

COMMENTARY

Care of caregivers – who is responsible?**Karpaga Priya P¹, Gouri Kumari Padhy², Mohan Kumar³**

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Abstract

Demographic and epidemiologic transition coupled with increasing life expectancy has resulted in high old age dependency ratios and rising burden of comorbidities; especially non communicable diseases. This demands large pool of caregivers to support the dependents; physically, psychologically and financially. But the problems faced by caregivers – stress, anxiety, monetary, physical exhaustion and sickness, lack of time for personal care and health resulting in caregiver burden – is often neglected. This article summarizes the importance and/or role of caregivers, their problems and recommendations to identify, manage and prevent caregiver burden. The involvement of various stakeholders namely medical and para-medical colleges through training and medical education, hospitals, physicians, psychiatrists and/or psychologists, research organizations, governments and their policies is the need of the hour.

Keywords

Caregiver Burden; Life Expectancy; Non Communicable Diseases

Introduction

Care giving is the largest growing occupation in the nation. (1) A person who helps with the physical and psychological needs of another person is termed as caregiver. (2) As life expectancy has been gradually increasing over the years, so does the co-morbid conditions associated with it; the harms of benefits. Since there is an epidemiological transition from communicable to Non-Communicable Diseases (NCD), (3) people who need care and support are on rise.

Such patients are taken care by two types of service providers; Formal and Informal. Formal caregivers are those who are specially trained in care giving and are paid for their job. They can be volunteers for

charity purpose or can make this their profession. (4) Formal caregivers are usually employed to provide service for a newborn (ex. Nanny), to sick patients and for elderly care. The care provided by the family members, which is unpaid, is the informal; largest sector of care giving.

No economy can replace informal caregivers with formal paid ones. This is not only due to rising old age dependency ratio and burden of NCDs, but also due to the cost of hospitalization and institutional care. Hence the need for home care is on rise. Also the role played by the care giver is more demanding; physically, psychologically and financially. Generally, women play this role more than men. In houses where both the husband and women work, it

becomes a shared responsibility. If they had to place a formal paid care taker, then the financial cost comes into play.

When care giving becomes for too long or if it is the occupation of the person, then the entire nature and mental status of such a person is altered. Their outlook becomes different. According to caregiver identity theory, care giving is a dynamic process, where changes keeps occurring in the care activities, in the relation between the giver and the recipient and finally the identity of the caregiver itself.(5)

Need for caregivers: A dependent person seeks care both in good health and sickness. In good health, certain elderly people need someone to take care of their basic needs due to their age induced changes (diminished vision due to conditions like presbyopia, age induced hearing loss). The other category is when people are sick with acute or chronic disease conditions; accident/trauma (ex. falls) related orthopedic injury, stroke, dementia, cancer.

Changing trends in care giving: Initially when India has treated family as a social institution, co-residence was the method of taking care of elderly and the sick. In India, elderly constitutes around 8.5% of the total population. According to NSSO (National Sample Survey Organization) 60th round around 5.2% of older adults live alone. With demographic transition, families are moving towards nuclear type resulting in a gradual shift from informal to formal caregivers.(6) Also it has been shown that majority of the elderly were receiving care from formal or informal sector only when they were living with spouse and family members.

Phases in care giving: When care giving is subdivided based on the demands and needs of the patient and/or dependent, the entire process falls under the following five categories,

1. **Awareness** – the patient realizes he has some problem with routine work and the family member/s notices the need of the patient
2. **Unfolding responsibility** – for the caregiver it may be a new experience, they may learn new roles, the recipient may face some discomfort, discrimination, they might feel some loss of control or power
3. **Increasing care demands** – mainly for elderly or chronic disease patients with worsening prognosis. The care giving task may expand to self-care, performing medical procedures
4. **End of life** – care giving becomes more urgent, intensive and demanding.(7) Caregivers tend to

experience highest level of stress and burden during this phase.(8)

5. Bereavement

This when plotted, we can see a linear graph in case of care for a dementia patient. It can be a reverse linear for a stroke patient and highly fluctuant and rapid for a cancer patient.

Problems faced by caregivers: The problems faced by the caregivers whether they belong to the same family or paid care providers are often neglected. They can be psychological issues(9), financial(10), physical exhaustion and sickness(11), lack of time for personal care and health(12) and are summarized in (Figure 1).(13)

Caregiver burden is defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the care giving experience”(14) It was found that around 70% of working caregivers had work related difficulties due to two jobs. According to the Family Caregiver Alliance, to meet the requirements of the dependents, 69% of working caregivers had to rearrange their schedule or take an unpaid leave. 39% had to leave their jobs to provide care for their family members in need. (15) Due to negligence in own care, 40.7% of caregivers reported two or more chronic diseases themselves. 36.7% reported insufficient sleep, 14.5% and 17.6% of them were found to have mentally and physically unhealthy days in a month respectively as per Centre for Disease Control.(13) The American Cancer Society National Quality of Life Survey for Caregivers on its five year follow up study on the caregivers of cancer patients, found that those who were providing care for five years were having poorest quality of life and had the largest increase in depressive symptoms.(16) Women were found to have more psychological distress as compared to male caregivers. (17,18)

Conclusion

Since care giving is evolving as an important part of health care sector, it is important for the medical professionals and the government to look into the needs of the caregivers. Being a caregiver should be considered as a job in itself, and all its related issues and burden should be considered as occupational diseases / hazards. A multisectoral involvement is needed to provide a wholesome approach in designing a healthy working environment for the care providers.

Recommendation

The recommendations grouped based on stakeholders involved are given in (Table 1).

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Tables

TABLE 1 RECOMMENDATIONS

Role of medical and para medical colleges	<ul style="list-style-type: none"> Routine workshops, training of doctors and nurses to provide empathic care to the caretakers has to be implemented Care coordination and advance care planning services available to patients should be made available to caretakers also
Role of medical education	<ul style="list-style-type: none"> Empathetic counseling has to be a part of the Undergraduate medical and paramedical curriculum
Role of treating hospitals	<ul style="list-style-type: none"> The art of counseling and providing psychological support has to be part of the comprehensive care at the primary health centers (PHC) as the routine follow up of patients suffering from stroke, cardiovascular disease, hypertension, diabetes, cancer, dementia, psychological disorders occur at the level of PHCs Placing ‘Personal experiences’ sticky notes on display boards of the hospitals. Here the care takers can pen down their feelings and emotions which they had gone through during the course of taking care of the loved ones. This helps the other caretakers not feeling lonely as someone had gone through all the same
Role of treating physicians	<ul style="list-style-type: none"> When a physician treats such chronic diseases, he/she should make sure that the mental health of the caretakers is also considered. There has to be routine mental health assessment and examination of such people who have played the role of being chronic caretakers The care givers should be referred to Psychiatrist and psychologist on a routine basis by the treating physician for their evaluation
Role of psychiatrists / psychologist	<ul style="list-style-type: none"> Special clinics for care takers to be held once a month -once a quarter. They would enroll all the referred relatives/ care givers of chronic patients Care giver intervention module should be available in all the hospitals and made appropriate use of
Role of employers	<ul style="list-style-type: none"> Regular breaks, vacations for the formal caregivers.

	<ul style="list-style-type: none"> • Incentives, motivation and appreciation for all the good and efficient work done by them. • Necessary arrangements for the caregivers to keep in touch with their families and friends. • To make sure that education of the caregivers is not hampered • To protect the caregivers from physical and sexual abuse
Role of government	<ul style="list-style-type: none"> • Separate department should be initiated to create job opportunities to employ care givers and those who need can contact government. This can create more employment opportunities. • A wide publicity of the tollfree number should be made available • Provision of such service in both rural and urban areas • Streamline the salary of the caregivers • A national policy on the role of caregivers, their health and risks should be drafted based on evidence. • Family care leave should be made available for both public and private sector employees for a total of 60 days per parent in the entire service.
Role of insurance schemes	<ul style="list-style-type: none"> • Risk pooling for the care givers to prevent them from financial hardships. • The existing insurance schemes, should include a separate provision for insurance claim by the caretakers as a part of the new scheme
Role of caregivers	<ul style="list-style-type: none"> • Forming support groups for the caretakers by themselves • Special breaks to rejuvenate the health of the care takers has to be ensured by other family members / employers
Research	<ul style="list-style-type: none"> • More research has to be undertaken in the field of health; support system available to care givers • Surveys at national level on the percentage of care givers in India, their mental, physical, social health has to be undertaken at least once in 5 years

Figures

FIGURE 1 PROBLEMS FACED BY CAREGIVERS

