

The High Cost of Caregiving for Alzheimer's Disease

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Abstract

As women have increasingly entered the labor force over the past century, their contributions to public institutions have been recognized, while their roles in the home as caregivers has remained undervalued, and often invisible. In the growing epidemic of Alzheimer's Disease, much of the caregiving to treat patients is done by women. Much of this care takes place in the informal sector in homes and communities, and is unpaid. The high costs of caregiving, which come in multiple forms, compel questions about the role this position has in society, along with its recognition in the private and public domain. A review of the literature draws connections among the financial, physical, and emotional burdens, and summarizes current feminist thought on caregiving. The paper concludes by examining possible solutions for the welfare of caregivers, whose number and importance are sure to grow along with the aging population.

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Introduction

Life expectancy has increased since the 18th century, especially in developed countries like the United States (Gapminder, 2012). Researchers expect that 20% of the U.S. population will be 65 or older by 2030 (U.S. Census Bureau, 2014). One of the consequences for this increase in longevity is the growing number of individuals who have developed Alzheimer's Disease, which is now the sixth leading cause of death among the world population (Alzheimer's Association 2014).

Alzheimer's Disease is the leading cause of dementia, which is a degenerative condition that lowers an individual's ability to perform everyday tasks by affecting their thinking, memory, and behavior (World Health Organization, 2012). Approximately 36.5 million people globally and 5 million nationally currently live with dementia. This number is expected to triple by the year 2050 as people live longer and the world population continues to grow.

One third of Americans over the age of 85 are diagnosed with Alzheimer's Disease, whereas one out nine Americans over 65 is afflicted with the disease. Rare cases show development as early as about 40. As signs for the disease typically do not appear until later in life, the gene that increases the chance for its development can be easily passed down through generations. The life expectancy of individuals with the disease is typically four to eight years after diagnosis (Alzheimer's Statistics, 2014).

In addition to Alzheimer's Disease, older adults are at much greater risk of multiple chronic illnesses and diseases as their bodies lose their ability to generate adequate immune responses. In many cases, including one that will be discussed in greater detail later, Alzheimer's Disease is not the only condition that the patient must

attempt to treat, but may be one of several that puts much financial and emotional strain on the caregivers' ability to coordinate their own lives in their attempt to juggle their patients' conditions.

Caregiving for Alzheimer's Disease highly affects the well-being of caregivers financially, physically and emotionally. According to the most recent report by the Alzheimer's Association, 10% more women than men in the United States are currently doing informal caregiving for patients with Alzheimer's Disease. On a global scale, women not only make up nearly 60% of Alzheimer's patients, but 65% of unpaid caregivers for Alzheimer's Disease are women (Alzheimer's Association 2014).

As Alzheimer's Disease and the process of providing care for patients impacts so many women in a multitude of ways, research on the issue, whether medical or political, must take a feminist perspective into account. Women's potential claim to economic benefits has been greatly limited by the role strain between reproductive work at home and the productive work in the public domain (Hooyman and Gonyea, 1995; Cruikshank, 2003). A woman who chooses to care for a loved one at home is often thought to be sacrificing her potential for financial income and independence, limiting her productivity as well as that of the economy (Estes, 2003). Mothers typically give their children their highest investment of time and resources. Caregiving by a mother may continue for an aged parent, a retired spouse, or both, making caregiving a lifelong job for many women.

Financial, physical, and emotional costs of caregiving can be ameliorated with support from the community, coordination with formal services, as well as government assistance in the form of family friendly policies. Adequate services for the growing number of patients with Alzheimer's Disease along with their caregivers will require an

investment of time and resources to develop a health care system that establishes coordinated support and accessibility regardless of gender, race, or socioeconomic background. This literature review will bring together several studies that address current health care systems and support groups that attempt to provide care for patients with Alzheimer's Disease and alleviate the burdens of informal caregiving. This paper explores the pathways by which access to adequate health care for Alzheimer's patients is highly associated with income, gender, race, and ethnicity, and suggests ways that health care systems, that tend to be highly driven by short-term benefits, can attempt to invest more in long-term benefits through highly coordinated health care systems driven by a feminist approach that involves more integration of the private and public sectors.

Literature Review

A Feminist Approach to Health Care Access

To understand why caregiving is such an undervalued occupation, we need to look at historical ideologies of caregiving, gender roles, and family structure as they heavily influence private and public policy today.

Private Sectors of Society

According to Hooyman and Gonyea,

Feminists argue that women perform caring work not because it is natural but because of the dominant societal ideology of separate public and private spheres for men and women in our society, the low value placed on the work of women in the home, societal disregard of the economic costs of caring to women, and the lack of public support for governmental and corporate policies to meet the needs of dependent citizens. (1995)

A critical analysis of women's transition from the private to the public sphere will deepen our understanding of our current archaic, long-term elder care system in the U.S. that is based upon and benefits a predominantly patriarchal family model.

Women's "innate" ability to care is related to female biology and reproduction. In addition to the biological explanation, social learning is also involved in this gendered role. According to Ortner (1976), a psychoanalytical approach to understanding why the role of caregiving is performed by mostly women suggests that girls imitate their mothers closely through observation and, in turn, question their "proper" place within the family. Boys, also primarily raised by their mothers, eventually reach an age for which the social pressure to prove themselves to their fathers molds them to imitate their fathers.

In U.S. society, men are more encouraged to be competitive and resilient to the pressures that could stand in the way of economic success, while at the same time

discouraged to be nurturant and family-oriented. Studies show that these tendencies derive from how men view morals. According to Carol Gilligan's theory on moral language, men have a hard time articulating moral concerns without the use of the moral language of justice and rights, whereas women voice moral concerns with the use of the moral language of responsibility and care (Tong, 2014).

Gendered roles in the private sector and industrialized economies in the U.S. increased in the 20th century as men became the predominant breadwinners, while women cared for the family as homemakers (Estes, 2003; Hooyman and Gonyea, 1995). In other words, men dominated the public realm through politics and business, while women dominated the private sphere of the home. The development of the public domain was changing at a much greater rate than that of the private domain with technological advances, globalization, the free market, and mass production during the 20th century. Meanwhile, the reproductive labor that was performed at home by women was essentially perceived as invisible and undervalued in society (Estes, 2003). The value people put towards care varies across different cultures. For instance, children of South American households with large family structures have a relatively strong social obligation to provide care for an aging parent. Outsourcing care is either not available or not preferred by these families (Bookman, 2011).

Women have experienced oppression as a consequence of their exclusion from economic participation and development in the U.S., and around the world. In actuality, the reproductive work performed by women in the form of care added, and continues to add, significantly to society, but in ways that are not typically defined in economic terms.

Until recently, society was not aware of the true costs of care because the care that women provide in the home was, and is still, not remunerated. Informal care has no economic value and often goes unnoticed in society.

Women in the Public Sphere

In addition to women's work in the home being undervalued, women's work in the public labor force is underpaid. Women earn about 80 cents for every dollar of men's wages, creating incentives for women, more so than men, to leave their jobs in order to provide care for a family member (United States Department of Labor, 2014).

Many cases have shown that the increase of women in the public labor force has not significantly changed the amount of work that they do at home, but, instead, has increased their role strain and overall work. Role strain is the perceived difficulty of managing multiple role obligations. In this particular case, these obligations may include caring for symptoms of dementia, personal care, transportation, arranging professional assistance, housekeeping, and emotional support, to name a few (Yang, 2012).

While many women have gradually moved into the labor force, starting shortly after World War II, men have not made the proportionate shift into the domestic domain, giving them a significant advantage in the labor force compared to women (Hooyman and Gonyea, 1995).

As Alzheimer's Disease tends to affect a greater number of women, in terms of patients and caregivers, social and political measures are necessary to ensure that working-class women and their families have access to health and financial resources regardless of their current family structure. Julie Matthaei, a professor at Wesley College

who has written several books and articles on feminist economics, eloquently describes a holistic approach to the issue in her review on economic reformation by stating more generally:

[A] solution to the feminist dilemma is both for women and men to become more alike and for femininity to be revalued, through an integrative feminism movement-through which individuals of both sexes begin to combine and redefine femininity and masculinity, while restructuring economic and familial institutions and practices. (2003).

Women continue to be denied equal pay to men, contributing to a lingering separation among genders in the workforce. The dilemma that Matthaedi may be referring to is the disproportionate value that is placed on the production, the work traditionally associated with men, and denies the value of caregiving, the work traditionally associated with women.

The Institute of Women's Policy Research (IWPR), established in 1987, works with other public interest groups, policymakers and scholars in order to establish more women-oriented social policy. IWPR provides informed policy and networking tools internationally through several programs that are geared towards employment, education, poverty, income security, family welfare, and health (Institute of Women's Policy Research, 2014).

Similarly, the Older Women's League, or OWL, is an organization established in 1980 that advocates for financial security and access to healthcare for women over the age of 40 (OWL, 2014).

Financial Costs of Caregiving

Patients with Alzheimer's Disease require direct and long-term care, especially

when they start to show signs of dementia, like a lapse of memory. In 2009, a report conducted by the Alzheimer's Association in the U.S. found that approximately 87% of Alzheimer's patients are cared for at home by a family member or friend, and a vast majority of that care is unpaid. More specifically, the report estimated that 9.9 million families and friends provided 8.5 billion hours of unpaid care at a value of \$94 billion. Only four years later, the 2013 report estimated that 15.5 million families and friends provided 17.7 billion hours of unpaid care at a value of \$220.2 billion. Worldwide, an estimated US\$605 billion is spent annually to treat patients with Alzheimer's Disease and dementia, which is about 1% of the world's gross domestic product (Alzheimer's Association, 2014). Though the costs of Alzheimer's Disease vary among countries, this review will focus mainly on the costs and trends within the U.S.

The financial constraints of caregiving have two basic forms: the direct costs for care and the indirect costs, or opportunity costs, of forgoing job opportunities in order to provide care. The direct costs can be covered by individuals and families out-of-pocket (17%), though, typically, come from Medicare (53%), Medicaid (17%), and other sources like private insurance and retirement benefits through Social Security (13%) (Alzheimer's Statistics, 2014). People who do not have access to these benefits must provide the care themselves informally. Informal and primary caregivers are particularly prone to the indirect financial constraint of caregiving because they are neither paid for their services nor eligible for most government aid based on their employment status.

Informal Caregiving: The “Shadow Workforce”

Informal, or unpaid, care services are typically done by a family member or friend in a home setting, and are thus more readily accessible. Depending on their training and whether they get paid, caregivers are classified as either informal or formal.

Though some families eventually access additional services in the formal sector, the home setting that is made possible through direct care may be more appropriate for Alzheimer’s Disease patients as they slowly become more dependent in later stages of the disease. Most informal caregivers must quit their jobs in order to offer adequate care for their family member or friends. Role strain makes this decision difficult, in which the level of adequacy for one position is sacrificed for the other. Though informal caregivers devoted about 17.7 billion hours of Alzheimer’s Disease care in 2014, as mentioned before, they were neither paid for it, nor will they be given the proper wage protection to receive retirement benefits. Nationally, most of informal caregivers are women, are not trained to give direct care, and often have a maximum of a high school education (World Health Organization 2012, Burnham, 2012).

In her article “Families and Elder Care of the Twenty-First Century”, Ann Bookman refers to informal caregiving as the “shadow workforce” in the geriatric healthcare system behind formal caregiving. Informal caregivers are typically made up of female family members and friends who perform “activities of daily living” (ADL), which include feeding and bathing, and “instrumental activities of daily living” (IADL), which include using transportation and technology. About 46% of family caregivers for patients with chronic disease also carry out medical and nursing procedures, like administering medication, IVs, and injections (Lai, 2012; Levine, 2010).

The free care that is provided by informal caregivers adds significant value to U.S. society by providing necessary care and service to one of the most vulnerable populations in the nation (Bookman and Kimbrel, 2011). As mentioned previously, the estimated value of this care is about US\$605 billion per year. Formal care services are able to finance adequate care to only 13% of the Alzheimer's Disease patients, so where does that leave the other 87% of patients? Unfortunately, the remaining 87% of patients with Alzheimer's Disease are given minimal financial support, which puts much of the financial strain on the caregiver.

Though the service for caring for an aged adult with a chronic disease like Alzheimer's is similar among informal and formal care providers, the financial burdens are dramatically disproportionate, due to federal spending policies and lack of coordination between the public and private long term care sectors.

Formal Caregiving

In the U.S., formal, or paid, care services include nursing homes and care facilities that offer institutionalized care options for aging adults and patients with degenerative conditions like Alzheimer's Disease. Financial assistance is available for families that are eligible in the form of Medicaid and Medicare. However, some studies have shown that because most nursing homes that offer financial assistance have higher patient-to-nurse ratios than private direct-care facilities and home-health care, they tend to be less preferred by the families who seek one-on-one care in a home setting for their aging family member (Boris, 2010).

Home-health care providers are paid poorly, receive few benefits, and are under great stress from the wide range of tasks they perform for their aging patients (Seavy, 2010). The average age of direct-care providers is 42 and nearly 89% are female. Furthermore, about 47% of direct-care providers are white, 30% are African American, and 16% are Hispanic (Seavy, 2010). This includes formal home-health services. Migrant workers make up 46% of the domestic workforce (Burnham, 2012).

Caregivers' ability to offer quality care is often sacrificed due to their lack of training and their level of stress. Home-health care providers are crucial at this time, especially in terms of long-term care. In fact, direct-care workers are among the potential beneficiaries in the key provisions of the Affordable Care Act, which seeks "to alter the fundamental institutions of healthcare delivery and financing" (Kats and Frank, 2010). How these alterations are being practiced is unclear, but financial incentives and public pressures to improve the standards for direct, long-term care are changing. Researchers believe that funding and community support for better training and wage protection for home-health aide could be a great solution for the growing aging population, as well as better access to adequate employment for informal caregivers (Seavy, 2010).

In recent studies conducted in Michigan, paid home-healthcare providers claimed that they only associated stress and financial loss with their position as a caregiver when they felt disrespected and undervalued by their employers. Many home-healthcare providers claimed they enjoyed the work when they were given more flexible hours and felt respected by their supervisors. Along with the intimate nature of caregiving for an individual in need, a level of accountability as well as self-efficacy over the position can be related to home-healthcare providers' satisfaction regardless of pay (Mickus, 2004).

Private home-health care businesses share characteristics of both formal and informal care services. Based on the rapid growth in the number of aging adults, and the overwhelming burden placed on family caregivers, home-health aides have been in high demand by families who can afford to outsource private care. The home-health workforce has increased by about 50% in the past ten years and is the third fastest growing occupation in the United States (Seavy, 2010).

Physical and Emotional Costs of Caregiving

Several studies have shown a strong relationship between caregiving and chronic illnesses that are found among most caregivers (Lai, 2012; Brown, 2009; Chistakis, 2006; Covinsky, 2003). The chronic physical stress has been shown to be associated with the amount of time that is required of primary caregivers to care for a family member or friend, as well as financial costs. Difficulty sleeping, constant headaches, weight gain or loss, diabetes, and pulmonary regression are a few of the common physical costs that derive from the burden of caregiving (Lai, 2012). Studies have also found that inadequate self care and chronic stress can increase mortality rates among caregivers, especially in spousal relationships (Christakis, 2006). However, studies have also shown that there is less chronic stress for primary caregivers who provide at least 14 hours of care per week, and who seem to have found methods of coping with the burden of caregiving (Brown, 2009). Mortality and overall health can vary as a result of factors like patient-to-caregiver relationship status, as well as the level of support to which caregivers have access.

Depression and anxiety are the leading mental health illnesses among people who care for family members with dementia (World Health Organization, 2013). The time and

energy that are required to adequately treat patients with dementia are often underestimated, especially for primary caregivers who are treating their loved ones. One can only imagine the level of anxiety a caregiver has when a family member in a more severe stage of Alzheimer's Disease is at risk of wandering off, having a panic attack because they no longer know who they are, or even causing harm to themselves while performing daily tasks like cooking or taking a shower.

Much psychological support is necessary to relieve the emotional stress and anxiety of caring for a loved one with a degenerative disease. Several studies have reported that 32% of caregivers who treated patients with dementia reported experiencing symptoms of depression (Covinsky, 2003). Overall, the physical and emotional stress of caring for patients with dementia has resulted in about US\$9.3 billion in health care costs in the United States in 2012 (Alzheimer's Association, 2014).

The vigilance and role strain of providing adequate care ultimately lead to chronic physical stress and compromised mental health in most cases (Shultz, 2008). Studies have evaluated whether the physical and emotional stress among many caregivers are mostly a result of role strain, the financial costs, or caregiver-to-patient relationship dynamics.

A case study conducted by the University of Pittsburgh Institute of Aging surveyed 17,097 U.S. employees from a company in order to evaluate a possible association between physical costs and providing general elder care for a family member or friend (Albert, 2010). Role strain was tested by comparing evidence of chronic stress and diseases between employee caregivers and employee non-caregivers. The results showed that there were significant differences in health and chronic stress between caregivers and non-caregivers. Among employees, chronic illness such as pulmonary

regression, diabetes, hypertension, and depression was significantly more common for caregivers. Furthermore, the proportion of employees with diabetes, hypertension, and depression was significantly greater among female caregivers compared to male caregivers (Albert, 2010).

The employees in this study are classified as part-time caregivers, but what about the caregivers who give their full time in order to give adequate care? As Alzheimer's Disease patients with dementia are particularly dependent on constant, direct assistance, competent caregivers will typically be required to quit their jobs, placing a significant financial burden on caregivers who do not get paid for their services. As mentioned before, studies have shown that caregivers who care at least 14 hours per week have significantly less chronic stress than caregivers who spend less time caring for their family member in need. Caregivers who must quit their jobs to care for a family member have more flexible hours, and form more intimate relationships compared to caregivers who work at nursing homes, or part-time caregivers who must juggle caregiving and their careers (Brown, 2009).

By staying employed, many people are coping with the financial costs of caregiving, but are more prone to the mental and health costs associated with having to balance their different roles. Caregivers who choose to quit their jobs may experience financial stress, which may affect their physical and emotional stress, but studies have shown that the caregivers who show more commitment through direct care have less chronic stress than part-time caregivers. The certainty that adequate care is being given to their loved one could explain full-time caregivers' reduced chronic stress. Still, there are many caregivers, especially those who have limited resources and support, who

experience the financial, physical, and emotional costs of caregiving. Women and migrant women, in particular, are an especially vulnerable group.

Researchers are looking into ways to implement community-based support systems, which can aid caregivers in developing a more structured long-term health care plan to relieve the majority of burdens they experience. For instance, mutuality, or the positive quality of the relationship between the caregiver and patient, as well as preparedness were proven to relieve some aspects of caregiving, specifically role strain (Yang, 2012).

Lack of Protection for the Migrant Workforce: A Case Study

According to the Census Bureau's annual survey, the American Community Survey (ACS), the domestic workforce includes a large percentage (46%) of immigrants from Latin America, Philippines, the West Indies, Africa, and Eastern Europe (Burnham, 2012). Because of the language barrier between migrant workers and researchers of the Census Bureau, the undocumented workforce is highly undercounted. Migrant caregivers are generally paid 18% less than caregivers who are U.S. citizens (Burnham, 2012; Boris, 2010). Since migrant caregivers are at risk of being arrested, chief complaints of abuse or wage theft are rarely reported (Burnham, 2012).

Financial and health costs were more deeply examined during a qualitative case study involving a full-time female caregiver who was born in Pueblo, Mexico and moved to Santa Barbara, California in response to the growing demand for elder caregiving and to support her children. In *Intimate Labors: Cultures, Technologies, and the Politics of Care*, Maria de la Luz Ibarra closely examines Norma's life as a direct caregiver. After

she moved from Pueblo, Norma worked as a caregiver at a nursing home. After her second year, she quit because she found the working environment at the nursing home stressful. She preferred more flexible hours, while at the same time, more intimate care. It was then when she decided to offer more direct care independently as a home health aide. She characterized the experience as a deep alliance where she felt respected and valued for her work (Boris, 2010).

Long-Term Care System as a “Patchwork”

The increase in both privatization and informal caregiving among family members has led to a long debate over the allocation of public funds towards institutional or non institutional services (Hooyman and Gonyea, 1995). The coordination of public and private sector initiatives is necessary for improving the long-term care system in response to the increase in aged adults and the diversity of the family structure.

Fragmentation within the federal health system has caused the long-term health care system to become a patchwork. Patients with Alzheimer’s Disease require a continuum of care from both formal and informal services. It is therefore critical that open communication is constant between both types of providers. Studies have evaluated the uncoordinated nature of the current long-term care system, which leads to competition between programs rather than integration within the system in order to ensure access to various agencies, institutions, and funding streams.

Current long-term health care is also a patchwork among states. States differ in access, quality, and coordination of services, which has led many critics to believe that eligibility for long-term care has little to do with physical or financial need, and a lot to

do with geographic location. Federal spending cuts have also forced states to seek competitive bids from for-profit health care enterprises, which has led to market-competition within the health care system, prioritizing the financial incentives of health care over individuals' needs for adequate support (Hooyman and Gonyea, 1995).

The lack of coordination within the long-term care system has a more negative impact on the family than on institutional care providers because of the disproportionate funding of institutional care. Over 80% of federal funds for long-term care are spent on nursing home care, while less than 20% of aging patients with disabilities actually use nursing homes. People find more financial incentives to seek formal services because they offer more financial assistance than if people were to care for a family member independently (Hooyman and Gonyea, 1995). So then why do most families (87%) care for a family member informally? Either their socioeconomic status does not allow them eligibility for such services, or they believe that they themselves are their family member's best care option.

Long-Term Health Care Solutions

Currently, medical research funding to cure Alzheimer's Disease is minimal compared to research for cancer, AIDS, and nutrition. Research funding for Alzheimer's Disease is approximately US\$566 million, whereas, the research funding for cancer research is a little over US\$5.4 billion (U.S. Department of Health and Human Services, 2015). There is also currently no effective preventative treatment for Alzheimer's Disease. Pressure for government funding for research is minimal because victims and their caregivers do not have the time or resources to get to Washington. Some researchers

say that the lack of adequate funding for research is also a result of the social stigma that prioritizes younger populations that suffer from diseases like cancer and AIDS. This means that the aged population and their caregivers must compete for adequate funding for care. So far, there has been only one bill that seeks to establish a more coordinated health care system that is specific to Alzheimer's Disease. The National Alzheimer's Project is a bill that seeks to develop a national plan that will find the cure for Alzheimer's Disease.

Long-term care programs in the form of policies, employment benefits, and community agencies have been modified over the years to alleviate financial and emotional burdens for people who are primary caregivers for Alzheimer's Disease. These programs seek to eliminate the uneven distribution of the caregiving role among genders and socioeconomic classes, as well as to ensure that these individuals are getting the proper support and respect from their employers (Kalamazoo Area Agency on Aging, 2014). Coordination and transparency among these programs, each offering different resources, are necessary for caregivers to be able to access multiple sources of support from both the local agencies and the public policies.

Policy Revisions and Interventions

The long-term care and pension systems are set up to reward those in the paid labor force at the expense of those in unpaid caregiving positions. Since informal caregiving is classified as non-care, care penalties have been put in place to exploit the free care that is provided. Under U.S. Social Security policy, not one cent goes toward

the caregiver's retirement income, leading to the financial burden experienced by a large portion of the female population (Estes, 2003; Bookman and Kimbrel, 2011).

The next sections discuss programs and policies that have been set up to aid caregivers and their families financially.

Medicare

In Margaret Cruikshank's *Learning to be Old*, the adequacy of Medicare comes into question as she identifies the failures of U.S. health care policies, and documents how the health care costs of single, older women consume more than a third of their annual income. According to Cruikshank, Medicare's biggest failure is that it does not cover adequate health care for minority and poor women, and actually is a form of discrimination against them. Medicare disproportionately addresses acute chronic diseases, which are more common among men, at the expense of disabling chronic conditions, which are more common among women. It does not protect women from preventable health problems, especially stress (Cruikshank, 2003).

Medicare was originally supposed to provide comprehensive health care coverage, but today people over 65 spend an average of 20% of their annual income on health care. Much of the out-of-pocket costs are put towards medications, or disease control, rather than for preventative measures (Cruikshank, 2003). Furthermore, home-health agencies and the patients they serve suffer from fluctuating financial support and Medicare cuts. Reductions in public funding and home-health care is disproportionately harmful for people of color, who are twice as likely as middle-income whites to have chronic diseases including stress (Cruikshank, 2003).

The Affordable Care Act seeks to establish more family-friendly policies in order to alleviate the stressful lack of coordination often experienced in the long-term health care system. It has increased benefits for patients with chronic disease and their families by making more public services accessible and affordable. For example, prevention planning and services are now much less costly for low-income families because the law requires Medicare to cover annual wellness visits for all patients (Ness, 2011). However, preventative measure for Alzheimer's Disease have shown no substantial impact on the development of the disease.

Cruikshank, along with other critics, argues that giving every American over 65 more adequate preventative health care is actually less costly in the long run, reducing expenses for serious illnesses. She adds that women would benefit from this the most. But she does not believe it a likely solution because the system is organized by illnesses and disease rather than prevention, and profits from the treatment of the illnesses and diseases in order to maintain itself (2003).

FMLA

The overwhelming attention that is required to care for a patient with dementia can hold workers back from gaining promotions or even meeting the basic requirements to maintain a job. In a survey conducted by Travelers Companies in 1985, eight percent of unpaid caregivers averaged 35 hours per week of caregiving, which is equivalent to a full time job. In 1989, results from a study by Scharlach and Boyd revealed that about 25% of female caregivers quit their jobs in order to adequately care for a family member (Moen, 1994).

The Family and Medical Leave Act (FMLA), introduced in 1993, is a “family friendly” policy that allows employees a leave of absence from their jobs in order to care for a family member. Health insurance coverage continues throughout the leave period and they are able to come back to work after a maximum of twenty-six weeks (United States Department of Labor, 2014). While FMLA has had a positive impact for many caregivers who are eligible, revisions are being proposed in order to be extended to more diverse family structures. The U.S. Department of Labor’s Wage and Hour Division recently announced a Notice of Proposed Rulemaking (NPRM) that amended the definition of a spouse, which gives eligible employees of same-sex marriages FMLA leave to care for a family member or spouse (United States Department of Labor, 2014). A court ruling found that section 3 of the Defense of Marriage Act (DOMA), which allowed states to refuse to recognize same-sex marriages as legitimate, to be unconstitutional. The eligibility of FMLA was then extended to same sex couples.

Still, only a small percentage of middle- to low-income companies actually allow these benefits (Estes, 2003). Though FMLA was the first federal law to help workers balance their public and private lives, it has also been the last (Ness, 2011).

Social Security

Through the Social Security Act of 1935, Americans who work for wages are able to set aside monetary benefits, or retirement funds, which grant them greater access to adequate care in later years. Informal caregivers are not eligible to receive these benefits because this type of caregiving is not considered “productive” labor to society. Because it is unpaid, society saves millions of dollars of the cost of care. In turn, these costs are absorbed by the caregivers, who are mostly women. As a result, millions of women are

unable to accumulate wealth or have access to the benefits of Social Security unless they are married and receive benefits from their spouses' work (Estes, 2003). This vicious cycle of the impaired ability for women to access paid employment and benefits due to informal caregiving, and women's lesser social, political, and economic status contributes to the role imbalance between genders. The cycle can only be broken through a just role distribution, and by lifting the financial burden from informal caregiving.

Revisions to the act are being proposed to give Social Security "credits" to people who must quit or reduce their work hours to provide service to their family member with a chronic disease. The proposal will allow for the caregiver to receive Social Security credits that act as an imputed earning, to replace a monetary earning for up to five years of family service (National Committee to Preserve Social Security and Medicare, 2013).

Similar to the FMLA, further revisions are currently being proposed in order to eliminate discrimination against domestic and homosexual couples who currently do not receive the standard Social Security benefits. Furthermore, the same terms and conditions should apply to the children from these families as the children of heterosexual couples (National Committee to Preserve Social Security and Medicare, 2013).

Community-Based Support

Community-based support systems are important assets to caregivers, making it possible for patients to be cared for in the home setting. Community service providers and health professionals provide assistance to caregivers through emotional and educational support. A few examples of community services include adult day care, in-home assistance, Meals on Wheels, and support groups (Wehtje, 2003).

One of the leading nonprofit organizations that aid Alzheimer's patients and their caregivers is the Alzheimer's Association (AA). The annual walk hosted by the AA draws in millions of participants across the nation to donate for research for the cure as well as advocacy to give caregivers the opportunity to voice their concerns. AA has thousands of chapters across the nation, with about 4,500 support groups and 20,000 education programs. AA social workers and community members have been valuable in finding solutions for families dealing with Alzheimer's Disease, including advocacy for more up-to-date family-friendly policy and research for the cure for the disease (Alzheimer's Association, 2014).

Area Agencies on Aging also work closely with caregivers and their aging family members. Social workers and researchers who work for local area agencies are involved with people who provide elder care, not just patients with Alzheimer's disease. Services offered by the area agencies include support groups where caregivers can share personal experiences with people who can relate to the financial and emotional burdens of caregiving. The Area Agency on Aging in Kalamazoo, MI offers services to entrepreneurs in private home-health agencies that are trying to find ways to make a livelihood from the care they provide through education, training, and support groups (Area Agency on Aging, 2014).

Grassroots advocacy groups like La Colectiva de Mujeres encourage worker leadership and seek to change how domestic work is valued in the U.S. La Colectiva de Mujeres is a women's collective in San Francisco, California that advocates for the protection of female caregivers regardless of their immigration status. It was originally formed in 2001 by a group of undocumented domestic workers. The collective gives

migrant women the opportunity to help each other find jobs, training, community resources and legal advice (Burnham, 2012).

Community centers are heavily involved in setting a standard of care among home health agencies in order to establish a legitimacy of care. Ideally, centers and health providers coordinate to develop a system that maintains productivity by providing training and wage security to workers at home health agencies.

Conclusion

Much of the successful political reform has been possible as more women, who represented a majority of domestic workers, took positions in Congress. Shirley Chisholm was the first black congresswoman, and during her term in 1968, she successfully pushed for domestic workers to be included in the minimum wage. However, the bill did not include home care workers. The increase in home care workers has led to the reevaluation of the bill. In 2011, President Barack Obama addressed possible labor protections for home care workers. According to Roosevelt's Fair Labor Standards Act of 1938, home care workers are still within the same category as teenage baby sitters, in that they are not required to receive minimum wage nor are they required to be paid for hours of overtime (Kornacki, 2013). Though President Obama revisited these issues in 2011, nation-wide wage protection for home care workers has been delayed. The Labor Department reports that the wage protection will go into effect in summer of 2015 (Greenhouse, 2014; Kornacki, 2013).

Along with the support provided by the local community and government policy, how could long-term solutions address needs and eliminate injustices for caregivers, who will surely be key service providers as the aging populations continue to grow? Legitimizing informal caregiving and integrating the private and public sectors of society would go far to eliminate the injustices imposed on caregivers. Because these injustices are more likely to impact women, who make up the majority of caregivers, action must be administered through a feminist perspective. Organizations like the Institute for Women's Policy Research and OWL are important advocacy groups that seek to establish women-oriented policy.

Informal caregivers must demand access to the resources of formal institutions for more home-health eligibility and licensing. This incorporates informal caregiving into the public sphere rather than attempting to provide an equal opportunity for the existing, competitive occupations in the formal institutions like nursing homes. As a result, people can choose to care for a relative with a serious disease like Alzheimer's Disease without the financial and emotional burdens associated with the disease. It is not just about transforming the informal to the formal, but challenging how people perceive the opposition of these positions in terms of status and class, in which higher income families have more access to the formal services and lower income families must informally provide care in their home setting.

By setting a standard of respect for all employment levels in formal institutions, caregivers can experience enhanced self efficacy and respect in order to cope with the costs of caregiving. Community-based programs and their coordination with public policies can be a big step in developing a network of caregivers to share their knowledge and experiences in order to create solutions for themselves. Modifications to the retirement income and long-term care plans are necessary to balance the benefits that are accessible to productive and reproductive occupations (Estes, 2003).

Further research, both qualitative and quantitative, should closely evaluate revisions to the policies mentioned and their effects on the caregivers on an individual basis. It would also be worth evaluating how U.S. long-term care plans compare to other countries, like South Korea, who have greater percentages of aging adults (Rim, 2010).

Effective public policies must be made by and for the family. Researchers have speculated that simply increasing caregivers' financial benefits will do little for the

overarching issue of uncoordinated, undistributed long-term health care (Mickus, 2010).

Public awareness and advocacy for a long-term care plan that represents women and diverse family structures is dependent on individual responsibility, as well as the cooperative nature of the public.

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