide for our own action and opinions.

In a study done by Baron et.al. Two communities were studied on various attitudes regarding a relevant political issue. These two communities were different from each other only in one way, i.e. community A was a well-networked community and community B had less number of interpersonal connections.
between the cohabitants. A questionnaire was given to study attitude similarity between the two communities. It was seen in community A where cohabitants were closely related had more number of similar attitudes besides the information transfer was faster and most of the people knew of the political issue. This however was not seen in community B. The reason for this is the fact in a well connected community people are more likely to discuss on various relevant issues and also the interpersonal connections between them is more likely to provide safe and trusting environment to discuss relevant issues including personal health. The group members are also more likely to experience perceived social support.

Applying this information one is likely to expect that in a well-networked community there are more chances of transfer of health related information more so because it is socially applicable. Besides the affected people who perceive social support may be more open to discuss their problems with at least significant others and are more likely to seek help or intervention.

7. **Voluntary action and initiatives**

Voluntary organizations have established their credibility in being able to reach the masses through their outreach programs. The voluntary organizations are more flexible in their approach to community interventions. The governmental mechanisms are more likely to be rigid because these policies are more focused towards national needs rather than community needs. The interventionists from the governmental system are more likely to follow a hierarchical structure in which there is less flexibility in policy implementation. Voluntary organizations on the other hand are more likely to be sensitive to community needs. One such organization is 'KUSHTAROG NIWARAN SAMITI SHANTIVAN (KNSS).

IV Study of 'KUSHTAROG NIWARAN SAMITI SHANTIVAN (KNSS) and People’s Participation in Health Care

Kushthurog Nivaran Samiti Shantivan (KNSS) was launched in 1951 for undertaking the task of Leprosy patients at Nere in Raigad District of Maharashtra. In Panvel Taluka, the prevalence of leprosy was as high as 150 persons per ten thousand. The two eminent Gandhians chose Panvel Taluka. Annasaheb Dastane and Appasaheb Vedak establish the Kushhtarog Nivaran Samiti Shantivan (KNSS) in 1951 near Nere Village in Panvel Taluka to undertake leprosy eradication work. The Government of India entrusted to KNSS the triple tasks of Survey Education & Treatment (SET) program in Panvel Taluka in 1981. The Government of India entrusted the S.E.T. work in the rural areas of Panvel Taluka comprising 185 villages with a population of two lakhs to the Kushtarog Nivaran Samiti in November 1980 and State Government entrusted urban leprosy center consisting of one lakh of population to Kushtarog Nivaran Samiti in 1989.
At present, the KNSS looks after the leprosy eradication work in 248 villages in Panvel Taluka and caters to the needs of over 400,000 populations. The KNSS has divided the area of Panvel Taluka into the following eight rural units and one urban unit.

The KNSS seeks collaboration of social workers, school teachers and students volunteers for undertaking the survey and awareness activities. Every year, from 14th November to 30th January, the KNSS undertakes modified leprosy elimination campaign wherein the governmental health machinery in Panvel Taluka extends cooperation. This activity has been undertaken since 1981 and the campaign led to detection of over 7500 leprosy patients. The KNSS could eradicate over 700 patients of the curse of leprosy and 325 were undergoing treatment in January 2005. The KNSS rehabilitated 110 of these by providing gainful employment in its economic activities. This the success rate in over ninety percent which is an excellent record by even WHO standards.

Activities of the Kushthurog Nivaran Samiti in the sphere of Rural Development
The KNSS was initially a single activity oriented VO and was established to undertake the task of eradication of leprosy in Panvel Taluka, along with rehabilitation of the leprosy affected persons. It implemented the SET programme of the government of India. While implementing the SET programme, the volunteers of the KNSS have undertaken repeated house-to-house surveys, schools and factories in Panvel Taluka. Its survey work led to identifying of 7500 patients who were placed under treatment, and of whom more than 7000 were cured. The endeavors of the Samiti led to increase in the number of voluntary reporting. The rate of cure improved substantially due to the adoption of multi drug therapy. The prevalence rate has come down from 100 per ten thousand in the 1980 to six per ten thousand in 2000-01 in Panvel Taluka.
A much appreciated feature of its effort for leprosy eradication is the special campaigns undertaken by the KNSS in the months of severe monsoon to reach the hill tops for contacting the aborigines living there who, after the four monsoon months, migrate to the plains in search of work and thus fail to be subjected to prolonged treatment and administering to them, the new drug ofloxacin which brings about a cure after consumption of 28 daily doses.
The deformity caused by leprosy is a major handicap in productive employment. It is essential to prevent deformities, and when they are already there to help the victim to combat the disability by providing appropriate aides and training. The KNSS is implementing a pilot project for Preventive rehabilitation and Disability Managements, for the last six years, with a measurer of success. Under the SET program the accent is on rendering treatment to the patients in their own domiciles. However, some patients are in need of hospitalization for prolonged treatment, which is given in the leprosy hospital in Shantivan. Although cured of leprosy, the beneficiary may find it difficult to be accepted by society. In case he has no independent means of livelihood, his difficulties are further aggravated. Economic as well as social rehabilitation of the persons once suffering from leprosy is as vital as the cure from the disease.
Rehabilitation of persons cured of or under treatment for leprosy is therefore an important aspect of the
KNSS work. The KNSS organizes mass programs to enable the beneficiaries to get back in the societal fold and live a productive life. These efforts also involve family counseling. Thus, the 80 ex-patients who have been rehabilitated at Shantivan earn their own living by being engaged in the following gainful activities.

Social Activities:
In the endeavor for eradication of leprosy, social education assumes a very important role. The prejudice and superstitious beliefs must be removed and correct knowledge of the true nature of the disease imparted to the public in general for the twin purpose of bringing about social integration of leprosy victims and preventing their rehabilitation. Therefore, the KNSS organizes some social functions throughout the year, at which the invited dignitaries who are people’s representatives, freely intermingle with leprosy patients and ex-patients. These functions include "Rakshabandhan" which is hosted by high dignitaries such as Chief Minister and Mayor in the cities of Mumbai and Panvel and Bhaubeej, Ganesh Festival, etc., which are celebrated in Shantivan. There is also the Mitra-Melawa, a get together of supporters of our activities, which is held in January every year at Shantivan, and attended by thousands, who spend the whole day amongst the inmates. The occasion of leprosy week is also utilized for social education.

Shrama Sanskar Shibirs:
A notable activity of the KNSS is the series of three-day social education camps of school children from Mumbai, Thane & Raigad district held every year from November to February, for last 20 years. So far, nearly 78,000 school children and 3,500 school teachers have participated in these. In the camps, the children's minds are oriented towards social service through lessons in social service, story telling sessions, and Shramadan along with Shantivan inmates. They are also told about the real nature of leprosy and the national endeavor to control the spread of the disease. Thus, an attempt is made to rid their minds of the superstitions and stigmas attached to leprosy.

HIV intervention and peer groups
Similar experiments have been done with HIV intervention however these experiments may not have sustainable effects due to the fact that there is no unison between the public sector and the voluntary organizations that are playing the role of health interventionists and thus as a result intervention efforts are haphazard. The interrelationship between the interventionists is however not within the perview of this study.

Various voluntary organizations including the organizations in Panvel taluka working in the field of HIV intervention have initiated peer group activities for people affected with HIV. The peer groups act as facilitators of information transfer. There are support groups which enable the affected to deal with the crises situation and to comply with safe sex methods. This social individuation has led to responsible sexual behaviors. It was assessed from a longitudinal study conducted in Panvel Taluka by the researcher in a span of 4 years with discordant couples. The infected that were a part of the peer group were more
likely to use safe sex methods. Besides they were also more complaint with health seeking behaviors and psychologically more stable.

Besides the information relating to HIV is communicated across with the means of Nautankis (street plays), religious assemblies, awareness programs in schools, colleges, within panchayats and various socio – cultural organizations. The effects of this are reflected in the fact that the number of voluntary testing have increased significantly. The local doctors are also more apt in calling for an HIV testing.

V Findings and Conclusions

Some of the findings of the case study are as under:

1. The KNSS performs `agency role' by implementing the governmental programs. This duality of role makes it different from the most V.O.’s in India which are described by the critics as `extension of the administrative machinery of the state. The KNSS co-operates and collaborates with the government which puts it on a higher pedestal and displays the much sought autonomy in its working. Besides it coordinates with local leaders for organizing community outreach programs.

2. A bunch of highly dedicated social workers have brought about the transformation of village community and continue to work for the cause of Leprosy eradication. They work in concordance with the local community initiatives. This has led to sustainability of the leprosy eradication activity.

3. The outreach programs are culture sensitive and this is reflected in the messages conveyed to the community. Thus there is more acceptability. There are an increasing number of socially rehabilitated Leprosy patients.

4. The various programs not only involve the community representatives but also the entire community, during which relevant information regarding leprosy is communicated. These programs form a platform for community get- together’s.

5. The acceptance of leprosy patients has increased considerably which is reflected in the fact that local people participate in the programs organized by the KNSS. Also the number of rehabilitated patients who go back to the community has increased from 1.5 % to 52%.

Limitations of using the community networks are

1) The information transfer could lead to a grapevine communication. Thus interventionists have to use many such networks to convey information

2) The efforts at attitude change through community could bring about attitudinal reactance in which the persuasive messages would be mentally discarded.

3) The introduction of newer attitudes have to be in congruence with the existing attitudes of the community; at least the interventionists have to be careful that the attitudes are communicated in such a way that seems to be congruent with the existing attitudes.
Thus we can conclude that

1. Effective engagement of the community in health intervention is necessitated by the need to find cooperation between the health care workers and the stakeholders. The significant others of the stakeholders play an important role in availing to health care system in India.

2. Well-networked communities can be an advantage to health care intervention especially considering the importance of information transfer and eventual attitude change.

3. Implementation of intervention program can be effective when
   - There is sharing of educational materials and curricula across community nodes like community organizations.
   - Community networks are identified and monitored to mobilize health care measures. The interventionists along with connectors bridge the gap between community norms and health care needs.
References

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