

Elderly person as caregiver & Caregiver's perspective

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Introduction

With the advancements in health care and increased life expectancy, the world's old age population is gradually increasing. As per World Health Organization report, between 2015 to 2050 old age population will nearly double from 12% to 22% i.e., it is expected to increase from 900 million to 2 billion. As the risk of dementia rises with increasing age, instances of elderly caring for their spouse with dementia is likely to increase.

Impact of caregiving on caregiver

Caregiving has significant impact on physical, social, emotional, and financial conditions of the caregiver. On a positive note, some caregivers report that caregiving is enjoyable and gives their life meaning. Caregivers may feel that they are a role model for the younger generation. Caregiving strengthens the bond with the person they care for and increases life satisfaction.

Despite gratifications associated with caregiving, it can be demanding, overwhelming and stressful. None is trained to be a caregiver. It is a responsibility imposed on them. Caregiver has to make alterations in their lifestyle, daily routine, habits and finance. This leads to increase in emotional and financial stress. Caring for an elderly family member with dementia or chronic neurological illness like Parkinson's, multiple sclerosis etc is even more challenging as these patients suffer from incontinence, confusion, aggression, poor oral intake, sedentary lifestyle, vision and hearing impairment. In addition, patient's apathy towards the already overwhelmed caregivers further worsens the caregiver's emotional status.

Despite key role played by the family caregiver, they are not acknowledged for their services. Caregivers are often called 'unpaid caregivers' or "second patients" (Carmeli, 2014).

Case Vignette 1

An elderly couple from middle socioeconomic status live in the suburbs of Bangalore. The husband got retired 9 years back and the day-to-day expenses are met by his pension. The wife has been diagnosed to have Alzheimer's dementia 1 year ago. The husband finds it difficult to help his wife and manage day to day household affairs. Most of the family's income and savings have been spent on investigations and treatment. Due to financial constraints, they can't afford a maid or paid caregiver. Though the husband initially felt good about taking care of his better half, he is now feeling exhausted. He has trouble relaxing, is withdrawn, has sleep problems, and feels hopeless about future.

Case discussion 1

The scenario depicts plight of a sole caretaker who has no other social support system. He is taken away from his social life and recreational activities and his entire life revolves around taking care and providing comfort to the spouse. With the new role of caregiver, he is unable to look after his own physical health and recreational activities. He does not have time for his friends or for walking or yoga. This is typical dilemma of an elderly caregiver of a person with dementia.

3 Many studies have found that caregivers of 3 persons with dementia have higher levels of burden than other caregivers. People with dementia typically require more supervision, are less likely to express gratitude for the help they receive, not going to improve which leads to significant negative emotions in the caregiver.

3 Financial strain caused by dementia is significantly high. Direct costs include 3 medical visits, 4 investigations, medications, therapies, provision of paid caregivers, and residential care in the later stages. Indirect costs include loss of earnings by patients and family caregivers as they reduce employment, hours of informal care and mortality burden.

Case vignette 2

An elderly couple from high socio-economic status stay in urban Bangalore. The father is a retired professor and mother is a homemaker. The elder son is a software engineer and the younger son, is a person with moderate intellectual disability with behavioural problems. The elder son is not involved in care of his younger brother and has settled abroad. Most of their assets are intended for their dependent son. They know that he cannot handle the assets and needs a guardian after their lifetime.

Case discussion 2

The given scenario illustrates the elderly parents who have supported the son extensively in various aspects since childhood. They understood the special needs of their son and tended to them since childhood. Despite this, still parents are uncertain about the son's future "what will happen to our son when we get old", "who will look after him?", "whom we can trust in looking after his financial resources and future needs?". This is the typical dilemma of elderly caregivers who have dependent children with disability.

Elderly parents with dependent son/daughter with disability (intellectual disability or mental illness) feel exhausted in the long run. Seeing their wards unable to cross social milestones like education, job, marriage, is stressful for any caregiver. If there is a dependent son/daughter with disability, elderly caregivers should also think about "What after me" issues, and financially plan for next generation which also adds the burden to them.

Caregiver guilt

Caregiver's guilt is one of the significant factors leading to caregiver burden and depression. Major factors causing guilt are guilt associated with negative feelings, emotions or acts towards the care recipient, failing to meet caregiving expectations, guilt about neglecting other roles or relatives other than care recipient, guilt about having negative feeling towards the other relatives who don't participate in caregiving, guilt about taking time off for themselves rather than looking after the relative.

Anticipatory grief

It is a grief reaction that occurs before the actual loss. It can be either due to perceived impending death or perceived absence of patient. Perceived absence can be either due to current absence or future absence. Anticipatory grief secondary to current absence is caregivers had already started to feel the absence of patients in their day-to-day life, especially when patients stopped talking, become apathetic, or when they were admitted in hospital or old age home, which causes caregivers to feel a sense of loss even though patients are alive. Anticipatory grief secondary to future absence is caregivers anticipated loneliness, sadness about the future without patients. Caregivers worry about their future life being without the patient, taking decisions alone, fear of loneliness and preparation for new life.

Caregiver burden

Many factors are associated with caregiver burden. Poor functioning of the patient and active symptoms leads to severe burden.

The symptoms of caregiver burden include the following

- Physical and emotional exhaustion
- Decreased productivity in their work
- Withdrawal from friends, relatives and family
- Loss of interest in activities they used to enjoy before
- Feeling fatigue, dull, hopeless, and helpless
- Changes in appetite, weight and sleeping patterns
- Neglecting their own needs (because of busy schedule or you don't care about them)
- Even though most of the time is involved in caregiving, the caregiver may not feel satisfied.
- trouble relaxing, even when help is available
- being impatient and irritable with the care-recipient

Caregiver burden can increase susceptibility to non-communicable diseases/ chronic illnesses, and reduce functional ability. Physical health has an impact

on mental health and vice versa. Common mental illnesses in old age (like adjustment disorder, mild- moderate depression, anxiety disorders), substance use and other social factors like drop in socio-economic status with retirement, poor social support, bereavement, elderly abuse (often less reported), loss of leadership role in family, lack of emotional support, can additionally burden the caregiver.

Caregiver depression

The caregiver depression is a complex, multi-faceted process influenced by many factors like cultural background, caregiver, and patient characteristics. The following table illustrates some of the factors associated with increasing caregiver depression.

<u>Patient characteristics</u>	<u>Caregiver characteristics</u>	<u>Others</u>
Younger the age of patient	Female caregivers, poorly educated, employed, older age of caregivers	Cultural background
Severity of cognitive impairment	The closer the relationship with care-recipient/patient	Religious beliefs
Problematic behaviours like screaming, aggression, agitation, night time wandering, property destruction, asking repetitive questions, and reliving the past, losing or misplacing things	More hours spent in caregiving	Prior poor interpersonal relations in the family
More dependent on ADLs (Activities of Daily Living), immobility, incontinence, walking difficulties	Poor caregiver functional status, pre-existing medical conditions	Family's poor financial status
Severity of dementia	Poor coping strategies-avoidance/denial, escape	
Severity of patient suffering	Emotion focused coping instead of problem- focused coping	
	Lack of self-efficacy	
	Caregiver's guilt and anticipatory grief	

Caregiver burnout

Burnout is a state of physical, mental and emotional exhaustion in response to prolonged stress, high aspirations and unrealistic goals. It is a gradual process by which the person gradually detaches from work and other meaningful relationships.

The stages of burnout are:

The Honeymoon stage

- Caregiver has boundless energy, is enthusiastic and loves the new role



The Awakening stage

- Caregiver realizes that their initial expectations were unrealistic. Slowly, disappointment buds. They question their competence, ability and start losing their self-confidence



Brown out stage

- Caregiver's early enthusiasm and energy give way to chronic fatigue and irritability. They become indecisive, and productivity drops
- Caregiver's eating, sleeping patterns change. Caregiver indulges in poor coping methods (including smoking, drinking, drugs, partying, or shopping binges)



Full Scale Burnout stage

- Caregiver is exhausted physically and mentally. Breakdowns are likely. Despair is the predominant feature of this stage
- Caregiver is depressed, feels lonely and empty. They experience an overwhelming sense of failure, loss of self-esteem and self-confidence



The Phoenix Phenomenon

- Caregiver takes their time but comes back from burn out like a Phoenix
- Caregiver is realistic in their approach and creates balance in life

What can be done to improve the caregiver's health?

- A. The effective management of a chronic disease for both the patient and caregiver is to approach a comprehensive care team of skilled professionals and make an individualized plan.
- B. **Know more about the disease**
 - a. The more you know about your loved one's disease, the more comfortable and efficient you become in handling the patient
 - b. Seek information about caregiver support groups/ online groups, psychoeducational programs, books, workshops, local organizations, national organizations/ societies of specific diseases (like Alzheimer's disease)
- C. **Healthy lifestyle**
 - a. Eat a balanced diet
 - b. Get at least eight hours of restorative sleep
 - c. Exercise regularly (150 min of aerobic exercise per week)
 - d. Follow spiritual/religious practices for coping
 - e. Spend time in hobbies
 - f. Practice relaxation techniques like meditation, yoga, mindfulness
 - g. Regular health check ups
- D. **Emotional support**
 - a. Maintain personal/social relationships- Maintaining relations with children, relatives and friends also helps in mitigating the stress
 - b. Share your feelings with people facing similar situations (like support groups) relieves stress and may offer different perspective about problems
 - c. Identify and accept your emotions- persons in these situations can feel sad, hopeless, helpless, worthless, fatigue, tired. Acknowledge that these emotions are normal reactions to your situation
 - d. Early recognition of caregiver stress may reduce the caregiver burnout
- E. **Caregiving Essentials**
 - a. Ease the household task burdens (e.g.- hired help, recruiting other family members or friends, etc)
 - b. Take a break/holiday
 - c. Encourage the independence of your loved ones- with the help of modern assisted devices, technologies encourage them for being as independent as possible
 - d. Embrace caregiving choice and practice acceptance
 - e. Celebrate small victories in the day-to-day life
 - f. Focus on things you can control
 - g. Plan respite care

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