

“Who Cares?”

Public Policy on Support for Alzheimer's Disease Caregivers

Emma Quinn

Writing 50

Gina Vallis

December 3, 2009

Abstract

This paper explores the role government has in providing support for Alzheimer's caregivers. It discusses the effectiveness of current government-funded counseling programs which use allocations of federal and state budgets. The paper examines Medicare policies and changes in legislation relevant to the experiences of Alzheimer's caregivers. The paper looks at the deinstitutionalization movement as a key event in assigning family members responsibility in providing mental health care. The analysis of services available for Alzheimer's caregivers reveals policies that contribute to caregiver burden and inhibit establishment of intervention programs. With the onset of an Alzheimer's epidemic fast approaching there is an urgent need to create policies that provide more support for caregivers.

In 2009, families in the U.S. provide an estimated 94 billion dollars worth of unpaid care for those suffering from Alzheimer's disease (Alzheimer's Association, 2009, p.35). The healthcare system relies heavily on families to provide long term care for those with chronic conditions like Alzheimer's Disease, which is a progressive and fatal neurodegenerative disorder that causes severe memory loss and decline in brain function. Alzheimer's caregivers experience high levels of emotional stress, fatigue, financial burden, poor health, employment disadvantage, and in many cases clinical depression. These negative effects of caregiving can be described collectively as "caregiver burden."

Current Medicare and private health care insurance policies are designed only to cover treatment of acute illnesses, and do not provide coverage for long term care. These policies leave the costs of providing care and the administration of care the assumed responsibility of the family members of the person diagnosed with chronic conditions like Alzheimer's Disease. There are also extremely limited federal and state funded support programs or counseling services available for Alzheimer's caregivers.

The lack of long term healthcare coverage and availability of support services for Alzheimer's caregivers is problematic, as just because families are willing to assume roles as caregivers does not mean that policy makers are absolved from the responsibility of assisting in care. Particularly as intensive caregiving causes serious harmful effects on the health of those providing care. This problem brings up the following questions: Whose responsibility should it be to provide care? And should care or support provided by the government be limited to the person who is sick?

Burden Matters

With no current cure or effective disease altering treatment the care of Alzheimer's patients consists of maintenance of general health, assistance with daily living and control of problematic behaviors. The disease causes severe and progressive cognitive impairment Alzheimer's caregivers are required to provide increasing amounts of assistance with daily activities such as preparing food, finances, dressing, and bathing. Caregivers often provide close supervision of those with Alzheimer's to ensure they avoid unsafe situations and monitor their behavior.

Providing care for those with Alzheimer's can be traumatic as the disease causes severe behavioral and personality changes. Those with the disease may resist care, become superstitious and angry towards loved ones and have emotional or violent outbursts. The vast amount of assistance for daily living needed and behavioral symptoms contribute to high levels of emotional stress among Alzheimer's caregivers. Survey results from the Alzheimer's Association facts and figures report (2009) demonstrated that over 40 percent of Alzheimer's caregivers rated stress as high or very high (p.40). As the disease progresses slowly, family members often end up providing care for multiple years and are therefore under high levels of stress for long periods of time. The effects of high stress levels are intensified by the chronic fatigue associated with providing long hours of care without periods of relief.

There has been a lot of evidence recently to suggest that there is a strong relationship between chronic stress and poor health and not surprisingly Alzheimer's caregivers have lower immune function, higher levels of new coronary heart disease and hypertension than non caregivers (Alzheimer's Association, 2009, p.40). These statistics are strong evidence to show that caregiving has serious negative effects on the health of the caregiver.

As the disease progresses caregivers have less free time to spend with family and friends which often leads them to feel socially isolated. Reduced social networks can lead to caregivers to have fewer people to look to for support and relief from the tolls of caregiving. Conflicts can arise in families caring for those with Alzheimer's over issues such as shared responsibility of providing care and disagreements over financial coverage. These family conflicts are considered negative social interactions which can add to levels of caregiver stress and isolation. According to Lobarabhu, Lomax, and Molinari (2006), Pilemer, Sutor and Wetthington performed a study in 2003 which showed that improving social networking by using support groups to connect Alzheimer's caregivers was an effective way of reducing feelings of social isolation (p.67). This study indicates that providing support groups might be a useful strategy in reducing the social toll of caregiving and help improve caregivers wellbeing by providing a positive outlet for sharing experiences of the struggles and rewards of care with others who are in similar situations.

Providing Alzheimer's care can become in itself a full time job it is not surprising that caregivers suffer in the workplace. Caregivers may be forced to quit work or take on a less demanding job in order to provide care. The Family Medical Leave Act (FMLA) was established in order to stop employees from losing their jobs whilst caring for family members who are ill. The act only provided up to 3 months unpaid leave for children or spouses of patient. (United States Department of Labor, 2009, p.1). The benefits of this legislation for Alzheimer's caregivers are limited. Due to long term progression of the disease caregivers are often responsible for providing care for multiple years so the three months of leave allowed does not come close to covering the time frame of the disease. The leave permitted is also unpaid which is of limited advantage to the average family trying to cover the large medical bills

associated with Alzheimer's treatment. There are additional constraints that rule out eligibility for medical leave if employed by a small business.

In 2004 California made changes to its FMLA policy by introducing the Paid Family Leave insurance (PFL) which allows caregivers to take 6 weeks of partially paid (up to 55%) leave each year (California Employment Development Department, 2009). Although 6 weeks is a short period of time this compensated leave is a notable improvement from the original restrictions of the FMLA Act. The changes will benefit caregivers and is an example of governmental progress towards better support for caregivers. California is currently the only state in the U.S. to offer any kind of compensated leave for family caregivers. Both FMLA and the PFL policies are still limited to only allow leave for spouses and children and therefore exclude caregivers who are friends or non nuclear family members.

Effectiveness Matters

The New York University Counselling and Support Intervention for Caregivers performed a government funded study on the effectiveness of an intervention program for Alzheimer's caregivers. In this 2004 study Mittleman, Roth, Coon, & Haley used a combination of family counseling, weekly support groups and a phone support line for participating caregivers (p.851). Caregivers assigned to the intervention program showed significantly reduced depressive symptoms and a less negative approach to managing behavioral and memory problems than the caregivers in the control group. The study showed that providing counseling and support services was an effective method of aiding the caregiver and improving their wellbeing. This study acknowledges that there is a critical relationship between the health of the patient and the health of the caregiver.

In 2006, Mittleman, Roth, Coon, & Haley performed a further study which demonstrated that the intervention program also delayed placement of person with Alzheimer's in a nursing home by approximately one and a half years. The delay in nursing home placement would be beneficial to government as it would reduce the expenses of providing institutionally based care (p.1592).

Despite providing funding for a study that provided evidence that an intervention program would be effective in both improving caregivers wellbeing and delaying nursing home placement, federally sponsored intervention counseling programs have not been established elsewhere. Providing an intervention program would be a cost effective strategy as paying for nursing home care is vastly more expensive than providing caregivers with support groups and counseling services. Due to the severe negative effects on health caused by providing Alzheimer's care there is genuine need for support programs for caregivers.

Funding for research to find effective programs to assist and support dementia caregivers are miniscule when compared to the vast amounts of money poured into the development of drug therapies that have minimal benefits on the progression of Alzheimer's disease. The National Institute of Health estimated budget for Alzheimer's Disease medical research in the year 2009 was 423 million dollars (2009). Whereas the total 2009 federal budget for evidence based support programs for those with Alzheimer's disease was only 6.7 million dollars (Administration on Aging, 2009). This huge discrepancy in fund allocation between medical research and support services for Alzheimer's disease is troubling as although finding a cure for Alzheimer's is essential for future disease control, providing support for those currently suffering with the disease and their families is also vital.

Logistical Matters

Fifty years ago those suffering from mental health disorders including Alzheimer's disease were cared for in government funded psychiatric institutions. Patients were kept completely separate from their families, as it was believed that this isolation would benefit their therapeutic treatment. In the early 1960's there was a huge public outcry about the inhumane conditions in psychiatric facilities. The outcry combined with vast costs of providing institutionally based care led to the deinstitutionalization movement of 1965 (Psychiatry Online, 2007, p. 1383). Community mental health centers (CMHC) were established as an alternative method to providing care but due to major problems with the reallocation of funds during the changeover, community programs such as nursing homes and community centers were not able to meet public demand for care. Families were forced to overtake the responsibility of providing bulk of care for mental health patients.

The failure of institutionally based mental health care and inadequate alternatives available and severe lack of funding and poor planning during the establishment of the CMHC program meant that these services were never given a fighting chance to meet demands of deinstitutionalized people and their families or be an effective model for care.

Money Matters

Persons over the age of 65 with Alzheimer's cost Medicare on average three times more than those without Alzheimer's in the same age group (Alzheimer's Association, 2009, P.49). These higher costs are due to more frequent hospital stays for complications in the treatment of chronic conditions such as cancer, heart disease and diabetes in patients with AD.

As direct care for people with Alzheimer's takes up a large chunk of the Medicare budget there is a reluctance to cover any aspects of care that do not directly benefit the patient.

Medicare has specific codes that restrict coverage of psychotherapy service for family caregivers. Medicare Procedure code 90846 deems counseling without the patient as non-reimbursable (, 2009, p.11). This policy means that no effective counseling is covered as it would be impossible to discuss caregiver burden and concerns honestly and appropriately with Alzheimer's patient present. The code also rules out the possibility of cost effective strategy of having group therapy sessions for caregivers that was demonstrated to be effective in the NYU intervention study.

The California State Plan of Aging (2009) addresses issues specific to aging population. One of the goals in the plan is to "Enable older Californians, adults with disabilities and their caregivers to be supported in their homes and communities"(p. 5). The initiatives to achieve this goal are focused on the principles of "volunteerism" and "community outreach". The Plan discusses its reliance on volunteers to provide services for aging population and a need for community outreach to provide support for aging population. Reliance on only volunteer and community outreach to support aging population and their caregivers makes it difficult for government to ensure that the appropriate services are available based on needs as it becomes the duty of local communities to maintain levels of support. These policies could contribute to vast regional differences in availability of support services as there are no means to regulate the distribution of the services in place.

The State plan expressed acknowledgment of caregiver burden and need for support for caregivers. It called for an expansion of evidence based programs for family caregivers. They suggest expansion of the Savvy Caregiver program which aims to increase supportive services, reduce stress and improve caregiver skills. But the grant budgets set aside to cover these programs does not come close to the funds required to provide an effective statewide service.

The total 2009 California budget set aside for Alzheimer's disease supportive services program is \$1564, 382 (Administration on Aging, 2009) which when divided by the 1.1 million people in California currently caring for someone with Alzheimer's disease(Brennan et Al., 2009,p. 1) comes to one dollar and forty two cents per caregiver. This sum is barely enough to pay for a cup of coffee, let alone effective support and counseling services. Without allocating sufficient funds to providing appropriate support for caregivers can never be established or effective.

Trust Matters

As part of the reaction to rising medical care costs over the last decade Medicare has established Operation Restore Trust, which is a program designed to reduce fraudulent claims and waste of services. The program included evaluation of services for appropriateness and investigations into claims to monitor legitimacy.

Many of the established reimbursement policies are unfavorable towards Alzheimer's caregivers. In their discussion of Operation Restore LoboPrabhu, Lomax, and Molinari (2006) asserted "While such programs are irrefutably necessary, there are tragic examples of the pendulum swinging to far in the direction of excluding appropriate services"(P.257). For example assisting daily activities of Alzheimer's patients is classified under Medicare code as custodial care which is non reimbursable (Levine, 2004, p.139). With the vast majority of the kinds of care families provide deemed as non reimbursable family members must either pay for formal care out of pocket or provide the care themselves. These policies add to financial burden and stress levels of family caregivers by making it extremely difficult to find care and support that is classified as reimbursable.

Respite is the support service with the most funding allocations for caregivers. Respite is specialized day care for those with Alzheimer's which allows caregivers relief from duties and

leisure time. Respite availability and eligibility requirements vary dramatically between different regions and states. There are strict limitations on amount of respite care time available to caregivers for example using the funding from government grants central coast chapter of the Alzheimer's Association can only provide up to maximum of 29 hours per year (Alzheimer's Association: Central Coast Chapter, 2009). This respite service is intended to be used as emergency relief not for regular time off for caregivers.

The current Medicare policy in place on respite care for caregivers is respite care may be provided only on an occasional basis and may not be reimbursed for more than five consecutive days at a time (Centers for Medicare and Medicaid services, 2009, p.19). As respite is not reimbursable on a regular basis it imposes limits on caregivers use to only situations when stress and fatigue reach crisis levels. The policy does not encourage caregivers to take regular breaks or leisure time. Even though respite care is the most widespread outlet for caregiver support it is designed on the premise that it should only be used when the burden of caregiving is to overwhelming to manage. Post (2000) criticized policymakers by saying " Too much public policy focuses on the needs of individuals whose families have relinquished care because of lack of social support. Instead society ought not to allow families to become exhausted in the first place" (p.39). He calls for improvement in support services for the caregiver that maintain their wellbeing as opposed to overtaking care only when caregivers reach a crisis point.

In 2006 The Life Span Respite Care Act was passed to increase availability of affordable and appropriate respite care for family caregivers. The law will award \$289 million dollars in state grants over the following five years which will be used to recruit more trained respite workers, develop emergency respite services and establish state and local respite programs (National Family Caregivers Association, 2006). This act will benefit Alzheimer's caregivers

and help widen availability of much needed respite support services. This act also indicates acknowledgement from the government of the growing need for caregivers support services to sustain the family unit, which has become the foundation of Alzheimer's management.

Conclusion

The forecast for Alzheimer's caregivers is growing increasingly gloomy. Within the next twenty years the baby boomer generation will all be over 65 years old. The Alzheimer's Association predicts cases of the disease are set to reach epidemic proportions and 11 million people will be affected by 2050 (Alzheimer's Association, 2009, p.22). This epidemic will also lead to a dramatic increase in family caregivers. The resources and current support systems available will be spread increasingly thinly between greater numbers of caregivers. Medicare spending on the disease will skyrocket. Reliance on families to become caregivers will become an even more integral part of the management of disease. But if appropriate support and counseling services are not established the Alzheimer's caregivers of the future will be even more worse off than present day caregivers. The onset of the epidemic has not only stimulated an increase in urgency of finding a cure for Alzheimer's, it has begun to force public policy to evaluate the needs of family caregivers. Marie Shriver, the director of recent HBO Alzheimer's Project has been raising awareness about the disease. In a recent speech to the Senate about the challenges of the disease she urged "We have to put Alzheimer's on the front burner, because if we don't, Alzheimer's will not only devour our memories -- it will cripple our families, devastate our health care system, and decimate the legacy of our generation" (The World Newser, 2009). As more of us will become Alzheimer's caregivers in the coming years, it is imperative that the government prioritizes the needs of the families providing care, increases the availability of effective support counseling services and improves policies that supply caregivers with much

needed relief.

References

- Administration on Aging. (2005, Oct). *Savvy Caregiver: An Evidence-Based Intervention for Alzheimer's and Dementia Care*. Retrieved from Administration on Aging, Alzheimer's disease supportive services program website
http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/caregiver.aspx.
- Administration on Aging. (2009). *Alzheimer's Disease Supportive Services Program 2009 Evidence-Based Cooperative Agreements to Better Serve People with Alzheimer's Disease and Related Disorders*. Retrieved from Administration on Aging, Alzheimer's disease supportive services program website.
http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/index.aspx
- Alzheimer's Association. (2001, April). *Medicare and Medicare Costs for People with Alzheimer's Disease*. Alzheimer's Association. Retrieved from Alzheimer's Association website http://www.alz.org/living_with_alzheimers_medicare_and_medicaid.asp.
- Alzheimer's Association. (2009a). *2009 Alzheimer's Disease Facts and Figures*.p.40 Retrieved from http://www.alz.org/alzheimers_disease_facts_figures.asp.
- Alzheimer's Association California Central Coast Chapter. (2001). *What Now? Caregivers Quick Guide and Resource Manual*. Retrieved from
http://www.centralcoastalz.org/downloads/whatnow_book/What_Now_10-24-06.pdf.
- Brennan, C., Fox, P., Nazareno, J., Ross, L.K., (2009, Feb). *Alzheimer's Disease Facts and Figures in California: Current Status and Future Projections*. Alzheimer's Association. Retrieved from Alzheimer's Association webpage
<http://www.alz.org/cadata/>.

California Department of Aging. (2006). (State Plan). *California State Plan On Aging 2009-2013*. <http://www.aging.ca.gov/publications/default.asp>.

California Employment Development Department. (2009) *Fact Sheet: Paid Family Leave*. Retrieved from http://www.edd.ca.gov/pdf_pub_ctr/de8714cf.pdf.

Centers for Medicare and Medicaid Services. (2009). *Medicare Benefit Policy Manual: Coverage of Hospice Services Under Hospital Insurance*.(p.11-19). Retrieved from <http://www.cms.hhs.gov/manuals/Downloads/bp102c09.pdf>.

Clay, O.J., Haley, W.E., Mittlemann, M.S., Roth, D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*, 67, 1592-1599.

Coon, D.W., Haley, W.E., Mittlemann, M.S., Roth, D.L. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, 161, 850-856.

Levine, C. (Ed.). (2004). *Always On Call: when illness turns families into caregivers*. Nashville. Vanderbilt University Press.

LoboPrabhu, S.M., Lomax, J.W., Molinari, V. (Eds.). (2006). *Supporting the caregiver in dementia: a guide for healthcare professionals*. Baltimore. Johns Hopkins University Press.

National Family Caregivers Association, (2006, December). *President Signs Critical Respite Bill for Family Caregivers*. Retrieved from http://www.nfcacares.org/press_room/detail.cfm?num=93.

National Institute of Health. (2009, May). *Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)*. Retrieved from <http://report.nih.gov/rcdc/categories/>.

Post, S.G. (2000) *The moral challenge of Alzheimer Disease: ethical issues from diagnosis to dying* (2nd ed.). Baltimore. Johns Hopkins University Press.

Psychiatry Services. (2007, October). Deinstitutionalization Movement Provides Lessons for Reforming Long-Term Care in the United States. *Psychiatry services*, 58(10) pg 1383-138.

U.S. Department of Labor: Wage and Hour Division. (2009, Jan). *Fact Sheet #28: The Family and Medical Leave Act of 1993*. p.1. Retrieved from <http://www.dol.gov/whd/regs/compliance/whdfs28.pdf>.

The World Newser. (2009, March). *Maria Shriver Talks About Her Father's Alzheimer's*. Retrieved from <http://blogs.abcnews.com/theworldnewser/2009/03/maria-shriver-t.html>.