

DAY 1: 26 AUGUST 2013, SEMINAR ROOM 2

India International Centre 40, Max Mueller Marg, New Delhi-110001

TIME: 2:00- 3:30 PM

The Session for Care Giving & Elderly Care was taken by

1. *Chair: Dr. Anjali Raje, Executive Director, International Longevity Centre, India*
2. *Dr. Anjali Capila, Associate Professor, Dept of Development Communication & Extension, Lady Irwin College, Delhi*
3. *Dr. Sarita Anand, Associate Professor, Dept of Development Communication & Extension, Lady Irwin College, Delhi*
4. *Dr. Aparna Khanna, Associate Professor, Dept of Development Communication & Extension, Lady Irwin College, Delhi*
5. *Dr. Asha Patil, Associate Professor, SNDT Women University, Mumbai*
6. *Dr. Rohini Sudhakar, Associate Professor, SNDT Women University, Mumbai*

Topics Covered:

- a) 'Care givers for the elderly, an initiative in enhancing skills of young people' by Dr. Anjali Capila, Dr. Sarita Anand, Dr. Aparna Khanna (*Department of Development Communication & Extension, Lady Irwin College*) and Ms. Srishti Mandaar (*Annada Shankar Das Memorial Foundation*)
- b) Home Caregivers for Elderly People by Dr. Asha Patil
- c) Healthcare needs of the elderly by Dr. Rohini Sudhakar

Abstracts from this sessions are:

1. Title: Caregivers of the Elderly: An Initiative in Enhancing Skills of Young People

Author: Dr. Anjali Capila, Dr. Sarita Anand, Dr. Aparna Khanna (*Department of Development Communication & Extension, Lady Irwin College*) and Ms. Srishti Mandaar (*Annada Shankar Das Memorial Foundation*)

India is undergoing demographic transition. The Indian elderly population which stands at about 7.7% of the total population is likely to be 19% by 2050. Elderly at this stage of life need care and support for carrying out day to day activities, however due to social and economic reasons, the traditional carers that is women and young children may not be available for care giving. It makes elderly care a challenge for the families. Family is assumed to be the prime institution to

provide care and support, but the contemporary reality is that individuals/family finds it difficult to devote time to the aged due to the process of urbanization, migration for work and changing family patterns from joint families to nuclear families.

Though the medical advancement has increased the life expectancy but it has not made elderly free from illness and disability. Hence these people who gave their resources to the families and society get pushed to the periphery as their own resources are eroded. Families may therefore need additional support outside the family to provide care to the older people who may need a range of services from general care giving to professional nursing along with preparedness to meet the emotional needs. Thus, with this there arises a need for professional care giving. It is an emerging field and a livelihood opportunity for the youth. People of the younger generation can be trained in the field of elder care to meet the increased demand for trained Caregivers in homes and institutions.

Recognizing the urgent need for creating a cadre of trained Caregivers and support services for the elderly within homes/communities/institutions Annada Shankar Das Memorial Foundation initiated a process of developing a training programme for young women with low literacy skills. Lady Irwin College's Department of Development Communication and Extension took a lead in designing this training programme based on the experiences of working with young girls from resource poor backgrounds for enhancing their livelihood opportunities and evolved an integrated training program. Other Institutions and organisations which facilitated the process of designing training curriculum for the program were, Institute of Home Economics, National Institute of Social Defence, Helpage India, All India Institute of Medical Sciences, Institute of Physically Handicapped, and The Trained Nursing Association of India. A pilot was carried out to transact the module and based on the participants' feedback, the training module was revised and standardised by dividing the module for different levels of certification based on the competence/ need of the trainees. The Foundation conducts training programs to train the youth in age care related areas. Till date the Foundation had conducted various training programs and had trained people from the areas of Delhi, Madhya Pradesh & Uttar Pradesh. In its continuing efforts the Foundation seeks to network and partner with like-minded organisations, expand the coverage, undertake research studies and work towards evolving an umbrella program for holistic care of the elderly.

2. Title: Home Caregivers for Elderly People

Author: Dr. Asha R. Patil, *Dept. of Continuing & Adult Edu. & Extension Work, S.N.D.T. Women's University, Churchgate, Mumbai-20*

India has a varied and rich culture. In all the religions, care of the aged has been accepted as one of the important duties (*Dharma*) of the family. The term 'elder' has a special meaning in Indian

society, because it is related to that person's contribution to his/her family and community with perceived social values and wisdom. Taking care of an elder is a part of the traditional custom of an extended family. But, this tradition is declining in the present era as most people are adopting nuclear family set up due to various reasons. Industrialization and urbanisation has resulted in the increase of small families especially in urban areas. Life became more and more stressful which subsequently led to number of divorces and separations.

Life expectancy of human beings has increased due to advancement in clinical care leading to increase in the population of the aged people. Some of the elderly people stay alone as either they are childless or their children stay abroad or they cannot get along with their children. Some of them are forced to live alone as they are unmarried. Modernization has gradually but definitely dislodged the old people from the safe cocoon of the family. The traditional respectful position of the old and the available security within family is lost. Unfortunately, when they are in the dire need of help, care and kindness, they are pushed out of their homes.

Aging is a biological process. With age, one's health weakens, physical and mental capacities start failing. They become dependent on others even for their day-to-day life. In such a condition, they expect help from family members i.e. from their own children and/or spouse. They expect love, care and affection for which they have worked all through their life.

Many of the elderly have various degrees of disability. They are often dependent on others for their activities of daily living. Some of them remain bedridden due to various reasons. Clearly, in view of such a demographic trend, care giving to the rising number of dependent elderly is a major problem India is going to face in the near future.

Family caregivers- Concept of Family caring for loved ones is not new, especially in India. Most of these caregivers are females who spend more than 28 hours per week providing care to elderly in the family-either to their in-laws or parents. Caregiving refers to offering *unpaid* assistance either full or part time by someone. It also reflects the feeling of giving back to the loved one. It makes one feel needed and can lead to a stronger relationship with the person receiving care. Usually caregiving involves both physical and emotional care, depending on the problems faced by the elderly people.

Home care services are different for different situations such as -natural aging process, chronic illness, medical emergencies, etc. Elders are not a monolithic group in terms of their needs. A few elders need a little help to function independently at home. Others have significant health care challenges and need a fairly high level of services to be provided at home. Every care giving case is different and it is hard to know how to prepare for them.

Paid home care services are coming up in metropolis. What about the rural areas? How many people in the cities are aware of these services, this is a subject for research. **In this paper I will focus on home caregivers, discuss steps to be followed to assess the needs of elderly people, suggest precautions to be taken by the home caregivers themselves.**

Family caregivers- The prevalent nuclear family set up has increased the problem of care of elderly at home. There are very few siblings who readily want to share the responsibility of the care of elderly. Family caregivers are the ones who have enormous knowledge of the elderly persons' needs, moods, likes and dislikes. Hence, it is preferred that elders should stay at home, instead of being at an old age home. It is also less expensive. Every elderly will have different problems and the need for caregiving will differ from person to person and family to family. There cannot be a single guideline to solve all problems and answer issues on care for elderly in home. Still, following are certain common tips which will help the caregivers to perform their duties in a better way. With the right approach and resources, it is possible to take care of elderly in home for a longer time.

Role of family caregiver-When a family member takes the responsibility or is forced to take responsibility of looking after an elderly person (especially when a loved one is inflicted with a sudden illness), he or she may obviously need a lot of help. S/he should take following steps:

- Assess the needs of the elderly person.
- Prepare a plan for the areas where the elderly needs help.
- Adjust time to coordinate family responsibilities and care of elderly person, if needed hire a home care services
- Monitor services and reassess them periodically
- Manage financial issues collectively with family members and relatives
- Try to get services from government, hospitals, NGOs, etc

Let us deal with some of these points in detail.

Assessing the needs- The first priority of a caregiver should focus on knowing the needs of the elderly person. One must know elderly person's (parent's, mother-in laws, father-in-law, husband's or wife's) ability to manage independently. In professional language it is called 'Activities of Daily Living' (ADL). It includes basic activities needed for personal care and household work. The caregiver should make a checklist to assess the physical limitations and memory problems affecting the elderly person's ability to perform the routine tasks/work.

Physical degeneration is common to all of us. Normally, the elderly people develop difficulties in physical movement due to failing eye sight and hearing, arthritis, etc. A few people may have cardiac problems, diabetics, dementia, Alzheimer, etc.

Understanding physical capacity, vision, hearing, nutrition requirements (providing nourishing meals in right quality, quantity, at different intervals) is an important aspect of home care.

Home Caregivers should:

- Discuss the elder's needs with all family members
- Divide responsibilities among the family members
- Have regular dialogue with all relatives, apart from family members
- Take a break for some time and assign the task to someone responsible.

Steps to be taken by home caregivers

Learning about the fundamentals of caregiving can help the caregivers take more effective decisions. If you are a woman, traditionally the chances of your becoming the elder caregiver are very high. Following are some tips:

Information: The caregiver should put up a sheet of paper on the fridge or cupboard or a wall or at a prominent place, where it is easily visible. It should contain important phone numbers of doctors to whom one can contact in case of emergency, addresses of hospitals, medical information, etc. It should also include detailed schedule of medication for the elderly.

Home modifications and repairs: Several researches have shown that one-third to one-half of home accidents such as falls can be prevented by modifications and repairs of the homes. The facilities should be such that the elderly can carry out their daily activities independently. e.g. Alterations to the physical structure of the home, modifications in the physical set up of bath room include putting water taps at the lower level, no water logging, hangers for keeping clothes at reachable level, etc. We should make sure that everything required by them is within their reach.

Assistive technology: Certain elders require mobile devices such as walkers, wheel chairs and mopeds. They increase the mobility of individuals with disabilities. The caregivers should pay attention to the requirements of their elder and accordingly choose assistive technology. This also helps to lessen the burden/stress of the caregiver.

Finance: All the above modifications at home and the devices of assistive technology are required for elderly people but they need finance. The family members have to do some adjustments and reshuffle their budget.

Caregivers also need care

The home environment significantly impacts the morale and capacities of caregivers. Initially, they do all these things because of their feelings of love and attachment to the person. In this process the caregivers sacrifice a lot. They sacrifice their rest, sleep, social contacts and personal hobbies. It creates a lot of stress for caregivers, as they have to be always on their toes. Sometimes they are physically and emotionally exhausted.

Caregiving is really a challenging job. Caregivers always face the problem of fatigue and tiredness. In certain cases the caregivers themselves have become patients. The tasks of a caregiver are endless and the responsibilities overwhelming. Following are some **tips for family caregivers** which will help them to reduce their stress.

Prepare list: Start talking to the close relatives and friends to share caregiving responsibilities, both of present and future. The caregivers must try to collect the information about different facilities available for elderly care. One can also pay a visit to local nursing homes and see caregiving facilities. Caregivers can also find about certain organizations that can provide day care centres for elderly. Such organizations provide food; organize recreational activities, skill development programmes for elders. By going to such centres, the elders get a chance to interact with other elders, exchange their feelings and feel comfort. This way the fulltime caregiver gets some time for herself.

Training: The concept of trained home caregivers in India is yet to find its roots and be popular and accepted by common people. In a family, at least two persons should be trained for caregiving. Multiple caregivers dilute the burden of one person and help to reduce the stress of a caregiver.

Caregivers need education and training to help them manage the complex health needs of their elders. Caregivers can find the agencies which can give them long/ short term training on how to take care of elderly. Caregivers need training in a variety of areas such as special diet especially for diabetic, asthma, cancer patients, first aid, dressing of a wound, how to monitor blood pressure, blood sugar levels, etc. If possible, the caregivers themselves should undergo training to reduce stress and fatigue. All this helps the elders to get safe service and keeping the home environment healthy and congenial. The training should also include information on how to take self-care and meet one's own needs. One must learn to cope with emotional as well as physical stresses. If needed, they can learn yoga and/or certain exercises which will help them to keep themselves healthy. Caregivers should not neglect their own physical and emotional health. If neglected, it may be very dangerous and fatal.

Respite care/ Reliever- This refers to temporary assistance that allows the primary caregiver to take a break. It is generally provided by other family members. Caregivers' work often goes unseen and unsung. Caregivers also need some time for themselves. The family members must give them a break.

Old age homes- In spite of a strong will to take care of elderly at their home, sometimes it is not possible due to many reasons. In certain extreme cases, family members are forced to keep elderly in old age homes. Before sending our loved ones to old age home, one should make sure the facilities available there and the reputation of it.

Taking care of oneself: Caregivers job is not restricted to ten to five or from Monday to Friday. It is a 24x7 job. The needs of caregivers often go unnoticed. Many caregivers show signs of

sweaty palms, neck pain, headaches, chronic fatigue, weight gain or loss, etc. In addition to these physical signs, their emotional conditions also change. They become irritable due to the lack of sleep, as many times the demands of the patients keep them awake at night. They suffer from bouts of sadness, crying, frequent mood swings. This affects their behaviour. The caregivers become impulsive and over reactive.

Managing stress- Family caregivers experience considerable burden, stress and disruption of their well-being and social activities. Research shows that caregivers are more likely to suffer from depression or anxiety, diabetes, arthritis. A few develop obesity. Most often this happens because they neglect their own health.

The caregivers must learn to keep themselves healthy and stress free. One must remember that taking care of oneself is not luxury, but is a necessity of caregiver. It is very important to learn to relax, go with the flow, and accept their physical and mental limitations.

Avoid stress. Do not ignore the symptoms of stress such as exhaustion annoyance, frustration, sense of loneliness, guilt for not able to pay more attention. Take out some time just for yourself, at least for 30 minutes a day. This time should be utilized for relaxation and/or recreational purpose or going for a walk. Practice yoga, especially breathing techniques/*pranayamas*.

Understand and accept your capacities and abilities. Do not feel guilty for your limitations. Identify what you can and cannot change. Do not drink too much of tea/coffee (not more than two cups a day). Eat a healthy diet and get enough sleep.

Find someone to whom you can trust. Talk to them about your feelings and frustration. Ask for and accept help. Maintain contacts with relatives and friends. Share your experiences.

If you are a religious person, read religious books. Listen to soothing music. Watch spiritual channels on television. Meditation also helps in reducing stress. Visit your doctor regularly and do necessary check-ups, if required.

Conclusion-Caring for an elderly and/or chronic person requires tremendous energy-physical as well as emotional. The 'right' approach for caregiving differs from person to person and family to family. However, caregivers are less likely to voice their difficulties as it is seen as a part of family life. Remember, a single caregiver cannot work for a longer time. It is always advisable to involve all family members in care giving. The caregivers must take care of themselves. This helps them personally and is equally good from patient's point of view. It prevents further serious consequences. Taking break is also necessary.

India being a developing country should formulate and adopt strategies to use the available resources at the optimum level, especially for caregivers for elderly people. It should be a collaborative and cooperative effort made by all people to make the life of elderly persons happier and meaningful.

