
UNIT 2 ISSUES IN CARING

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2.0 OBJECTIVES

After completion of this unit you should be able to:

- identify various issues of caring for the elderly and discuss the options in planning for it;
- enumerate challenges of caring in patients with mental and physical disabilities;
- discuss issues of neglect/abuse in the elderly; and
- describe the need for counselling for the caregivers and respite care.

2.1 INTRODUCTION

Aging brings with it physical, emotional and social changes. There is limitation of physical mobility related to joint and bone degeneration; memory impairment and general intellectual slowing. These all contribute to conversion of the independent and active individual to a dependant and often insecure personality.

Retirement is an extremely major milestone in the life of an individual. Suddenly these adults find themselves with much more time on their hands and much less productive work. Worst is the feeling of dependency on the other members of the family lowering of self esteem etc. They also feel out of place with the younger lot and let us not forget the physical challenges as poor energy levels, changing dietary habits, insomnia and adjusting to loneliness and relative isolation can be a major factor of concern. I'm sure you may have observed this with an elderly member at home. This is the time when they need you and your caring attitude and even more important the emotional support.

In this unit, you will learn about caring—when it is needed and why it is needed. We shall also explore the various options in caring, which may be day care, home care or institutionalisation. You should familiarise yourself with the disabilities—physical, mental or social which would require an elderly to seek or need a caregivers help. You

must also know about the stress of a caregiver and the negative issues like elderly abuse and neglect associated with care giving.

2.2 PLANNING FOR CARING

In order to plan for caring, one must understand why caring is required. The carers need to be identified. They could be part time or full time carers.

When does Special Caring Start and Why

Caring is the most basic of human needs, but becomes more important in the light of special requirements of the elderly. There could be predominantly physical or mental challenges but commonly one needs to focus on both aspects of functioning.

Identifying these needs is an ongoing process but may be precipitated with a medical illness as stroke, parkinsonism, a severe depression etc. It is at such times that the caring will require more specific inputs. Among the most complicated areas of caring are the dementia's where clients have little insight into their problems and cognitive deterioration makes their intellect feeble. Science and medicine can offer very limited options—it is only rehabilitative measures which help to support and make these clients lives manageable.

Identifying the Carer's

Who has the primary responsibility for the patient ? Is this caregiver a spouse ? An adult child ? A sibling ? A friend who has assumed the caregiving role ? or is it a trained but unrelated caregiver.

The relationship to the patient is of prime importance. The caregiver's prospective long term availability and commitment to helping the patient at home are very important decisions at the outset of this process. Let us look at the various categories of care givers.

Related (Part time) Carer

In our culture as in many other eastern societies it is considered the moral duty of the family to look after their elderly. With the changing social systems and dual wage earners not all families, however much they may want to, can look after the elderly at home. Family members are more likely to be well versed in the systems at home and know the home environment and its details better than an outsider. Knowledge of patients likes and dislikes are important in the care giving process.

Because of the constraints of time, the family members who should ideally be taking care of the elderly are compelled to look for alternatives—such as employing a nurse or a full time trained caregiver.

Unrelated (Full Time Employed Carer)

There are available trained caregivers apart from the nurses, though in a small number and limited mainly to the metropolitan cities. These are people with minimum basic qualification and some experience available for both full time and part time situations. The benefits of such caregivers are:

- 1) They are trained for the purpose.
- 2) Offer full commitment of their time.
- 3) They have reasonable accountability to their employers.

The caregiver (related or unrelated) should have at least basic education. It is necessary for him or her to be able to read the names of the medicines, follow the prescribed diet chart and should definitely have knowledge of HYGIENE.

A trained caregiver in addition to the above will also be able to :

- 1) Take Blood Pressure
- 2) Give First Aid
- 3) Help with bathing/toilet management
- 4) Help with exercises
- 5) Check for and prevent bed sores

The trained caregiver should also have some basic knowledge of mental health—handle the patient's mood swings/tantrums—which could be in the form of anger, aggressiveness. More so in the case of patients of dementia and Alzheimer's—handling them needs considerable tact and patience.

At times the patients can even turn violent and physically attack the carer. The caregiver ideally needs to be a calm and pleasing personality to be able to take care of such demanding situations.

Gender Issues

Male and female caregivers exhibit many differences with respect to roles, expectations, perceptions of their situations and behaviour. The gender may affect how a caregiver expresses emotions, adjusts to changes in role, utilizes social supports, and seeks and accepts help.

Female caregivers, being more naturally suited for the role of nurturers, may find the care giving role more compatible. It has been observed that there is a preference for female caregivers for female patients and a male caregiver for a male patient. It has also been seen that where the patient is heavy and has functional limitations male caregivers are more suitable.

It goes without saying that irrespective of the gender the caregiver himself/herself be in a reasonably good state of physical and mental health and their personality should have some desirable traits like:

- 1) Sensitivity to others needs
- 2) Positive attitude/friendliness
- 3) Flexibility
- 4) Conscientiousness
- 5) A sense of humor
- 6) Ability to keep an emotional "distance" from the patient.

2.3 OPTIONS IN CARING

The best place for providing care giving is the home. However, due to various avoidable and unavoidable reasons, it may not be possible to care for the elderly at home. In such situations, day care or institutionalization may be an alternative.

Home Care

There is no environment more beneficial for a patient than his/her own home. Yes, there are situations where the home environment may not be too conducive due to family discord/friction. Commonly, the elderly resist being moved away from their familiar surroundings and objects and are only too happy if they can be cared for at home.

The home care provider can either be a related member or an unrelated paid attendant. With the latter; family members get some regular respite—a very essential component of a home care programme.



Fig. 2.1: Reassurance for periods of agitation

If and when the family decides on utilizing an external care worker they would need to keep in mind :

- 1) His/her level of training and maturity.
- 2) The carer needs to be familiarized with the patient — as an individual — with his likes and dislikes, his hobbies etc. as this will help in the rapport building.
- 3) The family as a system has to be supportive towards the carer and understand their need for respite, stress reduction etc.

Day Care

Day Care is often a kinder option. A Geriatric Day Care is a ideal solution in the sense that the elderly get an opportunity to socialize with members of their own age group, may follow a pattern of activities, suitable to their needs and limitations. They are able to get the special care, which they may require, for example as in the case of dementia's and Alzheimer's disease.

This offers the family some respite with the patient being away from home for some hours. This way the patient gets the benefit of the home environment as well as special attention at the Day Care and the family is able to, without any feeling of guilt, do their duty and get their bit of respite as well.

Unfortunately the concept of Geriatric Day Care has not developed in India as it has in the West where this is a common feature and the patients are provided with pick ups and drop off's through community participation. This is definitely an area, which probably needs more attention in our country.

Institutionalization

The decision to place a relative in a hospital is usually not reached in a day. If not precipitated by an unexpected crisis, it is reached over time. Families find it extremely difficult to place the relative in nursing home or a hospital for prolonged periods. They often say "this is something I will never do" as they feel placing a loved one in an institution is like abandonment.

Caregivers vary in their reasons for nursing home placement just as they vary in their caregiving situations.

Common reasons for placing a patient in a nursing home/hospital include:

- 1) The patients need for skilled nursing.
- 2) The doctor insists.
- 3) The caregiver cannot manage the patient's behavioural problem.
- 4) Problem with home — health aides.
- 5) The caregiver is emotionally exhausted.
- 6) The caregiver becomes ill or dies.

Institutionalization is another phase in the continuum of care where necessary.

Check Your Progress 1

Fill in the blanks:

- 1) The carer needs to be familiarized with the patient as an
- 2) Special care is required in cases like
and
- 3) and are some desirable qualities in a caregiver.
- 4) A trained caregiver should be able to
..... and of a patient.
- 5) The options in caring are,
and
- 6) is the ideal option in caring because

2.4 CHALLENGES IN PATIENTS WITH FUNCTIONAL AND COGNITIVE DETERIORATION

Let us go over the challenges in patients suffering from the dementia syndromes most prominent of which is Alzheimer's disease (AD) :

2.4.1 The Initial Stage

In the initial stages the most noticeable outward signs include forgetting names, losing the train of thought during conversation, losing a word or expression or misplacing an important item (i.e. memory & emotional disturbances).

The Caregivers concerns are centred on:

- Decreasing situations which precipitate anxiety.
- Treating the person's manifest anxiety.
- Maintaining the person's involvement in usual activities.
- Watching for significant behavioural changes.



Fig. 2.2 : Forgetfulness — a sign of initial Alzheimer's disease

2.4.2 Mild Alzheimer's Disease

At this stage the person may get disoriented and often get lost. Patient may or may not need assistance as they can often recognize familiar faces and can travel alone to familiar places and perform activities of daily living like bathing, dressing, eating, toileting and commuting (i.e. difficulty in orientation to space/time/objects)



Fig. 2.3 : Mild Alzheimer disease can travel alone to familiar places

Here the Caregiver's concerns should be:

- Maintaining the patient's self esteem.
- Balancing the patient's need for independence and security.
- Obtaining legal and financial advice for long-term care planning.
- Avoiding social situations that increase the patient's anxiety.
- Planning appropriate physical and pleasurable activities such as long walks.
- Building a social/family support network.

2.4.3 Moderate Alzheimer's Disease

Patient's thought process becomes more disorganized and judgement and decision making processes becomes affected. The individual begins to have more difficulty with familiar activities and requires help for his/her day-to-day activities in the community and the home. The patient may even tend to forget basic things like home address and telephone numbers.

It is at this stage that the patient begins to exhibit anger and suspicion and to act out all these feelings on the caregivers, whose stress level definitely escalates. We will discuss this aspect later in the unit.

Here the Caregivers' concerns are likely to be:

- Insuring the patients security and safety.
- Obtaining treatment for his/her depression or agitation.
- Modifying communications with the patient to make it simple and supportive.
- Creating a daily plan for structure, stimulation and socialization.
- Taking over decision making—gradually but firmly.



Fig. 2.4: Patient exhibits anger

2.4.4 The Moderately Severe and Severe Level of Alzheimer's Disease

At this stage the patient's behaviour is most likely to become a major management concern for the caregiver as lack of awareness of surrounding, purposeless activity and psychotic symptoms increase (Gross cognitive impairment and psychosis are apparent).

Caregivers concern are largely:

- Maintaining the patients safety and security.
- Addressing toileting needs.
- Maintaining patients hygiene.
- Formalizing the home health care plan.
- Securing equipment and supplies for the patients comfort.
- Keeping the patient moving to avoid muscle contractures & deformity.
- Obtaining maximum emotional and social support.
- Implementing advance directives (e.g. a feeding tube)
- Considering hospitalization as a long-term care where appropriate.

Check Your Progress 2

- 1) What are the most noticeable outward signs in a patient in the initial stage of Alzheimer's disease?

- 2) What are three of caregiver's major concern at the moderately severe and severe level of Alzheimer's disease?

- 3) At the moderate level of of Alzheimer's disease becomes more disorganized and and processes become affected.
- 4) In an Alzheimer's disease patients and has to be insured at all times.

2.5 MAJOR CONCERNS RELATED TO CAREGIVERS AND FAMILY ADJUSTMENT

A) Why address the carer's issues ?

Carer's are an investment

- Carer's provide the majority of patient care inputs and the economics of the care they provide cannot be easily measured. This is a very major saving in healthcare cost to the family when you compare with the cost of institutionalization.
- Most people prefer "care" to be provided in their own home versus being admitted to an institution.

Carer's are "Patients" too

- Carer's health may be at risk because of their difficult and emotionally draining role and their own health problems may be overlooked.

Carer's are Partners

- Carer's are semiprofessionals; they have an important contribution to make and over time have developed an expertise in their approach.

B) It is important that from time to time the caregiver gets not only respite but also counselling for stress management.

- 1) Use of techniques like role play to increase a caregiver's awareness of his/her response style.
- 2) It is important to update the caregiver's skills.
- 3) Build the caregiver's self-esteem and self confidence.
- 4) Remind the caregiver that the patient never intends to be difficult and does not always have insight into his/her own problems.

You may like to use a behaviour log to help caregivers solve problems or modify their behaviour

We need to Remember : Since the patient cannot change, it is largely the caregiver's responsibility to adjust.

The family has to play an important role too. They have to provide an environment at home which is conducive to the functioning of the caregiver. Family needs to be supportive and co-operative towards the carer in order to ensure maximum positive interaction with the patient.

In some cases it has been observed where the family is too inflexible or demanding and the carer's have difficulty in performing their role. The caregiver has to be treated with mutual respect and not treated as equivalent to a domestic help. This is unfortunately a common attitude. They need to have regular timings, of course, with some flexibility to change during the times of emergency. Overwork can affect the caregiver's physical and mental health. Caregivers should be encouraged to voice their problems with the family members as this relieves them of tension.

The family has to be extra careful while employing female caregivers with regard to personal security and to ensure their safety within the family environment.

Check Your Progress 3

1) Why is it important to address the carer's issue?

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2) What is the role of the family in this set up?

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2.6 ABUSE / NEGLECT OF THE ELDERLY

When you as a physician find the client mentally disturbed or fretful regarding his/her children, it could be they have genuine fears of being neglected or ignored. Here you have to play your part of discussing/sharing with the family ways and means to tackle these fears/situations.

Acts of Omission or Commission:

The rights of the elderly are abused when the family does not give them adequate care and attention, some common examples can be

- 1) Not taking adequate care of their feeding habits—being erratic in quality/quantity and timings.
- 2) Not taking care of their personal hygiene—clothes, bedding etc.
- 3) The patient may suffer from lack of timely attention with regard to toileting as when he/she continues to lie in a wet bed—giving rise to bed sores.

- 4) Not taking care of their physical exercise/movement to avoid the development of stiff joints/deformities or sores.
- 5) No regular and proper medication. Ensuring that the patient gets regular health check ups done and proper prescribed medication is delivered with care and not experimenting with self prescribed medication which could create medical complications.
- 6) Not spending enough time with them—just talking to them, making them feel wanted and happy. The **Human Touch** is better than the **Best Medicines** science can offer.
- 7) Not maintaining their dignity and giving them their due self respect.
- 8) Property & related disputes among the off spring where the elderly are used as hostages to gain bargaining advantage. Overtly hostile attitudes of family members.
- 9) The client is made to live in areas of the house without adequate lighting/ventilation or even access.
- 10) Their daily routines are extremely circumscribed leaving no room for personal choices.
- 11) They are prevented from developing social contacts of their own choosing.

In all the above situations your role is very important because the elderly person who comes to you needs more understanding and sympathy. At times it may become your responsibility to build up understanding/empathy amongst the family members towards the elderly.

Check Your Progress 4

- 1) Mention any three examples where there is an abuse/neglect of the elderly.

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- 2) How is your role important in such situations?

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2.7 FAMILY COUNSELLING

The principle aim of family counselling is to foster the interdependence of the family members for the benefit of both the caregiver and the patient. By sharing the caregiver's role, they make it less stressful for him/her and allow the patient to remain comfortably and safely at home for a longer time.

The caregiver whether a family member or a long time friend exists within the ecological system of the family. Family counselling while important at all stages, can be strategically beneficial at the early stages specially in the cases of dementia and Alzheimer's disease.

You as the counsellor or the physician have to perform the balancing act by reframing from pressurizing the caregiver while conveying your optimism and reassuring the caregiver that you are there to support him/her.

Organizing the first meeting of family members can become a model for future problem solving and family collaboration. There are two aspects to this meeting :

- 1) Contacting family members.
- 2) Deciding when and where to meet.

The setting of the meeting should be private and conducive to open communication. It can be your office, the patients or family member's home. It is important to determine the emotional tone of the family. Is there family affection and loyalty ? Was the patient only feared and respected or loved also ? And other such related questions.

Families may present any of several dysfunctional patterns of communication any of these—lengthy silences or empty chatter to cover anxiety and/or the inability either to articulate feelings or hear what others are saying — can result in misconception and hurt feelings. Your role is to identify blocks to effective communication and help a family communicate in a “congruent” manner, each member saying what he or she feels.

Shared caregiving will depend upon the availability of the family members and their motivation level. Daily care giving if divided among the members will decrease the caregiver's stress and strain.

As a physician, you can play another important role to identify with the help of the members, the family resources, and then throughout the treatment process, counsel how to balance these resources with the caregiver's needs.

Potential strengths among family members include free time, willingness to help, caregiving experiences, geographical proximity, financial resources and skills (legal, accounting etc.) Potential limitations include, a full time workload, emotional alienation, responsibility for smaller children, geographical distance and physical illness.

Even a supportive family network needs ongoing counsellor support.

2.8 SUPPORT GROUPS

You are now well aware that caregivers need, and deserve, ongoing support both to care for their patient and to maintain their own well being. To further boost the caregiver's resources, it is suggested that you recommend that, the primary caregiver, and/or family members join other caregivers in a therapeutic group environment that is in a support group.

Although differing in setting, structure, composition, and format, groups all have the same goal: the well being of the caregiver and the patient.

Participation in a support group helps a caregiver emotionally socially and educationally and thus reinforces the effect of individual and family counselling. Its social functions especially important for caregivers who have limited interactions with family or friends. The effect of the group experience slowly filters into a members life. Interpersonal relations improve problem-solving skills increase, communications gets more direct and family issues get resolved.

Caregivers experience a wide range of difficult emotions, which are often overwhelming and exhausting. At one moment one may feel angry and frustrated, and the next, guilt and sad. Too often one tries to express one's negative feelings—and thus become more emotionally fragile and even depressed. If one attempts to share these feelings with other people in the support group without any shame or guilt, it helps a lot.

It is quite natural for the caregivers to feel isolated as no one has the time or the patience to listen to their woes repeatedly—this is the time when they find, people in similar situations, in a support group and form bonds with them.

These support groups are also the learning grounds where the different members share their various problems and the method adopted to solve them. They are most helpful with concrete issues like utilizing a Day Care etc.

Their personal experiences with paid home caregivers help others avert crises as well as require appropriate help at home.

On the other hand some caregivers because of their shy, and rigid personalities may not feel inclined to join such a group and rightfully they should not be encouraged for participation as premature joining may negate its intended function to improve coping and adjustment.

Respite: Many caregivers are reluctant to have paid help at home for various reasons like wanting to take care of the patient personally or due to an economic reason. The support groups may amplify the need for a professional help.

Physicians may help where necessary to initiate and build such support groups as they play a very important role and there is a definite need of them.

Check Your Progress 6

What is the main idea behind forming the support groups?

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2.9 LET US SUM UP

In this unit you have been introduced to aspects of caring—to identify the need for special caring and how to plan the same for the individual client. You have learnt about the constraints faced by family providers and the advantages the professional/trained caregivers have over them. The importance of selecting a caregiver and the attributes desirable in such a person have also been highlighted.

The options of institutionalization, day care and home care have been covered with the objective of help you to decide on the right option as and when required while dealing with such cases. The special care area has been dealt with in detail with the sole purpose of bringing to light the seriousness of caring in cases with dementia.

The topic of abuse and neglect of the elderly is to make you aware of the different ways in which the elderly can face neglect and abuse in their own home environment, at the hands of their own offspring or other family members.

Family counselling and support groups along with counselling for caregivers turns your focus on the need for respite for the care providers—to deal with their stress and give them an opportunity to open up and express their fears/problems to you as their physician/counsellor.

We hope this unit helps you to better understand various issues in caring for the elderly who have special needs.

2.10 KEY WORDS

- Alzheimer's disease** : It is a primary degenerative cerebral disease of unknown etiology with characteristic neuropathological and neurochemical features.
- Parkinsonism** : A hypokinetic disorder characterized by rest tremors, pill rolling movement, brady kinesia, rigidity and postural instability.

2.11 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress 1

- 1) Individual
- 2) Dementia, Parkinson, Alzheimer
- 3) Maturity, sincerity, sense of humor
- 4) Take blood pressure, help with exercises, check and prevent bed sores
- 5) Institutionalization, day care, home care
- 6) In home care, the patient is in familiar surroundings and feels very much at ease mentally.

Check Your Progress 2

- 1) Alzheimer's disease are the most notable outward signs in a patient in initial stage is losing train of thought, word or expression, forgetting names and misplacing an important item.
- 2) The three major concerns of caregivers are:
 - Maintaining the patients safety and security
 - Keeping the patient moving to avoid muscle contractures and deformity.
 - Formalizing the home health care plan.
- 3) Thought process, judgement, decision making.
- 4) Safety, avoiding anxiety proofing situations.

Check Your Progress 3

- 1) It is important to address the care issues because:
 - a) Carer's are partners and provide the majority of patient care inputs.
 - b) They are semiprofessionals with an expertise.
 - b) The economics of the care they provide cannot be easily measured.
- 2) Role of family in this set up is that the family
 - a) Provides conducive environment at home, for the caregiver.
 - b) Needs to be supportive and co-operative towards the carer.
 - c) Should treat the caregiver with respect and consideration.

Check Your Progress 4

- 1) Three examples where there is abuse/neglect of elderly are: Lack of proper diet, ignoring personal hygiene, denying them their legal rights.
- 2) Our role as a physician looking after the elderly is to build up understanding and empathy amongst the family members towards the elderly.

Check Your Progress 6

The main idea for forming support groups is to boost the caregivers resources and offer emotional, social and educational support in a therapeutic group environment.