

Informal Caregiving

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Background

Advances in medicine and nutrition are enabling people to live longer. However, living longer is accompanied by increased risk of debilitating diseases such as cancers, Alzheimer's disease, Parkinson's disease and stroke. These illnesses often have as great an impact on family members as those who are diagnosed with the condition. Currently, many middle-aged adults are caught in the middle of raising a family, holding a full-time job and caring for their aging parents, friends or relatives. In addition, older adults often become the full-time caregivers to their chronically ill spouses.

We often think of those who provide care as trained doctors, nurses and other health care personnel. But, when a person has a chronic illness or physical disability in which the basis of his or her medical care is assistance with eating, bathing, dressing, shopping, transportation etc., a family member or friend is often qualified to assist in these daily activities and often takes on the informal role of the primary caregiver. There are now over 52.4 million informal caregivers in the United States who care for their aging friends, spouses, extended family and children with severe disabilities well into their retirement. The roles that informal caregivers play are not only important to the people for whom they provide care, but also the overall economy of the state and the nation. Informal caregiving comes with many personal rewards and satisfaction, but also with emotional, physical, and financial challenges. Informal caregivers often go unnoticed and with less than adequate support at the local, state and national levels. As America's baby boom generation reaches retirement, the number of elders, and in turn the number of individuals requiring care, will continue to increase. It is vital that the leaders from all realms of society from public officials and policy makers, to clergy and educators, to the community-at-large, work together to provide recognition and assistance to the informal caregivers that play such an important role in our society.

Problem Statement

Informal caregivers often derive satisfaction and fulfillment from their relationships with those for whom they provide care. However, caregiving can be a physically and emotionally exhausting job, and people who provide care to their aging friends and relatives often do not receive the training, guidance or support necessary to carry out their responsibilities effectively. Because caring for friends and relatives is not considered an "official job", informal caregivers often do not know who to contact for information and support for both themselves and for those for whom they provide care. In addition, because their role as a caregiver is considered voluntary, the federal, state and local resources to assist them have traditionally been quite limited.

Caregivers, regardless of age, sex, race and ethnicity, report problems attending to their own health and well-being while managing caregiving responsibilities. Not uncommonly, they report: sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when ill, and postponement of or failure to make medical appointments. The physical and emotional fatigue of caregiving can result in depression, exhaustion and inability to function effectively in their personal and professional lives. The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age can place you at risk for significant health problems as well as an earlier death. To compound the problem, there is

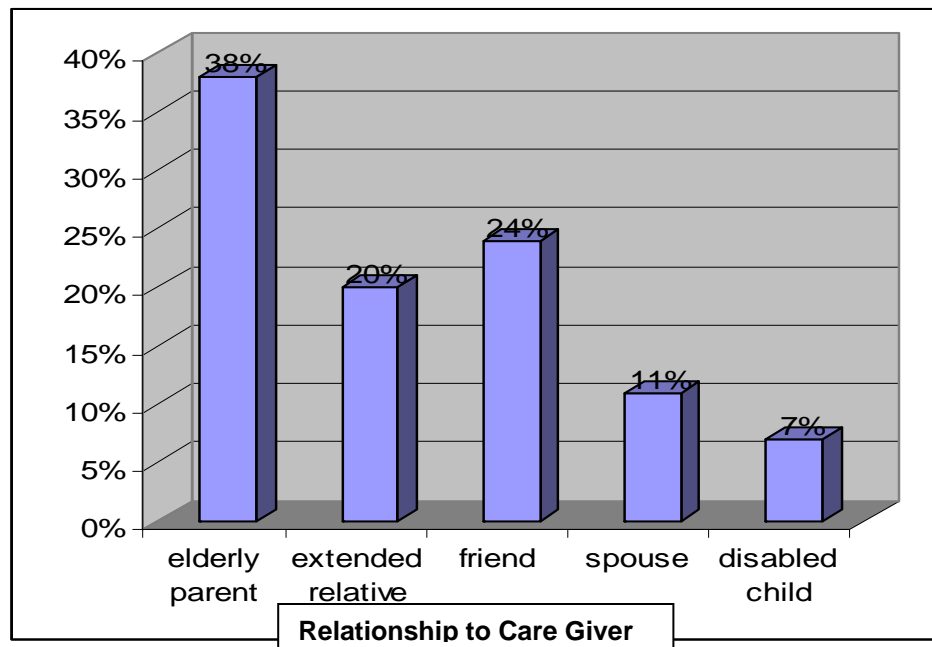
minimal financial assistance available at the federal and state levels to support informal caregiving, though informal caregivers save the federal government hundreds of billions of dollars a year in the care they provide privately.

Trends in Informal Caregiving in the State of Maine and the Nation

Caregiver Demographics

- More than 22.4 million people in the United States are informal caregivers.
- Caregivers are most commonly women (61%) and between the ages of 50-64 years of age (30%).
- The most common informal caregiving relationship is between a child and an aging parent. At least 7 million Americans are caring for a parent on any given day.

National Statistics of Informal Caregiving Relationships in the United States



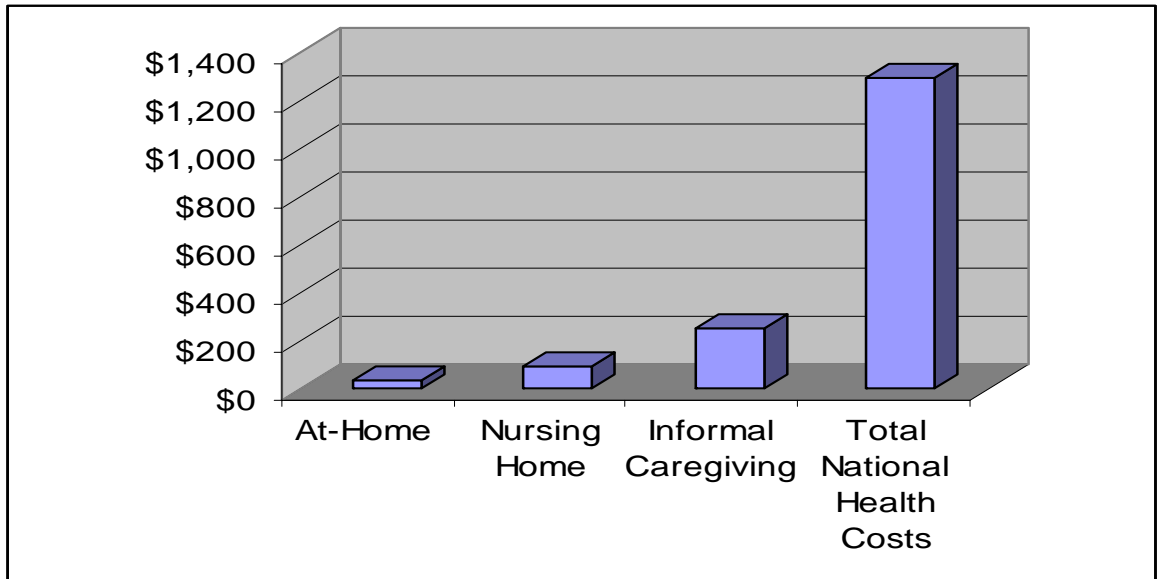
Source: Family Caregiver Alliance, 2000

- Studies show that an estimated 46% - 59% of caregivers are clinically depressed. (However, caregiving in and of itself does not result in depression.)
- Caregiving spouses between the ages of 66 and 96, who are experiencing mental or emotional strain, have a risk of dying that is 63% higher than that of people the same age who are not caregivers.

Economic Impact of Caregiving

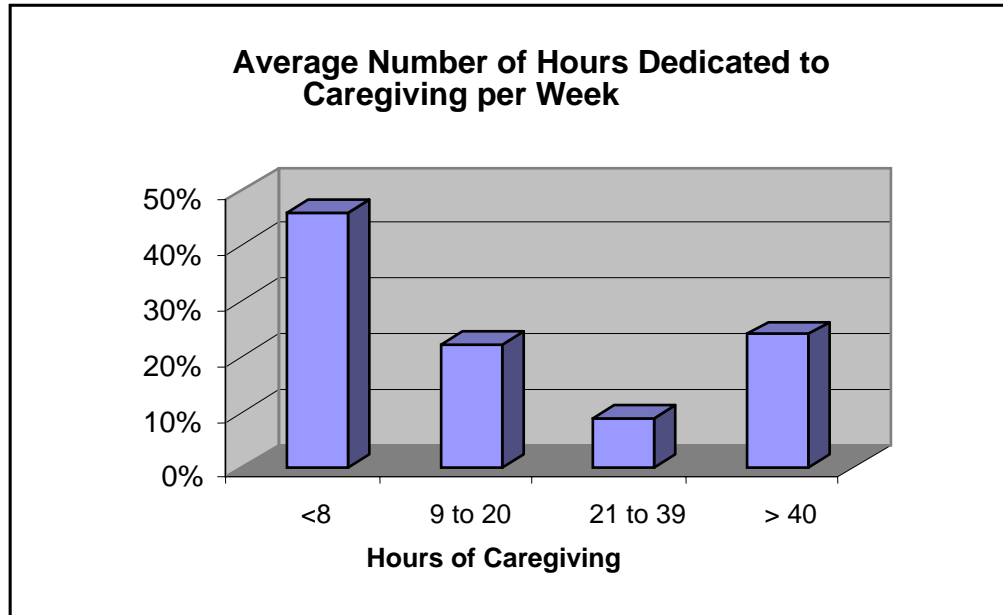
- Most older persons with long-term care needs – 65% – rely exclusively on family and friends to provide assistance.
- The economic value (to the U.S. government) of family and informal caregivers has been estimated at \$257 billion annually.

**Total Annual Costs of Different Forms of Healthcare
in Billions of Dollars, 2000**



Source: Office of the Actuary, Levit Kay, et al., Health Affairs, 2002, Arno, 2002

- Fifty nine percent (59%) of caregivers either work or have worked while providing care.
- Eventually, approximately 12% of working caregivers quit their jobs in order to provide informal care full-time. Work disruptions due to employee caregiving responsibilities result in productivity losses of \$1,142 per year per employee nationally.
- Twenty four percent (24%) of informal caregivers provide care 40 or more hours a week.



Source: National Survey, Arno, 2002

- As the baby boom population ages, the need for informal caregiving is likely to rise nationwide.
- Maine is currently the oldest state in the nation (based on median age - 40.6 years), indicating that the need for informal caregiving for state residents is likely to continue to increase.

Options

Receiving support from friends, family, and formal services is often critical in relieving some of the stress of providing assistance to someone who has a chronic illness. A combination of assistance from a variety of sources can ensure that both the caregiver and those to whom they provide care maintain their physical and emotional health.

Informal Help from Friends and Family

In some cases, while one person takes on the role as the primary caregiver, others who are close to the caregiver and/or the one who is providing care can work out a schedule to offer supplemental assistance to the caregiver. The caregiver can take this time to tend to his/her own needs and obligations (designated respite time), and the person receiving care can look forward to weekly visits from others that expand their social circles. In addition to having others come in to help with the daily care of an aging friend or relative, weekly in-house gatherings with others can help alleviate feelings of depression and boredom for both caregivers and those who receive care. Often both the caregiver and the person for whom they provide care can feel trapped in their home and/or immediate community, but there are options. Many vacation sites offer senior-friendly discounts and provide physical accommodations for disabled guests. The caregiver and the person to whom they are providing assistance can both experience positive emotional and physical effects from a change of scenery.

Adult Social Day Groups

There are some outside sources for caregivers and those for whom they provide care as well. The State of Maine Department of Health and Human Services offers a variety of programs for older adults to come together during the day. Some of these programs cater to adults with chronic illnesses such as Alzheimer's disease while others are designed to give older adults an opportunity to interact with their peers.

State Agency Support

The reauthorization of the Older Americans Act and the National Family Caregiving Support Program (NCSP) on November 13, 2000 required that Maine's five area agencies on aging provide information, assistance, individual counseling, organizations of support and caregiver training, respite care and supplemental services to caregivers of older adults or grandparents over age 60.

Assistance with Meal Preparation

In many areas of the State, volunteers and paid staff at Maine's five area agencies on aging deliver meals to older and disabled people who are homebound and unable to prepare well balanced meals for themselves. The meal is packaged in a special container to make sure that when it arrives, the meal is hot and ready to eat. Taking advantage of these programs can help relieve the responsibilities of an informal caregiver.

MaineCare

Those with chronic medical conditions often require on-going medical care. The program MaineCare is designed to offer assistance to those who cannot afford medical services, which, in turn, can help lessen the financial strain of their illness on overall household income.

In-home Help: In-home Respite and Home Care

In-home Respite: A state-funded program to assist both formal and informal caregivers, provides caregivers several hours a week of time off from their caregiving duties occasionally or on a regular basis. In addition to assistance during the day, this program offers up to two weeks a year of *overnight respite* and is available at certain nursing homes, residential facilities, or even at home. The "Partners in Caring" program at your local Maine Agency on Aging may help to cover the cost of these respite services.

Home Care: Combines health care and supportive services to help homebound sick or disabled people continue living at home as independently as possible. The hours, types of services, and level of care provided offered depend on the health and needs of the care recipient and the caregiver; physician approval may be needed. Home health care services can assist with medical needs, nursing services and physical therapy, while non-medical services include help with daily chores, housekeeping and good conversation. The more medical expertise needed, the more expensive these services will be. Fees vary from agency to agency, so it is best to shop around.

Employment Assistance/Protection: Caregiving can often make it difficult for the caregiver to maintain full-time employment. Caregivers are encouraged to contact employers to see if there are ways to alter their hours, location, etc. in order to accommodate their informal caregiving role. Some employers have already instituted programs and policies to help with this issue (see *Implications for employers* below). By law, companies with 50 or more employees must comply with the *Family and Medical Leave Act* (FMLA), which protects job security while providing for up to 12 weeks of unpaid leave to care for a seriously ill parent, spouse or child. Smaller firms can use the FMLA guidelines to provide support for individual employees. Unfortunately, FMLA does not offer assistance to those providing care to distant relatives or friends. However, the guidelines offered by FMLA can serve as a resource to employers who wish to accommodate employees involved in other caregiving relationships.

Transportation Assistance: The Americans with Disabilities Act (AAA) requires transit agencies to provide curb-to-curb paratransit service to those individuals who are unable to use regular public transportation. Paratransit generally consists of wheelchair-accessible vans or taxis for people with disabilities. Paratransit may be run by private, nonprofit, and/or public organizations and is usually free or low-cost. In addition, in more rural communities (which describe the majority of the state of Maine) there may be volunteer driver services to help older adults get to doctor visits and other appointments. These services can help relieve caregivers throughout the state and allow them to balance the transportation needs of those for whom they provide care and other obligations. It should be noted, however, that these services are unevenly distributed throughout the state and are less likely to be available in extremely rural communities.

Legal Assistance: It is important that both the caregiver and the person for whom he/she is providing care plan for the future. A lawyer can help those who receive care and their caregivers: Legal issues that can challenge the caregiver include: 1) formal instructions as to how the assets of those who receive care should be spent; and 2) specification of the kinds of medical assistance those who need care wish to receive if there comes a point at which they cannot speak for themselves. A durable power of attorney (DPA) and a durable power of attorney for health care (DPAHC) addresses these situations. These two different sets of documents enable a person to designate another person to manage his/her finances and health care decisions. Through these documents a caregiver has the legal means to ensure that the one to whom they are providing care can have his/her wishes carried out.

Because laws vary from state to state, caregivers and the people for whom they provide care should consult with an attorney who is knowledgeable in estate and assets management for assistance in legal planning. One way to locate an attorney is through an attorney referral service. *The Bar Association* in your community may have a panel that refers callers to lawyers in various specializations. Initial consultations generally include an introductory fee.

Barriers

Barriers to informal caregiving include a lack of public awareness of the prevalence of this important and demanding role in our society, and lack of knowledge of the limited assistance available to these individuals. Information is not readily available, not only to the general public but to those giving and receiving informal care

Informal caregiving is often considered to be a volunteer activity and/or a choice freely made by family and relatives. As a result, friends, employers, community members, policymakers, and relatives themselves tend to see it as a personal issue between the caregiver and the person for whom he/she provides care. It is not seen as an issue automatically warranting supplemental assistance from other informal supports or formal community agencies.

Caregivers can potentially feel that they have an obligation to keep the needs of the people for whom they provide care private. In addition, informal caregivers often see themselves as responsible for the care of their loved ones and feel guilty, or view it as a personal failure if they are unable to meet these needs on their own.

The laws surrounding job-leave, available to those who provide informal care, require the person for who care is needed be a close relative, which is often not the case in caregiving relationships. In addition, these laws are only applicable when the person receiving care is near death and do not protect the jobs of people in long-term informal caregiving relationships.

There is limited formal support to those providing informal care. Governmental programs are usually restricted to only those under a certain income, and many require out-of-pocket expense, so that not all people qualify or can afford to take advantage of the few programs available.

Implications

Implications for Caregivers

Caregivers can take steps to ensure that their needs and the needs of those for whom they provide care are met. Paying attention to their own health, keeping lines of communication open by voicing their needs to family, friends and community members, as well as educating policy members can help them cope with the stresses of taking care of a loved one who is chronically ill.

Family and friends of elders should make an effort to discuss their wishes for care if and when they need it, while they are still healthy. If a plan is in place to support the primary caregiver and the person who potentially needs care before illness occurs, both members are less likely to become overwhelmed when conditions change.

Caregivers should make every effort to maintain their own health. This includes, but is not limited to, eating a healthy diet, having medical check-up, and exercising regularly. As little as a thirty-minute walk or an hour or two working in the garden can help manage stress and lessens the chances of heart disease and stroke. It is also important to help those to whom they provide

care also maintain a healthy lifestyle (under the consultation of a doctor). The healthier emotionally and physically the person for whom they are providing care is, the less stress he/she will put on the caregiver.

Caregivers should take an active role in finding assistance for both themselves and those receiving care. Friends, relatives, and formal care services can offer relief to both members in the caregiving relationship and though often not readily apparent, should be sought out.

Caregivers provide a unique perspective to policy makers and government officials, and it is important that those making decisions that greatly affect both caregivers and those receiving care, be informed of their concerns. Personal family experiences with service agencies, 'round-the-clock' care, and financial and emotional hardship can translate into compelling scenarios to be shared with policy makers and program planners. This puts family caregivers in a unique position to act as advocates. Caregivers can educate elected officials charged with development of public policy and determination of funding priorities. Advocacy does not have to be time consuming. Phone calls to a local or state senator or representative's office, and short letters that directly voice support for particular bills or budget decisions with personal justification can provide policy makers with the information they need to help family caregivers and their infirm relatives.

Implications for Policy Makers: Support/Institute Programs that Assist Caregivers

While there are some laws in place to assist caregivers, overall these individuals lack recognition, information about available resources, education regarding caregiving, financial support, and personal assistance to cope with the stress associated with their helping role and responsibilities. The implications for policy and programming are multiple.

Consideration can be given to legislation that requires that employers provide reasonable accommodation to meet the needs of their employees who are informal caregivers. This is essential if those who are providing care are to be able to also support themselves. Many caregivers are not close relatives of, or even have legal or blood-relationship with the person for whom they provide care. Legislation that supports caregivers despite their relationship to the chronically ill person may be worthy of consideration on both humanitarian and economic grounds. As a rule, the cost of formal care is much greater than that of supporting informal caregivers.

Programs that encourage local, state and nationwide campaigns to promote awareness of the vital role that informal caregiver play in the United States appear needed in terms of the ways in which they support family well-being and bolster the economy. Their need for financial and personal support needs also to be better appreciated by the public-at-large. Arguably, the majority of the U.S. population is unaware of the significance of informal caregiving. Campaigns could potentially include, but are not limited to distributing/making available flyers (carried by direct care workers and placed in medical settings), advertising, mass mailings, businesses using billing stuffers, and challenges issued to foundations to do more outreach on the topic of caregiving. These campaigns could also be used to publicize currently existing programs that support caregivers.

Lack of awareness of currently available resources is a definite issue for caregivers. Programs supporting the creation of informational materials that are made available to healthcare providers, town and state officials, clergy and other leaders in the community to distribute to caregivers to enable them to receive more support appear needed. In addition, educational campaigns appear needed that would focus on hospice, dying with dignity, and the roles played by family and friends in such situations.

Many informal caregivers struggle financially in an effort to provide adequate care to their chronically ill friends or relatives. These individuals would benefit from the support of programs that offer financial assistance to those who need to give up their jobs or decrease their hours in order to provide informal care to a family member or friend. The emphasis on how financial assistance made available earlier on in the caregiving process could save the public from additional demands in terms of long-term care provides justification for such a program.

Implications for Employers

Though still relatively rare, informal caregiving is now recognized by a growing number of employers. As caregiving becomes an increasingly common obligation of employees, and a recognized component of the United States economy, employers should begin to more voluntarily look into ways to accommodate their employees who are informal caregivers. Employers can provide aid and support to their employees with caregiving responsibilities in a variety of ways. The most readily available service that an employer can offer a caregiver is time, flexible hours, decreased work schedules, the option of family/friend-illness days and working from home. These options can help a caregiver balance the demands of work and meeting the needs of the person receiving care.

Employer human resource staff can also help caregivers get in touch with counselors and support groups to help them cope with the stress of caregiving. In addition, in some cases, employers can consider offering private long-term care insurance coverage for employees, their spouses, and dependents to lessen the financial burdens of caregiving.

Community Implications

Informal caregiving is a vital part of Maine's culture and economy and should be supported on a private and public level. Community leaders should work to institute local campaigns to educate the community in the importance of caregiving. Various organizations in the community, charities, businesses, and religious institutions should recognize the importance of informal caregiving and work to coordinate efforts to assist these individuals in the community.

Volunteers who provide a few hours a day of help with informal caregiving can dramatically improve the quality of life of both the caregivers and those for whom they provide care. If volunteer programs are already in place within a community it is easier for the caregiver to seek out help if and when needed. Benefits can be expected to accrue to volunteers because of the personal satisfaction of helping others at the same time that they are developing friendships that grow out of their involvement with both the caregiver and care recipients.

End Notes

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