

Home Care for the HIV Affected

- Activity
- Presentation
- Additional Information

Objectives

- **Knowledge**

Understanding various aspects involved in home care.

- **Attitude**

Developing empathy towards the affected individual.

- **Skill**

Learning specific methods to take care of the patient and at the same time protecting oneself from the infection.

- **Expected outcome**

Home care is essential and it is possible to provide care while safeguarding oneself from getting infected.

- **Lesson plan**

Activity 1 Importance of home care.
Presentation Role of the family.
Presentation Issues the family needs to know.

Activity 2 Understanding the affected and afflicted.
Presentation Providing Physical and Emotional Support.
Presentation How the family can protect itself?

Activity 3 Working through grief.
Presentation Providing care for someone who is dying.

Introduction

Home care refers to any form of care given to HIV / AIDS afflicted individuals in their own home or in the community. They can be activities that HIV / AIDS victims might undertake to take care of themselves or the concern shown to them by their relatives, friends or health workers within their homes. HIV/AIDS being a chronic condition, it is essential to recognize that those affected do not always require to be hospitalized and care within their families might be more appropriate at some stage of their disease.

The burden of home care is borne predominantly by women and girl children. Typically, a woman or a girl child will find herself in the position of a care giver as a matter of course, of cultural expectations. The stress they experience and the distress encountered by them, are legitimate.

- Financial hardship when the breadwinner falls sick.
- Oppressive workload - taking care of the sick person and managing the household.
- Secrecy and fear of disclosure leading to lack of support from other members of the family.
- Guilt resulting from inability to meet the needs of children.
- Isolation, insecurity and fear of the future.

Home can be a shelter

- Where a person is assured he or she is respected.
- Where one doesn't have to hide one's feelings.
- Where one won't feel isolated.

The role of the family (Transparencies for Presentation)

- Giving emotional support, love and care.
- Helping with daily chores at the time of sickness.
- Providing relief for minor illnesses.

Helping him to handle the fear of death and make plans for the future.

How awareness helps the family to deal with the issue (Transparencies for Presentation)

HIV infection and AIDS are often associated with a high-level of stigma, fear and lack of acceptance of those afflicted. These feelings make it difficult for families to provide care at home; but awareness helps in decreasing their fear and stigma.

- Understanding the facts and issues related to HIV/AIDS will help them to accept people infected with HIV/AIDS with empathy. They will be less afraid and prepared to provide care and support to infected people and this in turn will reduce stigma and discrimination.
- They will know how to identify and manage common AIDS-related health problems, recognize danger signs and learn when and how to seek more help.
- Family will learn to protect themselves from infection.

Activity 1 - Importance of home care

Purpose

To sensitize participants to the importance of home care with full awareness of the blocks to be overcome and the resources to be explored to achieve the desired aim.

Materials needed

Instruction sheet

Chart paper

Art supplies

Time needed 60 minutes

Methodology Maximizing benefits of home care

Steps

1. Ask the participants to divide themselves into three groups.
2. Explain the rationale and the purpose of this activity to the group.
 - It is a planning exercise done in an informal, creative, and Interactive way.
 - Make full use of personal knowledge of the problems / impediments Which may affect appropriate home care.
3. Ask each group to take a chart paper and to draw, on the extreme left side, a "family space" (a square representing the problems of the family and immediately below that, a circle representing the problems of the HIV infected individual in their families). Both the "spaces" should be labeled 'NOW'.
4. The group should define very clearly the problem represented in the "NOW" situation by asking itself questions such as:

For family

- What is my attitude towards providing care to the patient?
- How does it affect my feelings?
- How is my life stigmatized or marginalized?
- What kind of problems do I encounter from my children, his relatives, my relatives, neighbors and friends?
- Why has it happened to me? Do I deserve this punishment?

For HIV infected individual

- How is my life stigmatized or marginalized?
 - Can anyone understand my feelings - my pain and suffering; fear of death; uncertainty about the future?
 - "I feel guilty and regretful for what I have done. Will my family ever understand my feelings and forgive me"?
 - If I die, what will happen to my wife and children? Will society and extended family accept them or continue to discriminate them?
5. The group should then turn its attention to the right hand side of the chart paper. Here they need to visualize and depict graphically in some way their VISION of how the NOW situation could change for the better within a given span of time (say by the end of two years). This future space is to be called, MBC i.e., Maximizing benefits of home care. There will be 2 MBCs - one square and 1 circle.
 6. Each group should now draw lines connecting the unsatisfactory "NOW" situation on the left to the desired goal on the right. The lines can take any shape they wish. They can be straight or curved, single or with branches, level or with ups and downs; they can play around with major obstacles or use tunnels and overpasses to speed ahead.
 7. In creating their roadmaps, participants should clearly indicate what specific hindrances they are likely to encounter along the way - impediments (practical, attitudinal and conceptual barriers) which obstruct changes. Similarly, all available or potential resources should be identified on the map with indication of their source and potential impact.
 8. Upon completing their maps, each group should prepare a short written statement to accompany their maps, listing some of the problems and specific actions to deal with those issues.
 9. At the plenary session, which concludes this activity, all three groups in turn should "visit" each of the 3 sites to study and comment on the maps at closer range and to draw joint conclusions.

Facilitator Notes - A sample MBC chart

Now	MBC - Vision
<p>For the family</p> <p>Anger, despair and frustration</p>	<p>For the family</p> <p>Empathetic understanding of friends and family and help towards appropriate expression of feelings.</p> <p>Emotional and spiritual support through family support groups.</p>

<p>Lack of Information about transmission leading to fear of getting infected.</p> <p>Financial problems.</p> <p>Rejection by family members and neighbors.</p> <p>Too much dependence of the client on the spouse.</p> <p>Extra burden to run the household, hence no time.</p>	<p>Empowering them with knowledge.</p> <p>Financial support.</p> <p>Acceptance by the community.</p> <p>Opportunities for reintegration into the community.</p> <p>Creating a climate wherein the client can take care of himself.</p> <p>Physical help from neighbors.</p>
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For the patient	For the patient
<p>Fear of transmitting the disease.</p> <p>Guilt and shame.</p> <p>Depression, rejection and isolation.</p> <p>Worries about future of family members.</p> <p>Lack of employment and financial problems.</p> <p>Rejection by neighbors and community members.</p> <p>Non availability of nutritious diet and medicine.</p> <p>Tendency towards relapse.</p> <p>Fear of death.</p>	<p>Availability of condoms and creating awareness.</p> <p>Opportunities to make amends.</p> <p>Participation in household activities.</p> <p>Involvement in recreational activities.</p> <p>Making future plans in consultation with family/ extended members.</p> <p>Taking up employment which can be done at home.</p> <p>Financial support.</p> <p>Acceptance by the society and opportunities for reintegration.</p> <p>Availability of nutritious diet and medicines through NGOs and GOs.</p> <p>Taking sobriety as the priority and attending self-help groups.</p> <p>Counselling services provided at home.</p> <p>Emotional support from family and extended members.</p> <p>Counselling to face the realities of life.</p>

Problems	Actions
Spread of infection	Availability of protective gear like gloves, condoms Creating awareness about universal precaution.
Fear of death	Availability of elders and religious persons for providing spiritual counselling.
Financial crisis	Making people know about the resources available in the community. Self employment through NGOs.
Social stigma	Creating awareness in the community by NGOs and religious organizations for the rights of HIV affected individuals and family members.
Isolation	Through sensitization, enabling the community to accept and permit integration.
Tendency towards relapse	Availability of counselling services at home.

The family needs to know the following (Transparencies for Presentation)

- What HIV and AIDS are?
- How HIV is transmitted (and how it is not transmitted)?
- What they can do to prevent the transmission of HIV?
- What problems or symptoms are commonly associated with AIDS?
- How to recognize and take care of emotional and physical problems caused by HIV infection and AIDS?
- When in need of help, where to go for shelter / medical help / counselling / vocational training / spiritual guidance?
- How to lead a normal and satisfying life.?
- What their legal and human rights are?

The care giver needs

- Emotional and spiritual support to deal with day to day problems.
- Counselling to deal with death of the near one.
- Practical advise about nutrition, hygiene and preventive health care.
- Basic nursing skills to take care of bed-ridden family members.
- Help with domestic chores and towards meeting the needs of children.

Activity 2 - Understanding the infected and the affected

Purpose

To enable the participants become aware of the various needs of the infected and the affected individuals.

Materials needed

Question sheets

Flip chart

Marker pen

Time needed 30 minutes

Methodology 'Brainstorming'

Steps

1. Divide participants into four groups.
2. Read out the following questions
 - (a) There are some simple things the family members can do to help someone with AIDS feel comfortable at home. It can be physical or psychological support. Imagine you are going to give the family a few basic tips. What would you request the family to do?
 - (b) The family members have to protect themselves while providing care to the AIDS victim. List the precautions the family has to take.
3. Give question (a) to 2 groups and question (b) to 2 groups.
4. Ask them to list out as many points as they can. Each group discusses for 15 minutes and 1 person from each group presents the details.
5. The trainer adds any other detail which they have left out.

Providing Physical and Emotional Support (Transparencies for Presentation)

Physical support:

- Provide nutritious and balanced diet.
- Ensure prompt medical help if the patient has opportunistic infections. In case of illnesses like tuberculosis, make sure he follows the treatment regimen.
- Keep him comfortable by tuning yourself to his needs. Many people feel shy about asking for help, especially help with things like using the toilet, bat drinking water, soap, towels, extra blankets and other things the person might need close by so that these things can be reached from the bed or chair.
- If the person has to spend most of his time in bed be sure to help him change position often.
- Keep the home clean, looking bright and cheerful.
- Shaving, eating.

Recognize and meet emotional needs:

- Respect his independence and privacy and treat him like a normal person.
- Keep him involved in his care. Allow him to take care of himself and make decisions. This makes him feel in control.
- Provide him opportunities to be of help - filling up water, dusting, helping children in their studies etc. Everybody likes to feel useful.
- Involve him in common family activities like watching television, praying, playing carom, discussing current events etc.
- If the person is mobile, take him out to the park, beach, temple, music performance / social functions.
- Come to an agreement about the people whom you are going to inform about the HIV status. Invite those friends over to visit. A little socializing can be good for everyone.

Being supportive:

- Having AIDS can make a person angry, frustrated, depressed, scared, and lonely, just like any other serious illness. Listening, trying to understand, showing your care, and helping them work through their emotions are vital parts of home care.
- Touch them. Hug them, kiss them, pat them, hold their hands to show that you care. Some people may not want physical closeness, but if they do, touch is a powerful way of saying you care.

How the family can protect itself (Transparencies for presentation)

- Wash hands in running water with soap for 30 seconds. Wash palms, fingers, back of hands, knuckles, thumbs, finger tips and wrists (picture provided).
- Use a piece of plastic or paper, gloves or a big leaf to handle soiled items. After using, the gloves should be removed, taking care that the exterior surface of the glove does not come in contact with the hands or the body. The used gloves should be immersed in household bleach.
- If blood from an infected person is spilt, then it should be immediately cleaned with a disinfectant such as bleaching powder.
- Protect abrasions and cuts in the skin by water proof dressings / bandage / any open wounds they may have.
- Use apron or gown when soiling is expected.
- Use a mask when splashing is likely to happen.
- Not to share sharp skin-piercing instruments / toothbrushes, razors, needles, or anything else that can cut or come into contact with blood.

It is necessary to emphasize that HIV is not spread during normal social contact. However, it is important to avoid other common infections that are spread by normal social contact, such as diarrhea and respiratory infections.

Activity 3 - Working through grief

Purpose

The aim of this exercise is to enable participants understand emotions experienced when a person faces any loss, and develop empathy.

Materials needed

Nil

Time needed **20 minutes**

Methodology 'Role play'

Steps

1. Ask for six volunteers. Let them form three pairs.
2. One person has to share any loss which he has really experienced in his life. It can be anything- loss of health, loss of a close relative, loss of money / job etc. The loss has to be real. He has to share the feelings he experienced and the coping methods he used to deal with the loss.
3. The other person will act as counsellor and help him open up with his supportive responses.
4. When the 3 pairs finish, the rest of the participants should give their feedback about the counsellor - whether his responses were supportive or not and also about the client - whether some other coping method also could have been tried. (Refer Chapter on Counselling for supportive and non-supportive responses).

Providing care for someone who is dying (Transparencies for Presentation)

Most people prefer, or are forced by circumstances, to remain at home. What are the goals of caring for someone who is dying?

- Give physical and emotional comfort.
- Respect requests, for example not wanting to see visitors.
- Listen and allow the person to talk about how he feels. Accept the person's feelings of anger, fear, grief and other emotions.
- Assist him in grieving for, and coping with the sense of loss he is experiencing.

- Help him prepare for death; this may include making a will, tending to relationships in the family or friends and arranging for the transfer of responsibilities.
- Openly talk about how the family propose to manage after his death. This will reduce his anxiety towards family's well being.

Additional Information

Prepare for death

Talk about death if the person wishes to. Many people feel that it is not good to talk about the fact that someone is going to die, as if mentioning death is a wish for death. But by discussing death openly, those around are helping him prepare for death. It may take great courage to talk about it but it can be a big help for the person to feel that his concerns are heard, that his wishes will be followed and that he is not alone. **To avoid talking about death is a form of denial.**

One of the most common worries is for the future of the children in a family. People may fear that their children will be hungry or lack money for school fees after they have died. Begin planning with relatives or friends for the future of the children. It will ease such worries if the person knows that suitable arrangements have already been made.

How does the community worker help the family after the death?

Immediately after a person is dead, the family may need help to grieve or to arrange practical matters. You can offer this by listening to them. You can also assist them with the funeral arrangements in accordance with their rites and customs.

The family may face several practical difficulties after his death. These may include, rejection or withdrawal of support from husband's relatives, getting a job and becoming financially independent, relocating residence, playing the role of the father and the mother to the children, protecting the children from stigmatization and so on. Giving them a patient hearing and providing practical guidance during this painful time will help them manage their lives better.