

Caregiving: A Public Health Priority

“Health-care” is often seen as a service provided by doctors, nurses and other health professionals. Individuals with health problems, especially those with chronic illness or disability, need constant care and assistance from others. Such “health-care” is often home-based and provided almost entirely by co-resident family members, who are not part of the formal health-care system. This unpaid care, given voluntarily to ill or disabled persons by their families or friends is called “informal care”. This is the back bone of long-term care. Contributions of informal caregivers go unnoticed, except by those who benefit from their care. However, we must recognize that the contributions of informal caregivers are irreplaceable. No society, rich or developed, can afford to replace all informal caregivers with paid workers.

Caregiving is an issue, which affects the quality of life of millions of people world-wide. Providing informal care, particularly for a person needing assistance for activities of daily living, is a demanding task, which requires time, dedication and perseverance. Most caregivers derive personal satisfaction while caring for someone close to them and that enables them to cope with the stress and burden of care. Until recently nobody considered caregiving as a public-health matter.^[1] Instead, caregiver research focused only on psychosocial dimensions and the burden of care.

HISTORIC EVOLUTION

The nature and function of caregiving has evolved over the last two centuries. Life expectancy has increased and there is a definite change in the profile of illnesses. Communicable disorders are less prevalent than before. Non-communicable disorders are emerging as public health problems. The proportion of people with functional impairment and disability are also on the increase. Caregiving was typically short-term in

the 19th century and until the early part of the 20th century. Now in the 21st century, we have more people with chronic disabling conditions and they need care over longer periods of time.

The demand for long-term care is likely to increase in the future. Demographic aging is not the only reason for the world-wide increase in the demand for long-term care. Escalating costs of hospitalization and institutional care is leading to briefer hospitalizations and increased need for community care. Medical advances are also leading to better survival of infants with life-long disabilities. Survival of adults with brain damage and other serious injuries also add to the need for long-term care.

HUMAN RESOURCES

There is tremendous pressure on families to take on the care of disabled. As the need for care keeps on increasing, the human resources seem to be dwindling. More women are taking up employment outside their homes to supplement the family income. Even now, the majority of caregivers are women. Many men and women continue to be caregivers while being part of the work force. This can be very stressful and demanding. They may be forced to cut-down on work or make suitable adjustments to accommodate their caregiver responsibilities.

BURDEN AND IMPACT

A survey conducted in 2004 in the United States found that caregivers were present in one in five households and 21% of the U.S. population older than 18 years were engaged in providing care for an adult. The majority of these caregivers (an estimated 34 million or 16% of the U.S. population) provided care to someone at least 50 years old, and some provided care for more than one person. (Caregiving in the U.S. Available: <http://www.caregiving.org/data/04finalreport.pdf>). The majority (83%) were family caregivers—unpaid persons such as family members, friends, and neighbors of all ages. Though, we do not have comparable data from India, it is reasonable to presume that things could be similar in India and elsewhere.

The provision of informal care over prolonged periods of

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time can have profound consequences for the caregiver. The responsibilities of caring often constrain social participation and necessitate withdrawal from the work force. Intensive caring can have adverse effects on the psychological health of carers. There is consistent evidence that carers are more at risk of mental health problems, particularly stress and depression, than other adults of the same age. For example, providing care for individuals with dementia has profound consequences for family caregivers.^[2-4] The caregivers often need to manage behavioral disturbances, attend to physical needs, and ensure safety.^[5] Home-based long-term care leads to substantial economic disadvantage. Caregivers do not receive any form of caregiver allowance in India. Most often they stop working or cut back on their work to provide care at home. Additional expenses for medical care and reduced family incomes can lead to further impoverishment of low income households.

CAREGIVER INTERVENTIONS

Family caregivers are largely neglected by the health and long-term care systems. We need to realize that the physical and mental health of the caregiver is at the core of successful care giving. Better health will enable caregivers to sustain care. Many a time, caregivers may not have time to look after their own health and may not undergo health checkups for themselves and encounter health problems that could have been averted.^[1] They may become depressed due to the overwhelming demands of care giving. Caregiver interventions can improve the quality of life of the caregiver and the care recipient.

Information and education has a central role in caregiver interventions and shall form the basic ingredient of caregiver interventions. The caregiver and the care recipient should have easy access to information regarding the health condition and its management. This information should include practical management tips, especially about difficult symptoms. Caregivers should also be made aware of issues related to informal care and about their own health. Opportunities for discussion and guidance from health care providers will help. Providing emotional and social support to the care recipient and the caregivers is another essential ingredient of caregiver interventions. It is always important to offer long-term care and support instead of a onetime intervention. Caregivers should also know where to get help when home-based care faces a crisis.

There are three partners in long-term care. The triadic model by Talley and Crews^[1] gives equal importance to the care recipient, informal caregivers and professional care providers. Each of them has special needs and responsibilities. These three are the dedicated

partners in the process of caregiving. Many factors, both contextual and environmental, could impact the caregiving process. Some of them could facilitate or inhibit the care process and affect the outcome. It is important to identify them and be mindful of their influence.

It is possible to develop caregiver interventions which can make care giving less burdensome. The Indian Network of the 10/66 Dementia Research Group has developed a caregiver intervention module. The details are available in the website <http://www.alz.co.uk/1066/>. Reaching families engaged in home-based care is crucial. Community outreach services will have to play a major role in identifying and supporting families engaged in home-based care. The primary caregiver in each of these families has to be identified and their care needs should be assessed. Designing and delivering interventions will be next logical step. These interventions need to be culturally acceptable. Efficacy of caregiver interventions will have to be established and the initial results hold promise for home-based dementia care.^[6,7] Simple inexpensive caregiver interventions which can be delivered by the outreach services will have the potential for scaling up. We need to seriously consider generic interventions which would be helpful for all family caregivers irrespective of the diagnosis of the care recipient. Health workers with brief training could then be able to deliver these community based interventions to strengthen home-based care and ameliorate caregiver burden.

FUTURE DIRECTIONS

There is a need to share the caregiving responsibility among individuals, families, and the government. We cannot leave the responsibility of home-based care to the families and hope that the traditional family network is capable of absorbing any amount of stress. The burden of care is real and can have adverse impact. It is only fair and prudent for the governments and the society at large, to step in and support the efforts of these families. Support to caregivers and efforts to foster their well-being are crucial for sustaining long term care. A public health frame work will help in strengthening informal care.

Assuming a public health frame work would result in exploration of population based information on various aspects of caregiving. We need to know the number of caregivers in the population and their characteristics. How do caregivers of chronic schizophrenia differ from those who care for people with dementia? What are the current care arrangements for people with mental retardation? Do the caregivers get the information and support they deserve? Do they get any kind of support

from the health services? Do we know the levels of caregiver burden and adverse impact on the caregiver health? Are caregivers exposed to health risks which are related to or are a consequence of long-term care? We need to make concerted efforts to mitigate caregiver burden and improve the quality of home-based care. This will greatly help the family unit. Efforts to preserve and strengthen the family will promote mental health.^[8] This, we believe, is important in the Indian context.

Caregiver research should move on and address public health issues related to long-term care. We need to know the magnitude, costs and impact of caregiving. It is important to know the predictors of caregiver strain. Identification of cultural factors which promote interdependence and compassion will help. These factors may promote and sustain healthy caregiving. We should also recognize the life span nature of caregiving. It is said that “there are four kinds of people in the world; those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who will need caregivers.”

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