Caring in Alzheimer's Disease

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FORGETFULNESS appears to be a common feature among the elderly and for many years it was believed that the loss of memory–Senility–was part of getting old and it was considered a normal part of ageing. Forgetfulness, now described as Dementia can be due to Alzheimer's Disease (A.D.), which is also called the death of mind.

The A.D. is a cruel disease which not only destroys a person's mind but also robs him or her of memories. It is a progressive degenerative disease which attacks the tissues of the brain and results in impaired memory, thinking, behaviour and emotions. The process is gradual and is often associated with loss of the individual's ability to care for himself or herself.

Alzheimer's Disease was first described by a German Psychiatrist and Neurologist, Dr. Alois Alzheimer, in 1906, on a middle-aged patient suffering from Dementia. It was after the death of the patient, by autopsy, that Alzheimer was able to demonstrate abnormal changes in the brain.

Brain cells that function normally produce special chemicals called neurotransmitters which help send signals throughout the body to ensure its proper functioning. In patients with Alzheimer's Disease the brain produces a decreased amount of some of these chemicals which results in proper functioning of nerve cells involved in memory, reasoning and judgement.

Research Finding

Over the past 50 years careful research was able to show that this condition occurs more commonly in the elderly than in those in middle age. It affects 5-10 per cent of those over 65 years of age and more than 20 per cent of those over 80 years. As the proportion of people over 65 years is gradually increasing more cases of A.D. will accumulate and it may turn into a greater public health problem. In the United States and other western countries A.D. has become the fourth leading cause of death (after heart diseases, Cancer and Stroke) among adults around the age of 75. A.D. is becoming a problem in developing countries as well.

In India, according to the 1981 Census, out of a total population of 685.2 million, 44 million people were aged 60 years and over. In the 1991 Census the number of elderly was about 55.3 million, i.e., six per cent of the total population of 844.3 million. The number of people over 60 years is expected to touch the 60 million mark by the end of this century.

Although there is no exact figure of A.D. patients in India recent surveys in south India report that the rate of Dementia of the people over 60 years varied from 2.7 per cent to 3.4 per cent, a figure almost identical to the western countries. The author of the study observed that all patients with Dementia were looked after by their own families, so family members need to be prepared by the health team by giving knowledge about A.D. The role of the Community Health Nurse in educating relatives for the care of A.D. patients is vital. Nurses also need to keep their knowledge about A.D. up-to-date and develop skills needed for the care.

In Alzheimer's Disease the principal clinical manifestation is Dementia but many other problems cause Dementia, viz., Strokes, Huntington's Disease, Parkinson's Disease, Pick's Disease. Dementia is also related to head injury, metabolic changes, poor nutrition, drug interaction, thyroid dysfunction, high fever and depression. Dementia may be reversible if detected early and treated. But dementia in Alzheimer's Disease can not be treated.

The A.D., usually, has a gradual onset. Problems in remembering recent events and difficulty in performing familiar tasks are the early symptoms. In the initial stages short-term memory of recent events is affected. A patient often forgets what he had for breakfast or who came to visit him the evening before. As the disease progresses memory for the past events, i.e., long term memory, becomes impaired. The affected person is unable to recall significant past and personal information. He forgets where he was born, when he got married or when retired. During the later stages he can not even give his correct address.

Although memory disturbance is the most prominent feature, A.D. affects all areas of intellect and personality behaviour and causes disorientation, impaired judgement and loss of language skills. In some cases the memory problem may not be so apparent but a change in personality, mood or behaviour may be the first presenting feature: an elderly gentleman making sexually indiscreet remarks, or a timid woman becoming aggressive and quarrelsom. The initial stage lasts 2 to 3 years.

In the second stage further deterioration of all the abilities takes place with a decline in every day skills, speech, reading, writing and further memory loss. A patient loses tract of time and if he or she goes out

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of the house he or she has difficulty in finding the way back. He or she does not recognise relatives, friends and is even unable to recall their names. Gait disturbances start appearing and a person shuffles feet while walking. Personality changes take place and hallucination and delusions occur. Later on, bowel and bladder control is lost.

In the third stage symptoms become serious. The patient turns vegetative and is totally bed-ridden. One becomes apathetic and has epileptic fits. Within 10 to 15 years a person becomes totally disabled. Death occurs due to Pneumonia or recurrent illness. Prognosis is fatal. The average time from onset to death is eight years but ranges from 3 to 20 years.

The Causes

Alzheimer's Disease causes are still unknown. Hypothetical theories have been pinpointed. Some say slow virus disease or high aluminium levels cause it. Others say problem in the reduced levels of production of certain brain chemicals is the cause, as these chemicals are necessary for normal communication between nerve cells. An autopsy of a brain affected by Alzheimer's Disease showed the presence of fibre tangles within nerve cells (neurofibrillary tangles) and clusters of degenerating nerve endings (neuritic plaques) in areas that are important for memory and intellectual functioning.

Alzheimer's Disease may start at the age of 40 years but achieves its peak at around 70 to 80 years. There is no specific cause for A.D. and it is not contagious.

Investigation

There is no single diagnostic test for Alzheimer's Disease but to rule out any other disease it is essential to have a comprehensive medical examination which involves complete health history, physical examination, neurological and psychiatric assessments, blood work, urinalysis, chest X-ray, electroencephalography (EEG) computerized tomography (CAT Scan), Electrocardiogram (ECG) and Magnetic Resonance Imaging (MRI). Although MRI and CAT Scans do not provide information on A.D. yet these are necessary to rule out head injury or brain tumours.

Such an evaluation is essential to determine if Dementia is the result of a treatable illness. Once the diagnosis is confirmed the psychiatric health team can work with the family to explain the nature of illness and prognosis to the relatives. It will help to clear doubts about the behaviour of the patient, so they will stop blaming the patient for laziness or obstinacy. They will realise that the patient's constant demands, abusing or embarrassing behaviour is due to A.D. This will improve the ability of the family members to cope with the illness.

Treatment

Until now no specific medicine is available for A.D. A drug called Tacrine is used in the Western countries for mild or moderate cases, but the drug causes liver damage, so it needs to be used cautiously. Tacrine is not available in India. Psychiatric consultation regularly will help in the management plan to deal with behaviour problems like restlessness, wandering mostly at night. Anti-depressant drugs will help in depression, delusions and hallucination. Prescribed drugs should be given regularly.

Care

In India for Alzheimer's Disease patients are still looked after by the family members. Even the facilities for keeping the long-term patients in nursing homes are not available like in Western countries, so family members need to be prepared for meeting the basic needs of the patients.

- Relatives of A.D. patients can be encouraged to form support groups, who meet regularly to share their problems with others in the same plight.
- Alzheimer's Associations may be formed in all the districts to produce the related material to educate the support group, health workers and the public.
- The Trained Nurses' Association of India, with the assistance of World Health Organisation, can conduct workshops and seminars for Nurses for the caring component as the Community Health Nurse has to be prepared to work with the family members and to guide them to develop skills to look after the A.D. patients.
- Physical exercises, social activities and good nutrition, calm and well-structured environment help A.D. patients to continue functioning as long as they can.

Precautions

- Dangerous drugs and electrical appliances, sharp instruments or any dangerous item which can cause injury to be kept out of reach of the patient.
- Locks and bolts in the bathrooms to be removed to avoid the patient locking himself.
- For the safe wandering in the house remove objects which can cause injury.
- Scooter and car keys to be kept out of reach of a patient.
- At night in the bedroom and bathroom keep a dim light on.
- A band with patient's name, address, and telephone number should be tied on his or her arm.
- Keep a watch on the patient so that he or she may not slip out of the house alone.

An Alzheimer's disease patient will need constant care, so family members need to share the work among themselves, so that care providers' health is not affected.

Care givers need to plan the activities for an A.D. patient including both active and passive activities. Some activities patient should be able to perform alone and some in the company of others. Activities can help to lessen undesired behaviour such as wandering or agitation and also enhance his or her sense of dignity and self-esteem by giving purpose and meaning to life.

The daily routine activities are :

- Personal care, i.e., shaving, bathing and dressing.
- Meal time activities are preparing food, cooking and eating.
- Household chores are sweeping , dusting, washing clothes, folding dried clothes.
- Physical activities are taking a walk or playing outdoor games. (An A.D. patient should not go alone outside the house).
- Social activities are talking, having tea or coffee together, playing indoor games.
- Intellectual activities are reading or solving crosswords or puzzles.
- Spiritual activities are praying, singing and creative activities are painting and playing musical instruments.
- Work related activities are typing, fixing something or making notes.
- Spontaneous activities are going out, to visit relatives or friends, or for dinner.

While planning activities the patient's ability and interest are to be kept in mind and the planner should simplify the activities and support the patient's needs.

When an A.D. patient becomes bed-ridden then the caring component is to keep him clean, dry, and regular exercises for limbs to prevent contractures and also changing his or her position often to prevent bed sores.

Taking care of an Alzheimer's Disease patient is a challenging and untiring task which needs tolerance and patience by care providers. The Community Health Nurse can play a very vital role in preparing the family members for caring the A.D. patient.

Bibliography

1. Andreoli *et al., Essentials of Medicine*, 4th Edition, W.B. Saunder's Company, 1997, pp. 799-801.
2. Robins, *Pathologic Basis of Disease*, 5th Edition, W.B. Saunders Company, 1994, pp. 1329-1331.
3. *The Tribune*, November 12, 1997, p. 13.
4. *The Tribune*, October 4, 1998.
5. Material supplied by Alzheimer's Association, Southeastern Pennsylvania Chapter, 325 Chestnut Street, Suite 1120, Philadelphia, PH 19106, U.S.A.