



ALZHEIMER DISEASE AND THE DEMENTIAS AFFECT CAREGIVING

Care giving trajectory

- Gradual recognition that something is wrong
- Intensive home care and beyond
- Initial phase: Demands may be quite limited and easily incorporated into life
- Mid phase: Demands become more difficult.
- Later phase: After person may have been placed into a formal institution, caregiver frequently continues to provide supplemental or “invisible care”.

The most common reason for admission to hospital or hospice is a breakdown in the ability of the caregiver to continue providing the level of help required to allow the person to remain at home. Caregivers in this situation tend to experience a decreased role in care giving; a decrease in role overload; a decrease in symptoms related to anger, an increase in guilt; and an increase in social emotional support.

Organization of Stressors in the lives of Caregivers: Primary and Secondary

The primary stressors of care giving (the stressors caused directly by care giving activities)

- Primary stressors are the conditions, experiences, and activities that are problematic for people, threatening them, thwarting their efforts, fatiguing them, and defeating their dreams.
- Stressors have the ability to arouse stress which manifests itself as tension, uneasiness, anxiety; alarm, worry, fear, dread, upset, and physical illness.
- Cognitive impairment, functional disability; and the presence of problem behaviors in the care recipient are linked to the hours of informal care provided to the senior, which relates to primary stressors.
- Role overload: Caregivers to family members with progressive dementia are more distressed than the general population. Some difficulties of family caregivers of people with Alzheimer disease are seen from these statements by daughters caring for their mothers:

After a year, I just couldn't do it. Like, she would go to bed as six or six-thirty at night and I couldn't. So at five or six o'clock in the morning, she'd be knocking at the door, 'Are you all right?'—'Yes, mother'"; "I would just encourage people who have Alzheimer's patients to put them in a home because it's very hard to take care of them. Very hard. Even to eat, they're slow to eat, even your own eating is disturbed, and your whole life is disturbed.

- Role captivity is the sense of being trapped in the role as caregiver when one would



prefer to be doing something else. The distinguishing characteristic is not that the role is difficult or stressful, but that it is unwanted.

- Caregivers may come to feel that their spouse or family member has disappeared as cognitive abilities decrease, leaving this stranger with the same physical characteristics to be cared for. They may also have a fear of not being able to handle symptoms.

The secondary stressors of care giving (the stressors caused indirectly by care giving)''

- Over time, primary stressors may generate secondary stressors such as a diminished sense of self that may continue even after the senior's death.
- The care-related stress may have an impact on other social roles such as parent, spouse or worker and may create a diminished sense of self in the caregiver.
- Social support and mastery, that is, maintaining a positive view of one's ability and behavior during the care-giving process, may help to minimize secondary stressors.

Three major themes are related to undertaking the care-giving role.

- Life restrictions: This role combines events and activities impinging on the caregiver's own life. Younger caregivers have particular difficulty with these restrictions.
- Emotional consequences: Caring for a dying family member or friend is clearly stressful and a number of caregivers may have difficulty with the situation. Worries about the future are common. Communication is often difficult, but sometimes families may become closer to the senior or to other family members.

Support received: Family and friends are relied on most often, although help may not always be sought even if it is available. Self-reliance and independence are valued by caregivers and they are hesitant to place additional demands on family and friends. This can lead to caregivers' often feeling quite isolated in terms of emotional support. However, the support of health care and social service providers is usually appreciated.