

Caregiving and the Elderly

Current research suggest the increase for social services among our elderly population, specifically 65 years of age or older, will increase dramatically within the next two decades.¹ Current studies propose that older Americans are living with more chronic diseases and approximately 80% of people aged ≥ 65 have ≥ 1 chronic condition and 50% have ≥ 2 .² The technological advances of the 21st century along with the shortage of nurses and other health care providers, has resulted in an increasing number of the elderly population depending on family and friends to supply their care needs. To better explore an in-depth analysis of caregiving for the elderly, and the associated factors that influences the need for caregiver services, research suggest that the best time to identify and implement futuristic needs are before they are needed.³ This paper will focus on investigating the caregiving needs for elders in the 21st century as these needs pertain to the physiological and psychological impact on the caregiver and interventions to assist the caregiver in coping.

Elderly in the U.S.

Families in the United States are constantly confronted with decisions related to elder care. In the United States, approximately one in every eight Americans (12.4%) is an older adult.⁴ In 2004, the older population, defined as those ≥ 65 years of age, numbered 36.3 million. Translated, this represents a 9.3% increase since 1994. For the elderly, an at-risk group, research postulates by the year 2030, there will be more than 71 million Americans who are ≥ 65 years in age. A relatively small number, 1.56 million (4.5 percent) of the ≥ 65 population lived in nursing homes in 2000. The concerns of

dependence facing our older population suggest that individuals ≥ 65 might require assistance to perform daily living activities; thus, requiring the development of new approaches with respect to strategic planning.⁵

Caregiver

A caregiver is defined as a person who cares for other adults, a spouse, parent, or child, who is diagnosed with cancer, dementia, mental illness, or chronic conditions such as chronic obstructive pulmonary disease or multiple sclerosis.⁶ Caregivers are the spouses, adult children, daughters-in-law, friends, and other relatives such as grandchildren, siblings, nieces or nephews who provide assistance to older adults living in the community. The task of caregiving involves accountability and reliability. Caregiving entails, but is not limited to, grocery shopping, cooking, administering medications, bathing, toileting, dressing, home cleaning, transporting, and feeding. Additional tasks might include a decision-making process addressing financial legalities concerning resident nursing care, living wills, durable powers of attorney, and probate. A proliferation of knowledge can be attributed to the role of the caregiver charged with the innovative abilities to ensure that members of our elderly population are equally protected under the laws and provided with avenues sustaining mobility.

The notion of providing care for the aging elderly population steadily increases. Archbold, Ganzini, Hansen, Stewart, & Westfall⁷ assert that by the year 2050, the aging population of seniors, age ≥ 65 , will amount to more than 80 million. A critical analysis involving the factors of care gives credence to understanding in-depth the role of caregivers and the strain, if any, the role presents.

Statistics on Caregiving

Caregiver statistics^{4,8} show that:

- Approximately three-fourths of all caregivers are women.
- Most caregivers are 35-64 years old.
- The average caregiver is 46 years old, female, married, and working outside of the home.
- Women caregivers spend 50% more time providing care than men caregivers.
- The value of the services family caregivers provide for free is estimated to be at least \$257 billion a year.
- Eighty percent of all home care is provided by family caregivers.
- Three fourths of caregivers providing intense levels of care do not get consistent help from other family members.
- Sixty one percent of caregivers providing at least 21 hours of care a week have suffered from depression, and
- Two-thirds of caregivers have jobs in addition to caring for another person

Types of Caregiving

Two type of caregiving exists, formal and informal. Formal caregiving reflects assistance provided by a service center such as a nursing home, home care agency, adult day care or assisted living facility. On the other hand, informal caregiving denotes

caregiving performed by family, friends, neighbors, and church members. Informal caregiver and family caregiver are terms used to describe those who are not paid to provide care.⁹ Current research shows that over 22.4 million people are informal or family caregivers in this country.¹⁰ Among the elderly population living in the community and seeking some assistance with their daily tasks, 95% have family members involved in their care.¹⁰ Being able to provide effective care constitutes meeting the needs of the elderly. This calls into discussion, for both the caregiver and the elderly care recipient, the following questions:

- How does she/he see themselves in the role of the care receiver?
- What does she/he need from you?
- What can she/he do for themselves?
- Does she/he know what to expect from you?
- Can you meet those expectations?
- What support is available in your family and community?

Spousal Caregiving

In couple dyads, spouses are the primary sources of primary caregiving. However, even when the spouse is the primary caregiver, secondary and tertiary helpers such as adult children, relatives, and neighbors provide financial, practical, and emotional assistance.¹¹ On a whole, the majority of caregiving research has centered on women caregivers since women predominate in this role; therefore, for the purpose of discussing spousal caregiving, wives will be the focus. Wives are an important group of caregivers for several reasons. They are often elderly themselves, have their own health difficulties, and usually provide comprehensive care for the longest periods of time.

Through the process of interpretive caring¹² wives are able to use their knowledge of their spouses, the illness, and themselves to preserve both parties. The process usually involves the wife first noticing the change in their spouse's behavior or their changed responses to the husband's behavior. The wife then takes over the husband's activities and establishes new identities for both parties to accommodate the change in roles and activities. Lastly, the wife manipulates the surroundings to create a new daily life that leaves the spouse safe and comfortable while preserving her own well being.

The care spouses provide can be differentiated into several categories.¹³ Preventative care is described by keeping the spouse safe from harm, giving medications, exercising extremities, and providing nutritious foods. Protective or preventative care is that care that functions to preserve the care recipient's sense of self. Caregivers also carefully monitor the spouse for activity difficulties and provide assistance when required which is labeled supervisory care. Lastly, anticipated care reflects the caregiver's ability to try to predict the care recipient's needs and prepare for them. It is this invisible care that is crucial to the caregiver's experience.

Adult Children Providing Care

As the elderly population ages, the roles of adult children are expanding due to more middle age adults providing care to the elderly population. Approximately 421 hours of home care are provided by adult children annually.¹⁴ In addition to the time given, the adult children are also providing financial assistance to their parents and in-laws in the sum of approximately \$2700 annually. Along with that, many are employed in full-time jobs. One report demonstrates the effect of caregiving on a woman's career. The study depicts that (a) 33% of employed women decreased work hours; (b) 29%

passed up a promotion, assignment, or training; (c) 22% took a leave of absence; (d) 20% switched from full-time to part-time employment; (e) 16% quit their jobs; and (e) 13% retired early.

In this group of care providers, the term “sandwich generation”¹⁵ has been coined to collectively describe middle-aged adults, mainly women, who are caring for elderly parents and dependent children. The main issue for many of these “women in the middle”¹⁶ as they are often referred is work overload and role reorientation. The “women in the middle” are working full-time jobs and caring for their parents as well as having roles as spouses, parents, friends and volunteers themselves. The combination of the change in roles from child to caretaker with their various other responsibilities can be an overwhelming burden.

Others Providing Care

Approximately 25% of caregivers are not direct relatives. As with spouses and adult children care providers, the majority of these caregivers are also women. They are often daughters-in-law and extended relatives. When there are no relatives to assist in the care of the elderly, friends and neighbors will play an important role in helping them to maintain some autonomy by being able to stay in their homes.

Impact of Caregiving

According to Mattoon, health care coverage to 14 million elderly Americans is the largest single budget item. In order to secure the fundamental needs of elderly citizens, with respect to assistance programs for the purpose of ensuring elderly citizens are provided with food, shelter, clothing, medication, and safety, expenditures expanded from 2.8% in 2006 to 6.8% in 2007. Lowder et al. contend that the need to increase the

allotment of financial support to caregivers and caregiver programs for elder care is paramount to negate the process of inadequate care. Although there are many reasons why a person becomes a caregiver, there are even more ways for a caregiver to suffer from psychological and physiological distress which can endanger his or her well-being and limit the ability to provide adequate care to another.

Mental Health Impact

A major issue with caregiving is the impact on the caregiver's mental health. Depression is the primary mental illness diagnosed in caregivers. Studies show that the incidence of depression ranges from 18 to 47 percent in elderly caregivers.¹⁷ Also, it is reported that anxiety is present in 17.5 percent of those caring for the elderly. Both depression and anxiety are usually the result of the stress or burden placed on the caregiver.

Caregiver burden is the strain or stress endured by a person who cares for an elderly, chronically ill, or disabled family member or other person. It is a multidimensional reaction to the physical, emotional, psychological, social and financial stressors associated with providing care.¹⁸ A caregiver's burden is affected by several factors which include: the constant supervision that is required, disruption of family relationships, the mass amount of physical care required, role conflict from many obligations, the demands placed on the caregiver's time and attentions, an adverse impact on employment standing, and the unmet needs of the caregiver.

Research¹⁹ shows that eighty percent of caregivers state that the demands on their time interfere with obligations to family, friends, and career. Seventy percent of caregivers express frequent confinement to their homes as a result of the inability to leave

the care recipient for an extended period of time. Another major stressor for 65% of the care providers is the changes in personal plans to accommodate the needs of the care recipient. Caregivers report last minute cancellations of vacations and outings and frequent adjustments in daily schedules for accommodation purposes. In addition, 75% state that the physical impairments such as bladder and bowel incontinence along with the cognitive changes are upsetting due to the effect on marital, family and social interaction.

Seventy percent of care providers report financial burdens.¹⁷ Hardships are endured when the care provider has to hire someone to assist in providing care. Other expenses are incurred by the services provided by nurses, therapists, and physicians; medication costs; and special equipment. The financial burden is also seen with employment effects. Caregivers report turning down employment opportunities, changing from full-time to part-time employment, or retiring. Others lose money by arriving to work late, leaving early, or being called home from work to care for the recipient.

Caregiver burden often progresses to caregiver burnout, the state of physical, emotional, and mental exhaustion that may be associated with a change in attitude from positive and caring to negative and unconcerned. Caregiver burnout manifests in several ways. The caregiver may have an increase in somatic complaints such as headaches, indigestion, or changes in appetite. Caregivers may also have signs such as irritability, insomnia, social isolation, fatigue, weight changes, changes in appearance, and greater use of alcohol or other drugs. The most evident signs are increase anxiety and stress.

As a result of the stress and anxiety, their problem solving is often circular. An example of this is: "I can't afford counseling because I can't get a job because I can't

leave the house, and a counselor couldn't help me with that anyway." The caregiver will often find themselves socially isolated from friends and family members due to the demands of caregiving. Depression, powerlessness, and guilt of not meeting their own expectations will set in if the caregiver does not have some way to relieve their feelings of stress.

Beyond the affects seen in the caregiver, caregiver burnout can also have consequences for the care recipient. The emotional and psychological distress in the caregiver can result in the institutionalization of the care recipient. Elderly neglect is a second consequence. The caregiver may not be able to handle the responsibilities of providing care; thus, subjecting the care recipient to inadequate nutrition, hygiene issues, extended bed rest and failure to adhere to medical treatment. Taken to the extreme, the end result may be the infliction of willful physical injury or mental anguish, unreasonable confinement or deprivation known as elder abuse.

Physical Impact

Caregivers are at risk for physical health effects as a result of the high rates of mental health problems and the physical demands of caring for a loved one. Approximately 25% of caregivers suffer from health problems related to their caregiving activities. Research demonstrates that caregivers have worse physical health, increased morbidity, and a greater number of illness-related symptoms than noncaregivers and those with higher levels of caregiving stress are more likely to rate their health as poor, express more symptoms, and report poorer physical function.^{20,21}

One in ten caregivers reports that caregiving has worsened their physical health.²² Females who spend nine or more hours per week providing spousal care increase their

risk for heart disease twofold. Other effects seen include: elevated blood pressure and risk of developing hypertension, lower perceived health status, poorer immune function, slower wound healing, and an increased risk of mortality. In addition to these health problems, caregivers have several other stress related health effects such as: insomnia, diabetes, anemia, ulcers, heart palpitations, headaches, and weight gain.²³ Caregivers also are less likely to have their own health needs met. For example:²⁴

- Spousal caregivers who give 36 or more hours per week of care are more likely to smoke and consume more saturated fat.
- Women caregivers are twice as likely not to fill a prescription due to the cost when compared to noncaregivers (26% vs. 13%; respectively).
- Approximately three quarters (72%) of caregivers reported that they had not gone to the doctor regularly as they should, and greater than half (55%) had missed doctors appointments.
- Caregivers' health suffers because they lack the time and energy to prepare nutritious meals or to exercise. About six in ten caregivers in a national survey reported that their eating (63%) and exercising (58%) habits are worse than before.
- Caregivers that live in rural areas have more of a disadvantage for having their own medical needs met due to difficulty getting to the hospital and doctor.
- Caregivers experiencing stress have mortality risks that are 63% higher than noncaregivers.

Interventions

Nurses, physicians, and other healthcare providers who recognize caregiver burden can initiate appropriate interventions. These interventions include:^{25, 26}

- Providing more support to the caregiver. This includes advice about arranging the care recipient's medications, activities, and toileting to promote sleep in the care recipient and caregivers.
- Acknowledging the role of the caregiver so that the caregiver will know that others value their contributions,
- Referring the caregiver to classes for caregivers. This will enable the caregiver to educate themselves on the physical and mental care issues, community resources that are available, and legal and financial issues. Through this knowledge they can gain confidence in their roles as caregivers.
- Encouraging involvement in stress management classes. Stress management skills decrease stress, if they are learned and practiced,
- Referring caregivers to support groups. These groups offer social and psychological support by helping the caregiver realize they are not alone in their roles as caregivers. Those who provide care are able to learn from the experiences of others and share their own experiences.
- Referring the caregiver, care recipient, and the care recipient's family to counseling. This gives everyone an opportunity to voice their feelings and concerns in a therapeutic setting to build better relationships.
- Informing the caregiver of all available community services and resources. It is important to stress to the caregiver that the need for assistance is not an admission

of failure. Ensure that the care provider is fully aware of services such as respite care and adult day care services. Respite care²⁷ provides planned temporary, intermittent relief for the caregiver from the responsibilities of caring for the care recipient. Respite care is provided in various ways. Typically, a trained person will come to the home to care for the care receiver. Depending on the needs of the elderly person, an adult day care center can also care for the person. Some nursing homes or assisted living facilities also offer their services for caregivers to take vacations

Successful Programs

For a program to be successful it must be comprehensive, long-term, and individually tailored to meet the needs of the caregiver. The Rosalynn Carter Institute for Caregiving (RCI)²⁸ works on the local, state, and national level to provide support for caregivers in the form of developing a curriculum for caregiver leaders, conducting a needs assessment of caregivers, offering conferences and education for caregivers, and recognizing outstanding caregivers. The mission of RCI is to build more effective long-term care centers and provide more recognition and support for millions of caregivers. A second effective program is the Help of Ojai.²⁹ This is a 35 year old community agency located in Ojai, CA that offers caregivers classes in English and Spanish. In addition to those classes, Meals on Wheels, transportation services, a hospice, an adult day care program, and senior center is provided.

Conclusion

Caregiving in the United States represents an integral part of our civilized society. In support of our inalienable rights, being Life, Liberty, and the Pursuit of Happiness, the

type of care provided to elders remains a critical construct of Americanism. As only 10% of elderly Americans need long term care, the remaining 90% reside alone or with other family members. Caregiving involves sharing crucial responsibility with respects to providing care, sharing information, managing resources, and actively participating in a process of shared decision-making for the united purpose of maximizing all efforts to sustain an appropriate quality of life for members of our elderly population and for those that are providing care to our elderly.

Caregiver Resources

Administration on Aging
<http://www.aoa.gov>

Family Caregiver Alliance
<http://www.caregiver.org>

National Adult Day Services Association, Inc.
<http://www.nadsa.org>

National Association of Area Agencies on Aging
<http://www.n4a.org>

National Family Caregivers Association
<http://www.nfcacares.org>

National Family Caregivers Support Program
<http://www.aoa.gov/caregivers>

The National Respite Locator Service
<http://www.respitelocator.org/index.htm>

Eldercare At Home – Guide for Caregivers
(American Geriatrics Association)
http://www.healthinaging.org/public_education/eldercare/contents.php

Tips for Caregivers of People with Alzheimer's Disease
(National Institute on Aging)
<http://www.alzheimers.org/pubs/careguide.htm>

Guide to the Family & Medical Leave Act:
(National Partnership for Women and Families)
<http://www.nationalpartnership.org/portals/p3/library/FamilyMedicalLeave/FMLAGuide5thedition02.pdf>

Can We Talk? Families Discuss Older Parents Ability to Live Independently
(AARP)
http://research.aarp.org/il/ind_liv.pdf

Fact Sheet: Caregiving and Depression
(Family Caregiver Alliance)
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=393

Explaining Medicare to Caregivers
(Center for Medicare Education)
<http://www.futureofaging.org/PublicationFiles/EBPRApril051.pdf>

Prepare for Your Role as Caregiver
(American Federation of State, County and Municipal Employees, AFL-CIO)
<http://www.afscme.org/wrkplace/elder03.htm>

Caregivers: Rewards and Burdens (Myths of Caregiving)
(Center on Aging, University of Missouri-Kansas City)
<http://iml.umkc.edu/casww/caregivg.htm>

GeroNurseOnline
<http://www.geronurseonline.org/>

Paying for Long Term Care
(American Health Care Association)
http://www.longtermcareliving.com/financial_information/index.htm

An Easy 8 Step Guide to Selecting A Respite Center
(Health Caregiver.Com)
http://www.healthycaregiver.com/html/8_easy_step_guide.htm

Hiring In-Home Help
(Hospice Net)
http://www.hospicenet.org/html/hiring_help.html

Hiring In-Home Help
(Family Caregiver Alliance)
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=407

Endnotes

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