



Comprehensive Rural Health Project, Jamkhed, India

The Primary Health Care Approach to Leprosy

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Health is a fundamental human right. People have the right to basic health services, and they also have the right to have the knowledge and means to acquire and maintain their health. Persons affected with leprosy (PALs) are also entitled to such rights.

In the past few decades, with the rapid progress in medical science and technology, health care services have tended to become more technology oriented and expensive. At the same time a sense of dependency on the medical profession has been created. This monopoly of medical knowledge by the medical profession has resulted in the medicalization of public health. People in subtle ways are being denied the right to acquire and utilize health knowledge. In dealing with leprosy, the same phenomena have occurred. Leprosy has been treated separately and, right down to the local level, there are special leprosy workers who solely deal with this illness. Persons affected with leprosy as well as ordinary people are, unfortunately, given little knowledge about this disease.

Human beings live in a community -- be it a family, clan or the larger rural or urban setting. Their well being and development are affected to a large extent by the way they are treated by these community groups and the society as a whole. Persons with physically disabling conditions in general are not fully accepted by society, and PALs even more. Often even the family members disown their own kith and kin who are affected by leprosy.

In dealing with the problem of leprosy, it is important to address all aspects that affect the life of PALs and facilitate their leading normal lives with dignity. It is necessary to understand the socio-cultural factors that play a role in social deprivation and marginalization of PALs. People's actions and behavior in any situation depend on their own assessment and analysis of the situation, which in turn depend on their knowledge and experience. These are also dependent on perceptions and social norms set by the communities.

The Situation

The perceptions of the majority of people are that leprosy is incurable, it is highly infectious, and a divine curse. This understanding leads to a fear of the disease much out of proportion to the reality. This fear leads to the general public despising PALs. The PALs in turn tend to hide and not offer themselves for early diagnosis only to be exposed when deformity occurs, further enhancing the fears of the community and the social ostracization. Women affected with leprosy continue to suffer most.

There are several oppressive factors working from within and without the community that influence the actions and often keep communities locked into a closed space of limited knowledge, leading to further marginalization and social ostracization of the PALs. Being victims of poverty, illiteracy, unemployment and poor self-esteem, true knowledge and opportunities for development are denied to PALs by the powerful elite. Education, knowledge about special programs for people with disabling conditions and other amenities are not shared with them. All these actions tend to keep those who are marginalized from joining the mainstream of society. The continuous negative messages force PALs to have low self-esteem and a resultant sense of hopelessness.

Health professionals have slogans and messages that leprosy can be cured, that casual contact does not necessarily spread the disease, and that there is no need to

segregate PALs. Yet, treating PALs in special clinics reinforces existing beliefs about leprosy. Mystification of the disease further adds to misconceptions. Efforts of providing vocational training at separate training centers also prevent PALs from settling down in their own surroundings. Employers may not give jobs to those trained at such centers. Even children of leprosy patients whose address is a leprosy colony are denied jobs. Such programs inadvertently enhance the negative image. Even the frontline leprosy health workers are looked down on by the general public, leading to demoralization of these workers.

Leprosy continues to be regarded as a divine curse, or punishment for sins even among some of those who are aware of the nature and cause of the disease. In the name of religion, people are exploited, shamed and ostracized. PALs are often made to spend money for visiting holy places to appease the goddesses, atone for sins, and undergo various rituals.

Primary Health Care

One of the ways to overcome these socio-economic-cultural problems is through the community-based primary health care approach (PHC). PHC is a holistic approach whereby health professionals and people work in partnership to bring about positive health. Leprosy can be well integrated into the overall PHC program.

For centuries, a welfare approach has been followed in dealing with the control of leprosy. In this approach health professionals decide on what is good for PALs, set objectives, plan and implement programs. Health education materials are prepared by professionals, and a few carefully selected health messages are given to both the PALs and the people. This approach resulted in the development of special programs for leprosy. Such an approach was necessary when good treatment for leprosy was not available.

With improved understanding of the epidemiology of leprosy, availability of drugs for leprosy, and progress in the understanding of issues in human development, the concept of people being taken into confidence in health care programs was introduced. Those working in PHC have now found that, when empowered with knowledge and skills, people can effectively come into partnership with health personnel and work towards sustainability of health programs -- be it maternal and child health or leprosy control.

The main components of the PHC program are community participation and empowerment. The PHC approach includes the integration of preventive, promotive, curative and rehabilitation services, multi-sectoral collaboration, and appropriate technology.

Principles of PHC

In PHC the overarching and important principle is equity. Equity in health care does not mean equality or people receiving the same kind of health services. What it means is distribution of health services according to health needs. Needs are not entirely determined by the health professionals but by the people. Equity is about addressing those in most need. If resources do not permit all being served, those most in need must have priority and what is done must be relevant to their situation. PALs therefore must get priority for services in the PHC approach. They cannot be neglected and the fear that if leprosy is integrated into the health system it will be neglected should not be true if PHC principles are practiced.

Equity in health care implies more than providing health services to the poor. It implies getting to the root of the problem -- which is the socio-economic political and religious base of our society. It is only when these unjust structures are addressed that we can hope to achieve true equity.

Appropriate technology is the application of scientifically sound technology to suit the needs of the people. The Village Health Worker when trained is able to communicate far better with her peers than a health education. Local village artisans can make footwear for PALs once it is explained to the artisan.

It is important to enhance the knowledge and skills of the communities by providing audio-visual literature and other simple publications on leprosy that can be

understood by illiterate or semilliterate people in villages and urban slums. Educational materials developed on a national scale may not be suitable to the village people. Appropriate materials have to be developed, based on local proverbs and stories and building on what people already know. The participation of people in developing these materials makes them even more effective.

Multi-sectoral collaboration is an important strategy in the PHC approach. Health is part of overall development. To this end, nutrition, environment including safe drinking water and sanitation, social discrimination and poverty need to be addressed. All of these aspects are inter-linked. The health agency may not have the expertise, but they can be the facilitators to bring all these sectors (government and private agencies) together at the village level. Then the community organizations can avail them-selves of services, acquire more knowledge and skills, and incorporate them into their development activities.

Role of a Health Organization

Generally PHC programs include Mother and Child Health (MCH), family welfare, water and sanitation, control of malaria and tuberculosis. Integrating leprosy with these programs prevents the PAL from being singled out. A health worker visiting a family with children and leprosy patient does not face stigma of caring for leprosy patients as s/he may deal with a malnourished child or a malaria patient and examine all family members for leprosy, and treat the PAL.

The PHC approach calls for a paradigm shift for the health workers. From being health providers they need to become enablers and facilitators. They also have to learn to work in a health team with other health workers. Leprosy paramedical workers need to expand their knowledge and become multipurpose health workers. Weekly team training and learning from each other help in this process, as well as meetings with the VHWs. Professionals and other health workers should also understand the social aspects of leprosy. Team training also means involving local community members. Special training is needed to elicit community participation, community organizing, and various methods of collecting information and planning with the community, including participatory research, managing change and personal development.

In the Comprehensive Rural Health Project (CRHP), Jamkhed leprosy work is integrated with mother and child health, nutrition and tuberculosis control. In addition to a health centre, a mobile health team visits every village in the project area regularly. The CRHP health team consists of an Auxiliary Nurse Midwife (ANM), a leprosy paramedical worker and a social worker. All receive in-service training as multipurpose workers and in the concept of working with people as enablers rather than providers. No one is singled out as a special leprosy worker, though each has responsibility according to their own fields in addition to supporting the other members of the team (e.g. ANM for MCH, social worker for community organization).

Health team members share knowledge freely with village people and involve them in all activities. This encourages the community organizations to be empowered enough to take up the challenge of improving the health of the village women and children and marginalized groups including PALs.

Community Participation

Community participation is one of the key concepts of the primary health care approach in achieving health for all. Primary health care is ultimately about empowerment of individuals and community so they have control over their own health and lives. This means the involvement of communities in the development of services so as to promote self-reliance and reduce dependency.

This can be done only through empowerment of people. Community participation is not people just responding to services planned and implemented by experts from outside. It does not mean people passively following the health messages provided by the health professionals through health education and mass media. It means people being fully involved in the whole process of planning, implementation, monitoring, and review of health programs. It means people taking control. This is where primary health

care approach differs from traditional public health approaches.

The question that is often asked is how can people participate in such a technical matter as health and in particular leprosy? The reality in leprosy is that a large proportion of the complications of leprosy are preventable. Leprosy patients can lead normal lives in dignity provided they take a few simple precautions. No matter how good and efficient is the leprosy service provided by the health professional, it is up to the individual or family to utilize the information and knowledge. In short, people have to realize that they are the key actors in health and not the medical profession, and the medical profession has to realize that well being and care ultimately depends on individual and community action, more so with the socio-economic and cultural problems faced by PALs. Such problems can be effectively solved when leprosy is incorporated into a PHC program

In the case of leprosy, a person being aware of the symptoms of the disease, seeking early and regular treatment, and taking precautions are dependent on the individual. The community's knowledge and attitude further determine the socio-economic problems that the PAL may face.

Partnership with the Community

Rehabilitation and improving self-esteem for PALs need special attention and personalized care. The community around also has to be supportive. One of the principles of the PHC approach is that problems are reduced to a manageable unit -- that is the community, a unit of 1,000-2,000 population. Rather than finding a solution for a mass problem, a village of 2,000 population with a prevalence rate of 4/1000 will have eight persons needing treatment. Of these only two may need rehabilitation services in addition to education and medicines. The community knows each of them by name. If the local people shed their superstitions and deep-seated prejudices, they can be a tremendous force for the care of PALs. This calls for organization of the communities and sharing adequate information repeatedly until the community internalizes the knowledge about leprosy. Health professionals therefore need to change the paradigm from being providers to enablers. They must be willing to enter into partnership with the community and the PALs.

As the knowledge and experience in the community increases, health workers must work in partnership with the community organizations to set objectives. One of the objectives can be to work towards the elimination of leprosy from their community. The more the participation, the more likelihood of leprosy control programs becoming sustainable; instead of the program being the agency's program, it becomes the people's program.

Community Organization

In each village unit, local working groups are organized, who are in a position to contact all the people in the community. Socially minded persons are identified from various groups and factions and organized into Farmers' Clubs (men's group) and Mahila Mandals (women's groups) around their self-interest like agriculture or other income generation. The majority of members are from the marginalized groups. In each village a local woman is selected as a Village Health Worker (VHW) by the village people or village organizations so they will be accepted and supported by the village. Various health topics including leprosy are discussed with these community organizations.

Included in the training of Village Health Workers (VHWs) is maternal and child health, nutrition and hygiene, and how to conduct normal deliveries and treat common minor illnesses. They are also taught to examine, diagnose and follow up treatment of leprosy with the support of the CRHP mobile health team. They are especially helpful in the early detection of leprosy. They are present at all times in the village and have access to people. Often they go to the river or bathing places and look for early patches of leprosy as people are bathing. They share their know-ledge with the village people and work closely with both the men's and women's community organizations.

As members of these community organizations, VHWs participate in house-to-house health surveys that are conducted by the CRHP health team. These health surveys include examination for leprosy, in addition to other health problems. Such

involvement helps the communities to assess different health problems including leprosy and formulate action plans. Involving the community in surveys results in the community organizations taking interest in the control of leprosy, and they are often challenged not only to work towards the elimination of leprosy from their village, but also to ensure that all PALs are also included in rehabilitation programs.

Through the VHW information on each finding is given to the community members.

In the case of leprosy there are in depth discussions on cause of disease, possible mode of transmission, signs and symptoms of leprosy and the reasons for complications. By fully sharing information, people's fears are removed. The community organizations are encouraged to take up leprosy control as one of their objectives. Once they actively take it up, the village organizations make out action plans with the help of the health team. They encourage early detection and ensure compliance in treatment. The VHW and community organization members develop their own communication methods such as stories, skits, songs and puppet shows, and they go around villages to change people's perception and attitude towards leprosy.

The community also supports persons who are unable to look after them-selves. Occasionally there are patients who have no fingers. The members of the women's club or their relatives cook food for them, and the community members help such a person in tying their animals or helping in their agricultural activities.

Change of Community Attitudes

When CRHP began, PALs were often driven out of the house of the family and kept in makeshift huts on the outskirts of the village. Someone from the family supplied them food and water for the day. Through repeated cyclical inputs and sharing knowledge about leprosy by VHWs and the CRHP mobile team, people's understanding about leprosy increased.

Members of the community organizations accompanied the mobile health team to the huts outside the village. The health team demonstrated how to clean and dress the ulcers, the reasons for the complication, and what needed to be done. The health team also socialized with the leprosy patients to the extent of having tea or sharing a meal. Such actions made the PAL's family to realize that the disease was not as dangerous as they thought.

With the community, the health team uses participatory rapid appraisal methods, which include social mapping and focus group discussions, and analyze the socio-economic problems that marginalized people including PALs face. Such interactions with village people dispel fears. The community organizations support families in taking back their relatives into their homes.

Traditionally every PAL was taken to a famous goddess temple by a local healer, and these PALs did not get any treatment except to spend money for ceremonies. So in many villages the community members have prevailed on the healer to continue his methods but add modern treatment. In one community they convinced the local healer to become an involved member of the Farmers' Club. He then actively went from village to village and explained how healers like himself exploited people in the name of religion and showed how he performed his tricks to convince people.

Integrating PALs into Community

The rehabilitation programs for PALs are not carried out in isolation. It is part of the overall program where other marginalized groups, such as women, persons with other handicapping conditions and chronic diseases, are assisted in coming back into the mainstream of society.

Once fear of leprosy is removed, the community has no problem in rehabilitating the PAL. The Farmers' Clubs and Mahila Mandals identify what the PALs can do and assist them in getting the necessary credit or training. They encourage PALs to be active members of the community organizations. The PALs should be provided with social skills to participate in community activities. To enhance self-esteem and dignity of PALs, they are encouraged to participate in all village activities including village political elections.

The stigma of leprosy has totally been dispelled, and PALs are active in community life, cooperative societies, etc.

The village people assist in the marriages of PALs and their family members. In the villages in the CRHP area, there is no hesitation of people willing to marry persons with or without deformity. The community organizations and VHW play an important role in dispelling fears and acting as matchmakers in such cases.

Income-Generating Activities

Money is the greatest equalizer in a community. In a given village there are hardly two or three PALs who need substantial help in physical and economic rehabilitation. The VHWs and the community organizations help in identifying such persons, identifying suitable activities that the PALs can carry out, and recommend them for grants or loans. The village organizations ensure that the money is properly utilized for the purpose it was given. Income generation activities for PALs should make them independent entrepreneurs; training programs that make PALs employees should be discouraged in favour of self-employment. The common income generation programs are usually in keeping with what is normally possible in the village. Appropriate activities include raising goats and poultry, buying and selling vegetables, running grocery or stationery stores, or improving the water supply for the farm.

Integrating Leprosy Work into PHC

Ultimately the well being of PALs should be the only objective and this well being depends not so much on income alone, it depends upon the dignity with which s/he lives a full life in his/her community.

Leprosy work can be successfully integrated with other ongoing health, rehabilitation and development programs. Communities can participate in early detection of leprosy and prevention of deformities and in the rehabilitation of PALs. As the community groups get more and more empowered with knowledge, skills and self esteem, they take on more and more responsibility. As the other elements of the PHC approach also progress, communities can work towards sustainability of the leprosy control program.