Home Care of Persons with AIDS

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THE Existence of human beings beyond next century is threatened by many maladies including increased incidence of HIV and AIDS. The WHO estimates that a total of about 2.5 million AIDS cases have occurred globally. The intelligent forecasts also show that by 2000 AD majority of the AIDS cases worldwide will be the most vulnerable group in the community - women and children. The Indian scenario is also not different from the international picture.[1]

The home care of persons with AIDS is an absolute necessity of present day. The following arguments point towards the importance of home care.

The total number of persons with AIDS in India up to 31st October 1995 was 2095 (NACO Report). The unreported and underreported cases will constitute the major part of iceberg. The total number of hospital beds in India at the end of the Seventh Plan (1990) was 810548. The increase in number of persons with AIDS will be much more if we consider the seropositivity rate of 7.70 per thousand in India (NACO 1995). So the availability of bed per population (0.7 bed/1000 population) is negligible when compared with the HIV infection prevalence which must be much higher today.

The manpower available to take care of persons with AIDS is also very less. The World Report 1993 states the number of doctors and nurses per thousand population in India are 0.41 and 0.43 respectively.[7] This negligible manpower is totally inadequate to take care of persons with AIDS in institutions. One study conducted in Zambia reported that upto half of the patient days in medical wards of a central hospital were accounted for by people with HIV related illnesses.

The care of the persons with AIDS differs greatly from other illnesses. The major differences are[12] that even though AIDS can affect people in all age groups, the majority of persons will be young, the occurrence of multi-system disease with the co-existence of many physical, psychological and economic problems — that is zero positive health. They have to take a large number of drugs for a longer period of time. Most persons with AIDS know more informations about the disease and demand their involvement in planning and implementation of care. The disease is always associated with fear, prejudice, negligence and lack of compassion from society. So the social isolation of patients and family, subsequently homelessness, is another problem. The sick persons with AIDS may improve and make it difficult to identify the terminal phase, that is AIDS is a chronic illness with acute treatment being required intermittently over a number of years. Patient may become unconscious for a week or longer. So the need for long term supervisory care at home becomes a necessity.

Community Nurse's Role

Epidemiological investigations including effective screening in the initial stage is possible if Nurses make home visits. Studies show that more symptoms are reported by patients than doctors. Community nurse can play a major role in dealing with the symptoms that are of particular concern to patients, and which affect their quality of life (e.g. sleeping pattern).

The burden on health service in the country is increasing. One study report shows that in 1992, developing countries spent a total of US dollar 340 million on health care of people with HIV, and this is one-third of national health budget. The economic burden of family and community can be reduced considerably by home care and by supervision of care given by others.

Community Nurse can reduce the risk of transmission to family members or primary care givers by proper education and supervision. The patient and family members feel comfortable in their own environment and are free to participate in care. The vocational guidance and modification of job can be done in their own shelter which reduces economic problems. Nurses are able to observe the resources in home and care can be modified accordingly. She is able to observe the care given by family members.

Home care of persons with AIDS reduces the chance and risk of hospital acquired infections. Institutionalised care of patient with AIDS is a risk for other patients in our health care delivery setting, because of inadequate resources. Person with AIDS is also at a higher risk of nosocomial infection because of reduced immunity. The chance of developing more virulent and resistant organisms like resistant mycobactereum tuberculi also will increase with institutionalised care of patients with AIDS. The problems faced by affected families will be beyond any description especially if the affected person is the breadwinner of family and his or her spouse has to stay in the hospital to look after the patient. The problems of neglected children and other dependent population is also another entity. Hospital care is not always available or accessible for them. A community health nurse can manage very easily the HIV - related infections such as diarrhoea, cough

and fever. Cytomegalo virus retinitis is common in HIV/AIDS patient and this results in rapid and progressive blindness without treatment. Treatment is usually given through a central line for six days in a week for life. Most studies to assess people's need show that their greatest problems are poverty and lack of medical care and not HIV illnesses.

The non-governmental and private agencies working in India are focusing mainly on health education campaigns and institutionalised care rather than the home care. There are only very few examples to show like Yaogioto (YGR) Foundation in Chennai, which focuses on day care centres and home based short term care.[1] Lack of well planned home care programme for persons with AIDS is an area of concern.

Home-Based and Community-Based Care Programmes

Home care of persons affected with AIDS is not an easy task. A community health nurse alone is not capable to render this care. A governmental or non-governmental agency is needed to sponsor the resources. An effective team work and close link with different departments is highly indicated to take care of these persons.

Home care also relies on the family's ability to provide care, nutritious food and medical treatment.

The Aims of home-based or community-based care programme[8] are:

1. Make sure that all the patients are getting adequate nursing care, economic, emotional, social and spiritual support.

2. Train volunteers, health workers, family members and persons with AIDS regarding nursing care and infection control.

3. Reduce pressure on the hospital's inpatient department.

4. Mobilise resources to identify and to take care of persons with AIDS who are not using health services.

5. Plan measures for economic support.

6. Motivate volunteers and health workers to make frequent home visits.

7. The care of persons with AIDS should be included in the HIV education programmes.

Team Members

Community health nurse should assume an important position in the health team. All the health workers and volunteers should be trained to take care of persons with AIDS. A referral to clinic is needed for expert medical treatment, laboratory tests and to make use of the service of social workers and counsellors. Involvement of people from the community like local leaders, teachers, youth group, traditional healers, Red Cross people and other members of non-governmental organizations, in care programme, is necessary. Moreover the commitment of family members, friends and neighbours is a major factor in the care of persons with AIDS. Community nurse should maintain confidentiality if the person requests, but every effort for complete confidentiality may cause more fear and stigma for the disease in the community.

Starting HIV-infected anonymous group just like Alcoholics Anonymous groups also can be thought about, as comparatively well patients will be able to take care of sick patients without much hesitation.

Direct Care

"Caring for people with HIV infection of AIDS is not difficult if common sense is applied. No special training is required - simply first class clinical competence, a willingness to learn and to understand, and a desire to care with compassion". (Elliort, 1987, p. 106)

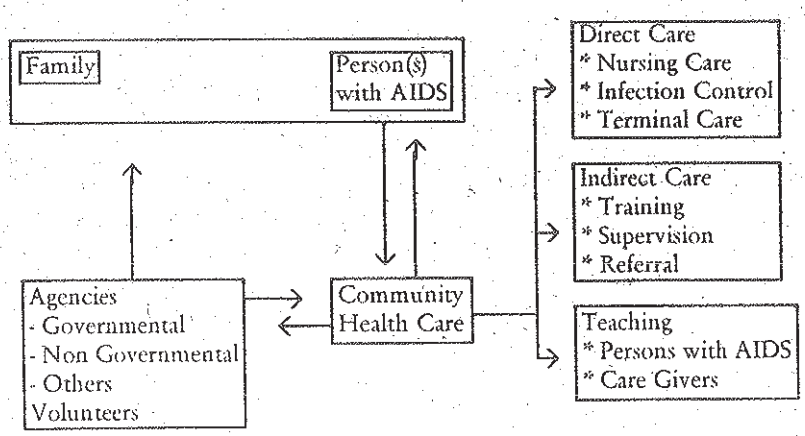
The principles of caring persons with AIDS in home are the same as any patient, but with some modification. Follow all universal precautions when there is a chance of contact with blood or body secretions. Agency has to prepare adequate standing instructions to care for persons with AIDS effectively. Over and above direct care, we also have to teach the patient, family members and other care givers about the care.

1. *Nutrition*: Nursing diagnosis: Altered nutrition less than body requirement related to nausea, vomiting, loss of appetite, dysphagia, diarrhoea.

(A) Small, frequent but complete diet is advisable by considering a person's preferences. The mixture of lemon juice, salt and ginger juice without water increase appetite and taste.

(B) Teach family members to keep the person away from cooking smell, cook small amounts of favourite food

A Model for Caring Persons with AIDS



often and watch for dehydration. Add sugar to ginger juice and drink if indigestion.

(C) Naso gastric tube feeding sometimes in the acutely sick stage leads to opportunistic infections with cryptosporidium which results in water diarrhoea and malabsorption. So total parenteral nutrition is necessary in that stage.

(D) Chewing little bit of cumin is effective for nausea. Smelling asafoeteda and garlic prevent vomiting. Drinking ocimum juice with cardomum powder is an antiemetic.

2. *Skin Care*: Nursing Diagnosis: (i) Impaired skin integrity R/T cutaneous manifestation of HIV infection (ii) self care deficit R/T fatigue, activity intolerance.

(A) Wash the open sores with soap and water. Saline can be made in home by adding salt (10 paise heap) to 200 ml of boiled water which is ideal to clean sores. Keep the sores dry. Dressings can be made from clean old clothes.

(B) If the person has diarrhoea, wash the area with warm water and soap after each bowel movement. Keep the skin clean and dry.

(C) For itching or irritation, rub calamine lotion on skin as required. Rub vaseline or oil for dry skin. Add potassium permanganate crystals in one litre of clean water and this solution can be painted on sore area. Use gentian violet as a mouth wash for oral thrush and for vaginal thrush, apply once daily for three days. Applying turmeric paste or sandal paste over boils is effective against boils.

(D) Take measures to prevent bed sore. Refer if culture of sores is needed.

(E) Paracetamol or aspirin tablets may be necessary for the pain associated with the rashes, especially which is secondary to herpes zoster.

3. *Care of Mouth and Throat*: Nursing Diagnosis: Altered oral mucous membrane R/T compromised immunity, neglected oral hygiene.

(A) Encourage to maintain maximum oral hygiene.

(B) Rinse mouth with warm water with a pinch of salt or lime with salt, especially after food.

(C) Eat soft, non-spicy food.

(D) Suck a piece of tomato or lemon for thrush if it is not painful.

(E) Apply gentian violet for the sores on lips and mouth. Make the common alum and honey to a paste and apply over gum for toothache.

4. *Pain*: Nursing Diagnosis: Alteration in comfort (pain) R/T altered skin integrity, chemotherapy, diarrhoea.

(A) Gently massage or rub sore muscles using oil.

(B) Chemotherapy as advised and local remedies like applying mimosa leaves paste over the painful area. Applying heated rice brand using a cloth over painful area if comfortable.

(C) Comfortable position

(D) Watch for side effects of drugs like myalgia from AZT and headache, nausea, gastro intestinal disturbances from other drugs. Pain associated with peripheral neuropathies are difficult to control. For headache, apply mimosa paste or mustard paste over forehead.

(E) Use of diversion and alternative therapies like massage, aroma therapy, spiritual or pranic healing, homoeotherapy, acupuncture, acupressure, hypnosis, vitamin and mineral tablets, herbalism etc.

5. *Fever*: Nursing Diagnosis: Altered body temperature (hyperthermia) R/T infections.

(A) Wash body in cold water and dry with clean cloth.

(B) Encourage to drink more fluids.

(C) Tab paracetamol or aspirin one or two four hourly.

(D) Refer if any infection is suspected, like malaria, tuberculosis etc.

(E) Watch for dehydration

(F) Remove thick clothings and blanket.

(G) The boiled juice ('Kashayam') of olden landia and skin pealed cyperus rhizome is effective to reduce high fever.

6. *Tiredness, Weakness*: Nursing Diagnosis: Activity intolerance R/T fatigue, malnutrition, hypoxia

(A) Rest as often as needed.

(B) Find ways to make activities easier (e.g. sit to wash rather than standing).

(C) Get help and support for daily activities. Tender coconut water supply natural glucose and relieve tiredness.

(D) If the person cannot get out of bed at all: (i) Gently move the arm and legs several times a day, (ii) Turn him her from one side, to the back, to the other side, every few hours, (iii) Put him/her on a pot every few hours or more often if needed, to empty the bowel or bladder, (iv) Keep the skin clean and dry, (v) Try general measures to increase sleep. Drinking ashgourd juice mixed with one spoon honey after dinner promote good sleep.

7. *Cough, Difficulty in Breathing*: Nursing Diagnosis: Altered breathing R/T cough; lung infection

(A) Cover the mouth while coughing and wash hands after that. Spit into a paper box or a small pot with water which can be burned.

(B) Drink more fluids. Add honey to lemon juice and drink frequently. Swallowing sugar candy and pepper powder mixture also reduces cough.

(C) Provide pulmonary care like deep breathing, coughing, vibration, postural drainage every 2-4 hours. Make the patient to sit up when possible or support with pillows.

(D) Moderate use of cough syrups may not help always. Refer if cough lasts for more than three weeks and we

suspect tuberculosis or pneumonia.

(E) Sit with the person, because difficulty in breathing is frightening.

(F) Discourage smoking

8. *Chronic Diarrhoea*: Nursing Diagnosis: Diarrhoea R/T enteric pathogens, infections, chemotherapy.

(A) Encourage to drink more fluids. Help the family members to prepare oral rehydration solution in home (Salt sugar solution).

(B) Continue to eat solid food, and fluids.

(C) Wash and dry the skin after defecation.

(D) Watch for signs of dehydration.

(E) Absorbents like Kaolin or antimobility drugs (lomotil) can be used to reduce cramps and pain temporarily, but this can prolong illness by delaying the elimination of organisms and toxic products. It is contra indicated for children below 5 years. Antibiotics and antifungal agents if infection is suspected. A combination of black tea and lime or ginger juice and salt is found to be effective against diarrhoea.

(F) Avoid bowel irritants like foods high in fat, fried foods, raw vegetables, fruits, nuts, onion, spicy food and foods of extreme temperature.

9. *Confusion, Fear Anxiety*: Nursing Diagnosis: Altered thought process R/T impaired memory, confusion.

(A) Be with the person, listen to him/her and talk.

(B) Get the help if any professional help is needed

(C) Let the person know that their feelings are normal.

(D) Try not to leave the person alone if the person is confused. Move away the dangerous objects and medicine.

Infection Control

Potential for infection R/T reduced immunity

(a) Hand washing is very important before and after caring the person, before cooking and eating. Hands have to be washed in running water with soap atleast 30 seconds with thorough rubbing. Prevent dry skin by applying oil.

(B) Maintain good hygiene in home. Kitchen and bathroom surfaces should be cleansed regularly with disinfectants in order to prevent fungal and bacterial growth.

(C) Follow universal precautions when soiling, splashing or contact with blood or body fluid is expected. Check skin integrity by rubbing alcohol or spirit before starting the duty each day. Protect the abrasion and cuts in the skin by water proof dressings.

(D) Use of gown, mask, goggles are needed when spalsh of blood or body fluids is expected like handling a bleeding patient or attending a vaginal delivery in home. Water resistant materials like plastic or rubber can be used if gown is not available in community bag.

(E) Body fluids or blood stained body fluids may spill during caring. Cover the whole spillage with absorbent material like paper or cotton. Completely cover the spillage with 1% household bleach or 1% sodium hypochlorite solution for 10 minutes. Remove the soiled material using rubber gloves or a modified forceps. Burn or bury deep the soiled material. Clean the area with neutral detergent and allow to dry.

(F) Materials contaminated with blood, pus or body fluids and the excretions or secretions like sputum, vomitus, faeces, urine should be mixed with household bleach and buried deeply or flushed in a bit hole latrine safely or burned.

(G) Soaking linen and clothes contaminated with blood or body fluids in disinfectant solution alone will not help because of the inability of the solution to reach the virus and the blood may inactivate the disinfectant. So leave the linen in a disinfectant solution which releases free chlorine (2% solution) for 30 minutes and then wash thoroughly using detergent and warm water. Dry it under sunlight. Iron the clothes if possible. Household bleach which is suitable for linen can be prepared by dissolving four table spoons of bleaching powder in two litres of water or by dissolving one bleach tablet (Halazone tablet) in one litre of water.

(H) Instruments used for the purpose of caring also can be washed and disinfected in a similar way. Disinfectants like 1% iodine compounds (e.g. providone, betadine), 70% ethyl alcohol, 1:1000 savalon, 1.5% dicloroxy lenon (dettol) can be used for this purpose. Denatured spirit is ideal for rubber tubings and other rubber goods.

Moist heat is effective for sterilizing instruments. Boiling for 20-30 minutes (100° c) is enough for instruments and equipments. Pressure cooker is ideal if temperature at 121° C is desired which has to be used for 20-30 minutes

(i) Persons with AIDS and their sexual partners are strongly urged to avoid exposure to body fluids during sexual activities.

Terminal Care

The presence of family members and other significant persons including spiritual advisors are also very important during the terminal care.

(A) Keep the person as comfortable as possible by providing pain medications to resolve pain. Help the person to relax by giving back rub, body massages and serving tea. Keep the person clean and dry.

(B) Help the person to be as independent as possible. Accept his or her requests, decisions, feelings and allow to grieve.

(C) Help the person and the family to prepare for death. Clear their doubts and help them to make future plans.

Even though indirect care and

health education are two different major areas of community nurses' function, here these aspects are discussed with reference to direct care. Community health nurse, along with her agency has to plan for community care of persons with AIDS in these three broad areas and the implementation of planned responsibilities takes place simultaneously.

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11. NACO (1995). *HIV/AIDS in India (Statistics)*. Ministry of Health & Family Welfare, New Delhi.

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Agenda Items: TNAI Meetings

Members are requested to send their agenda items separately for the TNAI meetings to be held at Chennai during September 20-27, 1997 latest by July 15, 1997 as follows:

* TNAI Executive Committee Meeting
* TNAI Council Meeting
* House of Delegates Meeting
* Concurrent Sectional Meetings: Nursing Service Section, Nursing Education Section, Public Health Nursing Section and Nursing Research Section.

Each Agenda item should be either self-contained or accompanied with explanatory notes. Only those items may please be included which require national level discussions/decisions.

Secretary General, TNAI