

Indian Perspective of Geriatrics and Gerontology



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elderly in January 1999. The principal areas of intervention are financial security, health care, nutrition, shelter, education, welfare and protection of life and property of older citizens.

Help age India is the largest voluntary organisation working for the care of older people. As part of National Social Assistance Programme, old age pension is being provided. Tax concessions and travel concessions are available for senior citizens. The national rural health mission has identified elderly care as one of the main areas.

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End of life care of person with dementia

Anand Ambali

Introduction

The end of life concept needs to be thought of by the family members on the day of diagnosis of dementia in the family member. The progress of dementia is unpredictable hence one need not wait for the dementia to progress and wait until last stage sets in. The concept of end of life care that it should begin during terminal stage will not hold true in person with dementia as it is true in people living with cancer.

The care givers being family members should insist the person with dementia to share their wishes and any specific needs to be met. The end of life care begins from the day of diagnosis of dementia and continues even after death of person, involving care givers. This article discuss on the issues related to person with dementia and the care giver who happen to be family member. This relation need to be coordinated, emphasized, the issues need to be addressed and provide comfort to both

Definition of end of life care

It is a multidisciplinary team approach toward "whole person care" for people with advanced, progressive, incurable or life limiting illness so that they can live as well as possible before they die. The process of care is not just limited to the person who is dying but extends to his/her families and caregivers (1).

Need for end of life care concept?

The concept of end of life care needs to be promoted among care givers of people living with dementia for following reasons.

1. The number of people living with dementia will be steadily increasing.
2. The median duration of survival of person with dementia will be anywhere between one to nine years.

3. There is significant morbidity involved in person with dementia
4. The responsibilities and stress of care giver increases with different stages of dementia in a given person.
5. The symptoms at end of life period of person living with dementia and cancer will be similar.
6. The occurrence of anxiety and depression is common in care givers.
7. The care givers need to take decision on behalf of the person with dementia which is more stressful and at times feeling of guilt prevails.
8. The goal of end of life care shall be the person with dementia should lead a dignified life and have good death.
9. Prediction of onset of advance stage in dementia is not possible.

Challenges of the care givers

There will be few challenges for the care givers, one of which is communication. The majority of communication with person living with dementia shall be essentially non verbal. The second challenge for the care givers will be acceptance of dementia as terminal illness. Third will be providing adequate support to improve quality of living of person with dementia, fourth shall be medical support for co morbidities like chronic obstructive pulmonary disease (COPD), hypertension, myocardial infarction, stroke and diabetes, and fifth will be handling the behavioural and psychological symptoms like aggression, wandering, anxiety, sleep problems and finally the greatest challenge is acceptance of death of person with dementia.

In between these major challenges, few aspects need special attention. The aspects are ethical issues, cultural values, advance directives, self care of care givers, bringing the best in person with dementia and coordination among family members.

Approach

A sensitive approach, good communication, symptom control, spirituality and keeping the person with dementia active are the key factors in end of life care. People with dementia must receive holistic care that recognises and responds to individual wishes and needs.

During course of remaining life the person with dementia may develop complications like bed sores, incontinence, nutritional deficiencies, falls related injuries which needs special attention.

The care giver shall have multifaceted responsibilities towards care of person with dementia. The person with dementia also need to be involved in decision making, allowing him to help to carry out his old hobbies and keep him engaged in local activities.

In India, the situation for people dying with advanced dementia and the experience of their carers is varied and literature is limited. There are no guidelines framed yet. The care giver provides the care by experiment and learns by mistakes. Sometimes such incidents leads to major breakdown. Also the fear of being judged is common in the care givers.

The approach will address the issues of the care givers and the person with dementia.

What are the problems in people with dementia?

The problems in people living with dementia are classified under three categories. They are physical, medical and psychological.

1. Physical – Pain, Breathlessness, Agitation, Swallowing difficulties
2. Medical- Pneumonia, Urinary tract infections, Falls, Pressure sores, Loss of appetite
3. Psychological – Depression, Anxiety, Behaviour problems.

Plan of care (Fig. 1)

The various issues in providing end of life care needs to be organised and well coordinated. The issues are

1. Communication
2. Nutrition care
3. Pain control
4. Creating awareness among care givers
5. Management of complications
6. Bereavement

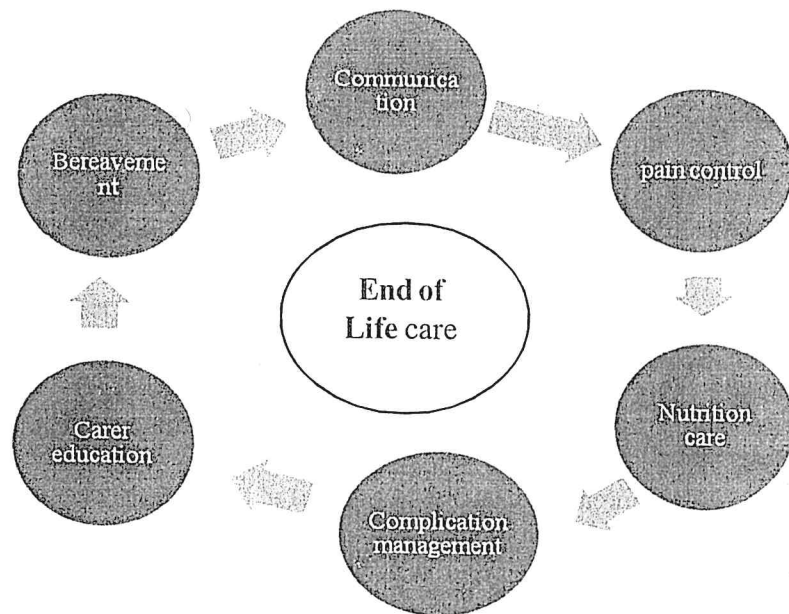


Fig. 1 Plan of end of life care

1. Communication

The most important aspect of end of life care is communication between person living with dementia, family members and professional carers.

There will be initial misunderstandings among the team which need to be sorted out by means of better communication and discussion of decisions among team members. The person with dementia who may not be able to communicate in certain stages, the carer or family members need to understand the message through body language and gestures of the person. The thinking and retaining capacity of the person is reduced, which poses a challenge for the carers. Certain behavioral changes like aggression, being silent, restlessness, decreased food intake suggest underlying infection or pain. The common causes of infection are pneumonia and urinary tract infection, while those of pain are pressure sores and injuries.

In the terminal stage of dementia there will be problems with communication. The person will generally have limited or no speech. They will also have a reduced ability to understand what is being said to

them. Relying only on verbal communication can lead to difficulties and understanding what the person is trying to communicate, possibly missing basic needs such as pain, hunger and thirst.

The carers need to be good in communication. Following are a few tips for the carers.

- i) Non-verbal communication from carer like gestures, body language, facial expression and touch, can help to identify certain problems.
- ii) Use of appropriate physical contact such as holding hands or a hug to reassure the person that you are there for them.
- iii) Always look for non-verbal signals from the person with dementia.
- iv) Continue talking to the person, even if you don't think they can follow what you are saying.

The non-verbal communication holds true even in advanced stage.

2. Nutrition care

The food rich in nutrition should be provided. The issue of nutrition is vital when the person with dementia stops eating for various reasons.

In such instances whether stomach tube feeding should be started or not depends upon the decision taken in coordination between caregiver, professional and the person with dementia.

The feeding by tube has its own complications like aspiration and pain. Various studies have compared the outcome between the person who was fed through tube and those who were not fed through tube. It was found that there was no difference as far as mortality is considered. However, in Indian context feeding till the person is alive has cultural values. The family members insist on feeding till the person dies and feel that starving the person at the time of death is not culturally acceptable. The family members insist on gastric feeding despite complications being explained. As such frequent feeding of water in sips and good oral care will be sufficient during the terminal stage.

According to Arcand, comfort feeding by hand is preferable to tube feeding. This avoids complications of tube feeding. It also aids interaction between family members and person with dementia. There should not be pressure on the person to accept feeds. Dry mouth can be

overcome by applying lubricants and frequent cleaning of mouth (2).

3. Pain / breathlessness control

Pain is the most bothersome symptom in person with dementia. The manifestation of pain will be agitation, decreased appetite and aggression. The care giver needs to be aware of these symptoms. Pain can be controlled by use of paracetamol suspension that can be fed easily. Pain can be due to injuries, arthritis, constipation and pressure sores. Sedation should be avoided in such instances.

Pain assessment in patients with dementia is difficult and research has shown that it is under detected and under treated (3). Scales have been developed to identify levels of pain and distress in patients with cognitive impairment.

The pain needs to be identified by NOPPAIN scale (4). In case it is difficult to identify pain, a trial of analgesic use can be tried. If the behaviour symptoms regress by use of analgesics, it can be assumed that pain was likely cause of the behaviour.

It is difficult to identify pain and assess its severity. There is no standardised tools for non verbal assessment of pain in person with dementia who cannot communicate. Hence a trial of analgesics use is recommended in situation where presence of pain is uncertain.

Breathlessness can occur due to pneumonia, aspiration or a pre existing disease like Chronic obstructive Lung disease. This can cause restlessness and agitation. Short term oxygen supplementation, nebulisation and clonazepam will help reduction of breathlessness. Caregiver can consider hospitalisation of the person for short duration till symptom resolves.

4. Creating awareness among care givers

The family members usually volunteer to provide care. They are not aware about dementia and nor are trained to handle various situations that they come across during care. There is need to create awareness about dementia care and should be allowed to share their problems and create a platform for them to develop a space to relieve themselves.

The geriatric clinic of my college organises care giver meet for the family members of person living with dementia once in there

months. Here the care givers are allowed to share their problems and also solutions they have found. Such discussions are considered vital by care givers because they feel someone listens to their problems and also they confirm that whatever they are doing was right or wrong. This encourages them for further care.

A caregiver in his narration mentioned an example. She gave her mother a glass of water with a straw and left to attend the door bell. Within few minutes she came back only to see that her mother was choking. Such incidents do happen and it becomes an example to learn for care giver.

5. Management of complications

Pressure sores are common in people with dementia which when infected leads to mortality. Identification of sore at initial stage and taking precautions to prevent infection will help healing. Measures like frequent change of position and use of air bed should be practiced.

6. Bereavement

The family members have to cope with loneliness and to re-establish life after the death of the person whom they cared. They need to come out of the psychological stress they have undergone observing persons deterioration and death (5).

The bereavement process is an important issue for the person with dementia and family members.

In Indian context, when a person is in terminal stage of disease or non curable state the family members in fact wish that the person living with illness should die early. This wish has significant effect on care givers and the person suffering. This thinking is also taken positively by all family members. It is seen as released from suffering.

The family members need to be counseled regarding the loss and various means to overcome them.

Interventions and services

The end of life care is a complex process and begins on the day the person is diagnosed with dementia. The care giver or family members may take some time to come to the terms of acceptance and willingness to provide care. Also the family requires assistance in understanding the course of dementia and the issues related in care

of the person living with demntia. They need to think of appointing a carer or a family member may volunter themselves as care giver. The family members will show little hesitance and resistance when one of their member is diagnosed having dementia. This leads to delay in initiating the care process. The family members hesitate to talk to the person living with dementia regarding his wishes and to initiate steps to complete the important unfinished work, if left in his life. The resistance is in form of non accepatance of the diagnosis. The family members visit atleast another two or three clinicans for confirmation of diagnosis due to which more valuable time is lost. The family members ask why this to my family? Why to a learned fellow? The family members need counselling and awareness about the process of dementia and issues involved.

The family of person with dementia needs lot of social and psychological support. The spouse specially needs more attention as she or he is going to face the issues concerned more deeply than other family members. The bottom line here is that the end of life care is a team work and all members of the family and friends need to involve over period of time and during different stages of the disease. The greatest onus on the spouse is to take decisions on the persons behalf which at times will cause mental breakdown in them.

Spirituality can be hard to define and it is not just about religious beliefs, although these may be a part of it. Everybody has their own unique spiritual life. Spiritual needs should be addressed and honoured just as much as the medical aspects of care.

Whenever possible, it is best to ensure the person is in a calm, familiar environment with people they are close to. The person might enjoy things that stimulate their senses, such as familiar music or aromas and hand massages. Personal or religious objects, symbols or rituals (including prayer or readings) may be used. Early memories are generally retained longest in dementia so the person may respond to older recollections.

Keeping the person with dementia active

It is very important to keep the person with dementia as active as possible. This improves overall quality of life. The persons preserved capacities should be emphasized by engaging them in activities which he or she can still perform successfully.

The environment should be free of clutter, sharp objects, air pollution, and should have adequate light. Measures should be taken to ensure the person with dementia does not sleep in day time so that sleep during night is not disturbed. The persons are kept busy making them play games and taking their help in cooking or cutting vegetables using blunt instruments. The person with dementia need to be kept clean, bathed daily, fed properly and groomed well. They should be encouraged to do certain meaningful activities feasible to them to keep themselves active and involved. They should feel that they can still contribute which in turn will enhance feel good effect. This will prevent episodes of agitation and improve appetite. Appropriate emotional support should also be provided to family members. At the last hours of life of person, artifical feeding and hydration should not commence if disclination to eat or inaility to swallow is considered to be part of progression of disease and will not change in future(6).

Case discussion

I wish to narrate an incidence that happened in our set up. The woman was suffering from heart failure and her husband was living with dementia. She was admitted in hospital under my care for hypotension. After examination I was of opinion that she will not live long so I told her son to get the father to hospital so that he can see her in her last hours. The son was reluctant and said how it matters as he is living with dementia and does not recognise my mother. I convinced him saying that let your father have a look at his wife during last hours of her life and your mother also will have an opportunity to spend time with her husband who at least recognises him. The son agreed and brought his father for which we arranged ambulance and a wheel chair. The old man with dementia was brought to intensive care unit and made to sit by side of bed and hold hand of his wife. The wife on looking at her husband had tears while the old man was not aware what is happening. Two hours after this meet the old lady collapsed.

Through him, the author has tried to make arrangement to meet the couple during last hours of the spouse (wife). Though the husband living with dementia is not aware of what is happening, meantime his wife communicated through the tears in her eyes.

Advance directives

The concept of advance directives in legal way has not been in practice in Indian scenario. The only legal document the person writes

his will which usually has concerns regarding property. As far as health issues are concerned, the directives are not written and legalized. Such system does not exist in my place. One example need to be mentioned here is of a 86 years old lady who was bed ridden for last two years. She gave following directions to her son in my presence. Bury me in the old cemetery of this town, do not cry on my death, donate my eyes to a hospital, do not waste money on my funeral and all of you maintain cordial relation with family members. She said that these were her wishes and to be followed. Such directives are still in practice in rural India. Also, some old persons when are active do keep informing their spouse that their neighbour Mr X who died being put on ventilator, He himself should not be given such pain during his terminal days. Such directives can also be considered while one happens to go through such phase in his life.

What can be the Barriers in providing End-of-Life Care?

- i. Failure of healthcare providers to acknowledge the limits of medical technology
- ii. Lack of communication among decision makers
- iii. Disagreement regarding the goals of care
- iv. Failure to implement a timely advance care plan
- v. Lack of training about effective means of controlling pain and symptoms
- vi. Unwillingness to be honest about a poor prognosis
- vii. Discomfort in telling bad news
- viii. Lack of understanding about the valuable contributions to be made by referral and collaboration with comprehensive hospice or palliative care services

Uncertainties in care of person with dementia

1. People with dementia lack the capacity required to make decisions about their care and treatment. This has profound impact on providing quality care at end of life and person centred care.
2. A person with later-stage dementia may have symptoms that suggest that they are close to death, but actually live with these symptoms for many months. This uncertainty makes planning for the end of someone's life difficult.

3. End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of end of life care he or she would prefer.

End of Life care guidelines in India

The guidelines laid down by Indian society of critical care medicine and Indian Association of palliative care does not mention "end of life care for person living with dementia" as separate entity (7). Guidelines are meant for people living with cancer. Few guidelines mentioned during advanced stage can be practiced as the symptoms during terminal stage of cancer and dementia are similar.

Conclusion

Access to end of life care is a human right. Everyone with a life limiting illness has a right to live a life free from pain and distress, have psychosocial and spiritual support, and also the right to a dignified life that includes the process of death. The legal and ethical issues also need to be addressed while providing care.

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