Chapter: 11

Information Education and Communication (IEC) & Counselling

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Learning Objectives: At the end of the session trainees will be able to
   ◆ Prepare Annual Plan for IEC and outline its implementation.
   ◆ Establish linkages with NRHM IEC plan
   ◆ Enlist key messages and describe methods to disseminate
   ◆ Describe counselling techniques

Teaching method/Activity: Lecture, Discussion, Role-play and Group work

Teaching Aids: Case studies, Experience sharing by persons affected by leprosy and
   Audio-Visual aids
11.1 Introduction

IEC is a strategy for delivery of correct information by the source (Health department /health functionaries) to the recipient (Community including patients) using various channels (print media, electronic media, public address system and visual aids such as pamphlets). It has three inter-related components – Information, Education, and Communication.

- **Information** is knowledge based on scientific facts and figures.

- **Education** is a process of bringing out ability of a person/ community through learning.

- **Communication** is a process of transmission of information, ideas, attitudes, or emotion from one person (or group) to another (or others) primarily through symbolic messages.

Purpose of communication is to transmit right information and develop mutual understanding.

Ultimate aim of IEC is to bring about desired change in the behaviour of the person.

Communication process involves:

Health functionaries must know and understand the NRHM initiatives related to IEC; interact with NRHM officials, members of Panchayati Raj Institutions, other community based institutions and utilize the various opportunities available under NRHM for effective dissemination of leprosy related messages.
11.2 Job Responsibilities related to IEC of Leprosy

11.2.1 Medical Officer
- Plan IEC activities for generating awareness, reducing stigma and encouraging self reporting and help team members, for their implementation and monitoring
- Train members of health team and other volunteers in IEC, identification of persons with suspected symptoms and signs of leprosy
- Counsel, train and encourage persons affected by leprosy, in self care practices for prevention of disability.
- Help members of health team in managing retrieval of absentees/ defaulter of MDT treatment and disability care

To accomplish these responsibilities, delegate various tasks to the other members of the health care team in the following manner:

11.2.2 Health Supervisor/ Health Assistant
- Impart health education to the community on leprosy and its treatment.
- Carry out retrieval of absentees/ defaulter.
- Counsel cases refusing to accept diagnosis and treatment.

11.2.3 Health Worker/ Multi Purpose Worker
- Impart Health Education on facts about Leprosy, related discrimination and availability of treatment to the community on routine field visits.
- Ensure completion of treatment and absentee/ defaulter retrieval
- Promote self-care practices by the Persons affected with leprosy having disability.
- Involve ASHA/AWW/PRI’s and village health and sanitation committee for IEC activities.
- Generate awareness through specific programme such as School health/ village health and nutrition day /health melas leprosy related IEC should also be included

11.2.4 Pharmacist at Block PHC/CHC
- Provide information regarding MDT and associated red coloured urine and darkening of skin.

11.2.5 Accredited Social Health Activist / Anganwadi worker / other volunteers:
- Generate awareness about leprosy and availability of treatment facilities to encourage self reporting
- Identifying suspected leprosy cases and refer them to Health centre for confirmation and management.
- Help adherence to MDT regimen
- Identifying persons with disability due to leprosy for self care practices.
11.3 Messages to generate awareness

To generate awareness in the community, message related to disease and its characteristics should be developed. Messages must be based on correct scientific information and contextualised in terms of local language, cultural and social/individual understanding.

11.3.1 Features of a good message: A good message has the following four components.

- **Content**: Should be Clear, short, specific and need based
- **Appeal**: Must lead to/ ask for an action
- **Relationships**: Express relationship among health care system and community (including persons affected by leprosy)
- **Emotions**: Convey pleasing emotions, concern, care and motivation

11.3.2 Key messages to generate awareness:

Following four key messages are suggested to generate awareness regarding leprosy in the community

- **Leprosy is Curable**: The disease is caused by leprosy germs and can be cured with medicines (MDT) that are available free of charge in all the health facilities.
- **Early symptoms of leprosy**: Leprosy usually starts as a skin patch with loss of sensation or as numbness and tingling in hands &/feet. Consult health worker on occurrence of any of these.
- **Disabilities can be prevented**: Early detection with appropriate treatment helps prevention of disability due to leprosy.
- **No place for segregation**: Leprosy is treatable and once on treatment patient does not infect others and hence there is no place for segregation of PAL.
- **Accept persons affected by leprosy**: Persons affected by leprosy, once on treatment needs compassion and empathy. Discrimination of patients is inhuman.

11.3.3 Massages to reduce stigma & discrimination

Generic massages about leprosy that can be delivered to reduce stigma & discrimination. Refer annexure-VII for stigma & discrimination in leprosy

- Deformities and disabilities are unfortunate remnant conditions of leprosy, which can be avoided if reported early
- Treated persons even with disability are not infectious to others. Residual deformity after treatment does not mean that the patient is still having leprosy and can infect others.
- People do not contract leprosy by dressing ulcers and attending to leprosy patients.
- Disability due to leprosy is preventable through early diagnosis and appropriate treatment of the disease.
- Continued self care by patients themselves improves their social life.
- Some deformities can be corrected by operations to restore appearance and function.

Treated person affected by leprosy can lead a normal life and become economically independent.
11.4 Planning IEC activities

The IEC plan needs to be formulated in line with the District IEC plan and NRHM initiatives. The plan has to be simple and achievable with limited efforts.

For planning IEC activities, identify the various problems that can be addressed through IEC. To identify these problems information is collected to analyse current situation during delivery of services, through Dialogue with community and other stakeholders like health care providers, active social groups, community leaders, opinion makers/ influencers) during formal / informal meetings or through evaluation reports.

The collected data should describe status of awareness, prevailing perceptions about the disease, and also dimensions of stigma in the target group like

- Knowledge about Leprosy, its curability and availability of treatment
- Usual Health/treatment seeking Behaviour
- Utilization of available services
- Reasons for non utilization of services
- Expectations of community members
- Reluctance to disclose the problem
- Exclusion or rejection from school, work, social groups and activities
- Blame and devaluation
- Diminished self-esteem
- Stigmatisation of family
- Influence on marriage customs and procedures in the community

Collected information is analysed for different target groups in relation to their influence in the community and programme expectations to prioritize the problem.

To make an effective IEC plan answers to the following questions must be sought.

- Why do we want to communicate?
- Who are the target audience?
- What are their interest, educational status, social needs, cultural background, and limitations?

Based on the above information identify:

- Focus areas for the particular target group.
- Identify the resources available
- Identify the most appropriate time for communication like festivals, fair, village melas and avoid the time when people are involved with other activities e.g. villagers with agriculture as the prime occupation; time of roping, manuring, harvesting the crops are avoided for such activities because every body in the family is busy during that period and people are not receptive.
- Identify most appropriate intervention, channel for communication from the available options. Decide the messages to be conveyed, for the target group. While designing the messages keep age, literacy, socio–economical, cultural aspects of target group and spill over effect of that particular intervention (e.g. generating awareness in children will also affect the awareness among parents and kins).

The following target groups presented in a table below are critical for a successful IEC strategy and need individual group specific education methodology.

<table>
<thead>
<tr>
<th>Target groups</th>
<th>IPC</th>
<th>Group discussion</th>
<th>Mass</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health providers</td>
<td>xxx</td>
<td>xxx</td>
<td></td>
</tr>
<tr>
<td>Influencers*</td>
<td>xxx</td>
<td>xxx</td>
<td>xxx</td>
</tr>
<tr>
<td>Clients</td>
<td>xxx</td>
<td>xxx</td>
<td></td>
</tr>
<tr>
<td>Family Members</td>
<td></td>
<td>xxx</td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td>xxx</td>
<td>xxx</td>
</tr>
<tr>
<td>Other target groups **</td>
<td></td>
<td>xxx</td>
<td>xxx</td>
</tr>
</tbody>
</table>

* Influencers are people who can influence a decision of a person/family/group/community. The influencers as change agents also facilitate a changing process and initiate a positive community response.

** Other groups include schools, service clubs, and youth and women groups

Decide on verifiable objectives & method of monitoring. Identify the person responsible for implementation of IEC activities. Impart training to the concerned person if needed.
Action plan is made by enlisting the identified activities for implementation with time schedule and person responsible for their implementation as given below

<table>
<thead>
<tr>
<th>Target group</th>
<th>Activity</th>
<th>Time of Implementation</th>
<th>Person responsible</th>
<th>Monitoring indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>School children</td>
<td>School Health talk</td>
<td>Once in six months</td>
<td>MPW (M)</td>
<td>No. of Schools visited in a year</td>
</tr>
<tr>
<td></td>
<td>School quiz</td>
<td>One week prior to Anti leprosy day</td>
<td></td>
<td>% age of children with 60% or more correct answers</td>
</tr>
<tr>
<td></td>
<td>Poster making competition</td>
<td>Anti leprosy day</td>
<td></td>
<td>Number of children participated</td>
</tr>
<tr>
<td>Women groups</td>
<td>Radio (Community/AIR/FM) &amp; TV broad/tele casting programme on leprosy &amp; success stories of PAL</td>
<td>Once in 6 months on leprosy. 15 minutes.</td>
<td>Health supervisor (F)</td>
<td>Women aware of health awareness programme in Radio/TV</td>
</tr>
<tr>
<td></td>
<td>Focus group discussion</td>
<td>Once in six months</td>
<td>MPW (F)</td>
<td>% of people aware of at least one sign &amp; symptom of leprosy</td>
</tr>
<tr>
<td>PAL at home/family members</td>
<td>Inter Personal Communication</td>
<td>1-2 PAL on village visit</td>
<td>MPW (F/M)</td>
<td>% of PAL completed treatment in time.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>% of PAL with grade one disability using protective devices.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>% of PAL with disability regularly practicing self care.</td>
</tr>
</tbody>
</table>
11.5 Leprosy Awareness Activities:

The leprosy awareness activities / campaigns are carried out to improve self reporting of cases and contribute to diminishing stigma against leprosy in the community.

Various activities for generating awareness in Leprosy:

- **Use of mass media**: Community radio, Television local newspaper, local channels may be used to sensitize the community in general

- **Interpersonal communication** for PAL and their family members

- **General Awareness activities can be** carried out for selected target groups like schools, youth clubs and colleges. Quizzes / painting competitions / debates may be organized to generate awareness

- **Leprosy stalls/exhibitions**: These are set up along with other NRHM health exhibitions and Melas.

- **Observation of Anti Leprosy Day**: Rallies and exhibitions can be organised to generate awareness. Elected representatives and district administration are involved to felicitate and motivate best workers in health staff, ASHA, members supporting the programme and patients working as ‘change agents’/ ‘catalyst’ in improving perceptions about leprosy in the community. This can also be used to encourage children with prizes in the competitions during the event.

- **Focus Group discussions**: Group discussions are conducted to discuss, share experiences of successful stories and events in different social groups like groups of women (Mahila Mandals), school children and youth.

- **Self Help Groups (SHG)**: Patient peer groups are organised for mobilising support and improve self care. These groups organise themselves to advocate & health functionaries and members of other organisations can also support and advocate in different forums on their behalf to fight stigma against the disease and their rehabilitation.

- **Block Leprosy Awareness Campaign (BLAC, Refer Annex IX)** to generate awareness to enhance self reporting in areas with increased load of leprosy cases

- **Spreading the message through modern communication tools like Mobile, Email, Toll-free number etc.**

11.6 Counselling

Counselling is a means to put oneself in the position of the client, guide/help the client to understand their own feelings, problems and situation bothering them and identify possible solutions for the problems and help client to decide on his/her own choice. This process takes time and perhaps more than one session. (For process of counselling refer Annexure-VIII)

The counselling depends on the dialogue process and talking points. The discussion is specific to each individual. Considering the principles of counselling, simple and understandable language must be used instead of scientific words.
Due to recognised stigma for leprosy, the patient needs counselling on at least three important points in time i.e. at the start of MDT, while making the patient RFT and at the time of the need.

11.6.1 Counselling at the start of MDT

It is a disease like any other communicable disease, caused by leprosy germs.

MDT kills the leprosy germs. If medicine is taken regularly every day for 6 months (PB) and 12 months (MB).

Person affected with leprosy can lead a normal life during and after treatment.

Facilities for treatment of leprosy are available free of charge at the nearest health centre.

Person will be cured after the scheduled doses are completed. However, anaesthesia and hypo-pigmented skin patches may persist even after treatment.

Please collect medicine on every 28th day.

If you cannot come to collect medicine for any reason, please collect MDT for that month in advance. Always collect MDT, 3-4 days before the last dose of BCP is taken.

MDT is safe to be taken during pregnancy and should be continued.

May get red coloured urine initially or 1-2 days with use of every new MDT pack. This is due to medicine taken on 1st day of each month. For this one need not worry, as the same will pass off quickly.

For MB patient- Don’t worry about the change in skin colour which is due to the medicine. Normal colour of the skin will return after about a month of stopping MDT.

Report immediately on development of skin rash that itches or jaundice or any other kind of problem

Report to the Health Centre immediately in case skin patches suddenly become red and swollen, nerves become painful and tender, feel pain and numbness in the limbs, weakness, and tingling sensation in the hands, feet or face; increase in area of sensory loss; increase in weakness of limbs, pain and redness in eye/s and any deterioration of the vision during or even after completion of treatment

New disabilities can occur any time during or after the treatment and must be reported immediately. New disability of recent origin can be treated but existing disability may or may not improve with treatment

Must practice self-care regularly to prevent disability and worsening of the existing disability.

Close contacts and friends must examine themselves and report voluntarily for examination on next visit. All the children must also be examined and brought for confirmation of diagnosis and treatment in case of any similar lesions.
11.6.2 Counselling on Completion of Treatment (RFT)

- Congratulate PAL for completing the recommended treatment and tell them that they are now fully cured of the disease and need no further MDT.

- The skin patches that are still remaining on the body will take time to disappear. Some patches may remain forever, but these are harmless.

- Recurrence of the disease is rare but if any change in any of these patches showing reactivation of the disease or appearance of new patches is noticed, please come to the Health Centre immediately.

- Loss of sensation, muscle weakness due to nerve damage will also remain and you must take all the precautions to save these from injury.

- Come to health centre immediately for treatment if any of the previous symptoms come back again or signs of new nerve involvement, worsening of nerve impairment, reaction, eye involvement appear.

- Continue to follow self-care practices as before to prevent further deformity of insensitive/ weak/ paralysed hand/foot.

- Existing residual deformity of hands and feet can be corrected with surgery and can be arranged in (specify) hospital, free of cost. If willing for the same, please let us know.

- On coming across anybody in the village having similar problem; please send him to the PHC immediately.

11.6.3 Counselling of family members of the Persons affected by leprosy

Leprosy affected person needs support of the family members and community. Hence, it is essential to counsel the family members of the persons affected by leprosy in order to encourage the affected person to take the treatment regularly, complete it and practice self care for prevention of disability and deformity.

- The disease is caused by germs.

- The disease is not contagious.

- Leprosy is curable with MDT.

- The patient once on treatment will not spread disease to others.

- The person affected by leprosy can lead a normal life during and after their treatment.

- Support the patient to take medicines daily for the scheduled period of treatment.

- Support the patient, reach health facility in case of problems.

- Ensure that the patient follows the principle of self care.

- If any other member of the family has similar problem, please bring him/her to the PHC for examination by the Medical Officer.

Note: Identify suitable staff in each health facility for counselling. The points given above are about issues on which counselling should be centred. However, presentation of these may vary from person to person in different situation.