Older Women Caregivers
What Do We Know?

A project of the Women’s Fund of Herkimer & Oneida Counties &
The Arthur Levitt Public Affairs Center, Hamilton College

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Interviews of caregivers completed by students in WMNST 327 Seminar on Women & Aging, taught by Professor Margaret Gentry, Hamilton College

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A very special thank you to the women who took the time to share their lives with us and educate us about what they need

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Introduction

With the steady increase in both the number and proportion of elderly persons in the United States, newfound attention must be given to caregiving for the elderly. Due to advances in medicine, Americans are living longer than ever and the elderly are more vigorous and more independent than ever before. Many elderly Americans prefer to live out their lives in their own home. They also often express preference for assistance from within their own families rather than public assistance. Families have become the primary support network for providing care to the elderly in their homes.¹

The Women’s Fund of Herkimer-Oneida Counties approached Hamilton College in 2002 to establish an ongoing study of the status of women in the two-county area. Prior research focused on a statistical portrait of demographics and trends related to age distribution, race and ethnicity, family structure, income and employment² and a second report studied the barriers to economic self-sufficiency from the perspectives of agencies and women themselves.³ This initiative aimed to assess the needs of older women who are providing home care for someone, usually a relative.

Locally, both Herkimer and Oneida Counties have an aging population, older than New York State as a whole and the United States. The number of Oneida County residents who were 85 years and older, though relatively small, grew by 33 percent in the decade between 1989 and 1999. Herkimer County showed similar growth in the 85 and older group.⁴ Consequently, there is both a question of how care will be provided to a predominantly female older population and how older women are providing care now to others.

Background

The Public Policy Institute of the AARP notes that family caregivers make significant contributions to services and supports that are provided to the elderly and disabled; services that often go unrecognized. The contributions, in fact, of informal caregivers are thought to be “not only the foundation of the nation’s long-term care system but an important component of the U.S. economy, with an estimated economic value of about $350 billion in 2006.”⁵ Overwhelmingly, it is female members of the family who care for aging relatives. Female caregivers are responsible for providing support for family members and make up approximately two-thirds of all unpaid caregivers. In particular, although studies show that women and men engage in similar types of care work, it is primarily women who serve as the caretakers of their aging spouses.⁶

Often, these female caregivers are senior citizens themselves. Not only are women stereotypically regarded as the more domestic sex whose responsibilities include caring for others, but they also have a life expectancy that is longer than that of men.⁷ Female caregivers over the age of 65 often face extra stress, less free time, little help from family members, and difficulty when using public services.
What constitutes caregiving? According to the Utah Coalition for Caregiving Support, caregiving “refers to the provision of assistance to another person who is ill, disabled, or needs help with daily activities. It often requires attention to the physical, mental, social, and psychological needs and well-being of both the caregivers and the elderly person requiring care.” An example of an elderly care recipient might be a 95-year-old man who had a massive stroke and is permanently disabled, can’t stand or walk on his own, and has dementia. An example of a caregiver might be his 65-year-old daughter who lives with him and everyday helps him get up in the morning, go to the bathroom, get outside the house, eat meals, and go to bed at night.

There are significant variations in caregiving situations. The caregiver may help the care recipient every day, or just a few times per week. The caregiver may live with the care recipient or may visit to help. The caregiver may or may not be related to the care recipient. Caregiving may last for months or many years. Lastly, the caregiver may rely on public services to help with caregiving or may find the services unhelpful, difficult to access, or against their personal standards and values. The typical caregiver, however, is a middle-aged woman who works outside of the home.

Concerns for caregivers run the gamut from the impact on her own health to long-term impacts for her economic well-being. Indirect costs of caregiving cited by AARP include:

- Out-of-pocket costs contributed by caregivers to the care recipient
- Lost wages and retirement income
- Lost productivity
- Health effects and those associated costs
- Effects on the long-term care and health care systems

Many different caregiving resources and services exist in the United States. The American Association for Retired People (AARP) supplies information and publications on caregiving. The Eldercare Locator helps anyone in the country find services to help with caregiving. But one of the most important and widely-used services available for caregivers is respite care. Respite care is short term care that helps family members take a break from the daily routine and stress of caregiving. Respite care is provided in a variety of ways. Usually, someone comes to the home to care for the family member. Some facilities such as nursing homes or assisted living offer to house and care for a family member for a day, a weekend or when the caregiver takes a vacation. In addition, if your family member is mobile, an adult day care center once or twice a week provides a break for a tired caregiver. A respite care person can cook lunch and care for an elderly person for a few hours, come to the elderly person’s home every day to help them get out of bed and get dressed, or care for an elderly person for a week while their caregiver is out of town, among others.

However, caregivers often experience difficulties in using public services such as respite care. For example, many people have problems paying for respite care. Oftentimes federal or state programs will help pay, but if a caregiver doesn’t have insurance it can become too expensive to pay someone to help, especially regularly. Another issue is accessibility to these public services. If an elderly person needs respite care but lives out in the country, far away from a big city, it can be difficult to even find the necessary services. If the caregiver and care recipient manage to find help, it is usually limited if they live far outside of a city. Also, many caregivers aren’t aware of what services are available because they aren’t advertised well. In
addition, the public assistance is not always consistent. For example, if help is needed in the middle of the night, the caregiver may not be able to get any kind of care for their elderly family member until the next day.

Due to these inconsistencies in service, the financial burden of caregiving, and the physical and emotional sacrifices a caregiver must make, many caregivers experience depression and/or a decline in their own physical health. The risk to caregivers’ own health is “a problem that is beginning to be recognized as an emerging public health concern.”\textsuperscript{13} In 2004, Evercare, a leading provider of health plans for people with advanced illnesses or disabilities, and the National Association of Caregiving (NAC) released the results of a study on the physical and emotional tolls of caregiving on the caregiver. The study found that stress and worry lead to millions of caregivers neglecting their own physical and mental health. This results in depression, fatigue, poor eating and exercise habits and over-use of medications. An alarming nine in 10 (91\%) caregivers surveyed - all in fair/poor health and having seen a decline in their health as a result of caregiving - suffer from depression, and eight in 10 (81\%) of those with depression reported that caregiving has made their depression worse.

The study also found that caregiving for another often replaces caring for one’s own health. Ninety percent of caregivers said that they experience more stress now that they are caregivers. This extra stress leads to a number of health changes including loss of sleep, pain/aching, and weight gain or loss. 72\% of caregivers said that they do not go to the doctor as much as they did before becoming caregivers. The results of this study have broad implications for caregiving. As Dr. John Mach, CEO of Evercare said: "Caregiving has to include caring for yourself. The fact that caregivers sacrifice their own well-being while caring for a loved one underscores the need for greater awareness around the issue and for programs that support their health needs."\textsuperscript{14}

These health risks are even bigger for caregivers who are over 65. Elderly caregivers who neglect their own health put themselves at great risk. Huat (2006) stresses the need for “accessible support and responsive community services” for elderly caregivers. These services are more needed than ever since the number of elderly caregivers is increasing. Also, Huat explains that elderly caregivers are a lot more likely to “suffer in silence” because, like the elderly person they’re caring for, they don’t feel comfortable asking for help, especially public assistance. They often may not know where to seek help in the first place, so there is a need for easier access and more advertisement of these resources.\textsuperscript{15}

Due to the obstacles caregivers face and the increased need for caregiving in the near future, these issues need to be addressed. Most simply, caregivers should hold a more important role in American society. This is no easy task, but if they did, they would command more respect, receive more help, and would feel more obliged to take care of their own health. Doctors should be aware that their patients are caregivers and should suggest better ways to improve their health, without the caregiver having to ask. Support services should be structured to help caregivers save time, reduce stress, manage their own health more effectively or provide them with caregiving expertise. There should also be services exclusively for caregivers’ well being, such as experts that caregivers can visit to talk about the stress they feel and other caregiving issues. However, the existence of caregiver support services is not sufficient to ensure that they are used.
Caregivers need to be made aware of support services through concerted communications efforts, and may also need encouragement to try whatever services are offered. With improvements like these made, the future of caregiving could be very bright. Gibson and Houser (2007) conclude that "for both economic and ethical reasons, it is essential to prevent family caregivers from being overwhelmed by the demands placed upon them." They continue to state that the cost of funding the needed supports and services is small when compared to the economic and social contributions made by the caregivers. Policy recommendations are:

- Implement family-friendly workplace policies and other supportive services in the workplace.
- Expand protections given by the Family and Medical Leave Act.
- Expand funding for the National Family Caregiver Program.
- Adequately fund the Lifespan Respite Care Act.
- Give caregivers a tax credit for the work that they do at home.
- Allow family caregivers to be paid by publicly funded programs.
- Respond to the needs of family caregivers themselves and refer to support services.

**Methods of Current Study**

In 2007 and 2008, students in the Women and Aging course taught in the Women’s Studies Department at Hamilton College with Professor Margaret Gentry were asked to interview caregivers as a part of their course and to summarize the results of the interviews. The results of those interviews (n=13) are summarized here. Caregivers were recruited in 2007 through the Oneida County Office for the Aging. Oneida County staff identified caregivers and contacted them with information provided by the College to ascertain their willingness to participate in the study. In 2008, caregivers were recruited through two programs suggested by Oneida County Office for the Aging: Acacia Home Care and the Ava Dorfman Senior Center. Similarly to the process used in 2007, potential caregivers were identified and provided with information from the College by agency staff; students followed up by telephone and arranged appointments in the home.

A questionnaire was used as a guideline for the interviews both years, and the Institutional Review Board approved the proposed study (Appendix A.) Caregivers did not receive compensation for the study. Most expressed appreciation that someone cared about what they were dealing with enough to ask. Student summaries were combined into one report with common themes identified. Demographic information is also summarized here.

**Limitations**

Interviews were completed with undergraduate students with some background knowledge provided in their course for issues facing women and aging in general and women caregivers in particular. Only thirteen caregivers were interviewed over the period of two years, and they were interviewed by different students. We are suggesting that the results presented here not be read as conclusive evidence of the general population, but as suggestions of trends and concerns that stood out as needing to be addressed and as areas for future research.
Findings

**Caregivers and Care Recipients**

Thirteen women were interviewed between the two years of the study. Most were over 55, with ages ranging from 58 to 85 years of age, and two were in their mid-40s. The most common care recipient was a husband (n=6), followed by a mother (n=5), with one father and one aunt. Caregivers tended to rate their own health as good or satisfactory, with two exceptions; health will be discussed in more detail below.

The amount of time that care had been provided ranged from just a few months (for her father) to 15 years. Since only one caregiver had provided care for less than 3 years, the average length of time spent providing care was calculated minus this most recent case. Respondents had been caring for their husbands for 3-15 years with an average of 6.3 years. Caregivers for mothers averaged 6.25 years, and one caregiver stated she had spent 15 years caring first for her father and now for her mother. The aunt had been receiving care for 4 years. The ages of care recipients ranged from 60s to 98 years of age.

Many of the care recipients have multiple handicaps or disabilities, and the primary disability is Alzheimer’s or dementia (n=8). Three recipients had a major stroke or multiple strokes as the primary disability, and some Alzheimer’s patients also had suffered strokes. The most recent one in care had chronic diabetes and needed dialysis treatments, and one listed Chronic Obstructive Pulmonary Disease (COPD) as the primary disability. Several also had difficulty with vision, speech and hearing, incontinence, and varying degrees of inability to walk, bathe or dress. Descriptions of specific situations are listed below:

- Quadruple bypass and four strokes. Cannot bathe or dress himself or go to the bathroom by himself, is incontinent, and cannot walk, even with walker. Progressively worse last two years.
- Permanently disabled, unable to sit up or stand after massive stroke.
- Alzheimer’s, limited speech, can walk a little with help, decline in hearing and vision.
- Dementia, legally blind, hearing very bad.
- Early signs of dementia, needs attention for medication and eating properly.
- Alzheimer’s, multiple strokes, needs someone with her at all times.
- Alzheimer’s, incontinent, unable to take him out of house, two brother-in-laws already died with Alzheimer’s.
- Multiple strokes and possible Parkinson’s disease.
- Alzheimer’s and another mentally disabled family member
- Alzheimer’s, dementia, Bipolar disorder
- Chronic diabetes, cardiac disease, kidney disease, mother also elderly with health concerns.
- Chronic Obstructive Pulmonary Disease (COPD), glaucoma, macular degeneration.

Many of the families had some economic stability, with several describing themselves as “comfortably retired.” Other families, however, mentioned the financial strain of caregiving and the cost of both respite care and home health aides. Many had no significant help from other family members, and a very few were satisfied with the help that they had from daughters or their own siblings.
Services and Service Providers

A range of services were used, from none consistently and occasional respite care to five days per week in adult day care. Agencies utilized included Ava Dorfman for Day Care, Senior Health Network, St. Luke’s physical and occupational therapists, home meal delivery, Visiting Nurses, Office for the Aging for information, and Home Health Care aides. One respondent mentioned the Veteran’s Administration in Syracuse, and two cited gerontologists as being helpful and the Geriatric Association. In describing those most useful, replies were:

- Intercom system
- Adult Day Care
- Visiting Nurses to stand husband up and bathe him
- Respite Care
- Meals on Wheels
- Aides to get out of the house

When asked what would make caregiving easier for them, suggestions made were:

- Care center for emergencies overnight
- Access to Medicaid
- Cheaper rates for homes/assisted living
- Better and more convenient bed
- Help for getting him into and out of the car for appointments or an enjoyable outing.
- Help in getting him in and out of chairs
- Home services for basic needs like haircuts or dentist appointments
- Better advertisement for services that are available for easier access to find the necessary help.
- Someone to be there at 3:30 am when he wakes me up and has to go to the bathroom.

A Patched-Together Network

It is through looking at individual families that one can discern the fragile network of caregiving that is in place. This is particularly important because the one family that had the strongest support from family members emphasized how important that support was in creating the caring for her husband as a positive experience. She explained that although the caring for her husband was stressful and draining, the teamwork between her and the rest of the family, in addition to the services provided by others, kept her strong and helped to make her situation manageable and enjoyable, rather than discouraging.

In another family, the network includes all of the generations of the family, including young grandchildren. They are described as “naturally” helping with caregiving, wanting to guide their great-grandmother around the house and help her to her favorite chair. A son provides emergency care when needed, a daughter provides transportation, and a niece visits often and takes her to the hairdresser, while another family member takes her out for rides to get her out of the house.

A third family, with much less family support, tells us that they can afford the services that they receive, and the caregiver is in good health. She sees problems arising, however, when her own health begins to deteriorate and she is no longer able to perform the daily tasks for herself and her husband. She is the sole caregiver with adult children who live out of town.
When she was in the hospital for an extended period of time last year, daughters came from out of town and took turns staying with their father.

Most caregivers were providing the bulk of care themselves, with very little assistance from other family members. They described getting 3-4 hours of sleep per night and spoke of the fragility of the network that they had put together. They often find it hard to entrust the care to others, however, and many have gotten used to and resigned to doing it themselves. Several rely heavily on the services that they've set up – one woman referred to the Ava Dorman Center as a “lifesaver”, saying, “I would go insane if it weren’t for the center.”

Additional burdens were cited in some families with other “hidden” family members that need services too. One family had an adult daughter who received services from ARC and another form of adult day services, and another had an additional stress for several years with an adult alcoholic son who moved back home. She told us,

_I found it difficult to care for both of them, who had very different needs. I was constantly worrying about both of them._

When families do have rich networks of family members, they work well. One family has several children who all live within a few hours of the family home and are described as providing much love and support to their parents. The children, she tells us, are “very attentive” and regularly bring them to get groceries, to doctor’s appointments, and complete repairs on the house. In this family,

_My family’s optimistic and fun-loving attitude has helped us so much. If we didn’t have the fun that we do, it would be much harder._

**Gaps in Services, Gaps in Coverage**

Home Health Aides were described as lifesavers, when the service worked well. One woman said, “It’s great to leave her mother in the hands of people who are trained, she is able to have peace of mind when everything is okay.” Another mentioned that the four hour blocks of time were most helpful, and that the two hour blocks come and go so quickly that it’s not possible to get anything done. The Aides also brought the most complaints, though:

_Caregivers don’t always come, and sometimes they will send someone when they aren’t supposed to be there._

One of the families interviewed in 2008 described having had eight different aides in one year. Some came once and simply never showed up again. The aide was responsible for relieving the caregiver by taking her husband on short walks and assisting with light cleaning. Much of her time is spent with numerous loads of laundry due to her husband’s incontinence and in changing him several times during the day as well as during the night. She cited a cleaning service as something that would be potentially helpful.

Services are viewed as help in alleviating some of the burden of caregiving, but the largest gaps noted were the time schedules and inconsistencies.
Physical and occupational therapists are very busy because they have so many patients to see. They can only spend a few minutes with [him] before hurrying off to their next appointment.

Their services were seen as very helpful, but the fact that the therapists were rushed was tiring for her husband. She expressed the wish that they could spend more time with him.

Also, while some families in more suburban or rural areas have difficulties with transportation or available health aides, one family in the city of Utica notes satisfaction due to a grant from the Office for the Aging that provides transportation for her father to and from doctor’s appointments and physical therapy as well as a consistent aide who provides help with grooming.

The women recognized that sometimes it was the services themselves that were missing, but it was also difficult for them to leave the job to someone else.

It’s finding someone to come in that I’m confident in.

I know that I just have to make up my mind and have someone come when I want to do something else.

I don’t feel my Mother would like to have other people coming in and taking care of her.

Another caregiver cited how well her relative did with therapy when it was provided, but when it stopped due to limits set by insurances, progress halted or the condition deteriorated.

It is hard for [her] to go in and out of therapy . . . the inconsistency . . . I think that regular therapy would really help [her.]

The Costs of Caregiving

Several people also talked about the cost, that the price of both respite care and home health aides is very expensive. People have a patchwork of services for home health aides from a variety of agencies, and several people pay out of pocket for any services that they use. Financial strain was a stress that was mentioned several times.

Families who are currently able to pay for the services they use worry that there may come a time when they won’t be able to. One family pays for Adult Day Care three days per week out of their retirement fund, because none of their health insurance policies pay for that type of care. They are retired and eligible for Medicare, but they mainly rely on private insurance to cover his medical costs.

Another family is coping financially at present through the care recipients’ savings, small pension, and Social Security. The caregiver notes, though, that “more money is spent on her care than is received” and wonders what they will do. She describes being “extremely careful” about hiring additional help, because as her mother’s condition worsens, medical expenses are also expected to rise.
An Important and Valued Role

Most of the caregivers expressed love for their mother or husband or other relative and would not imagine “not doing it.” Some caregivers viewed their abilities to take care of people as “a gift” and were happy to provide that support for people they love. Another woman also saw herself as “luck” because she is “very good at caring for people with illness, while many others are not . . . I adapt well to it.”

I care for my husband because of my love for him and because he has been and always will be my best friend . . . I would not trade my position for anything and will continue on until I’m physically incapable.

I never imagined this would happen to me . . . but ultimately you cannot put a price on the care you provide for a loved one.

I believe that part of the role of family is to love and support those who need it . . . life is good and you must accept gracefully what God gives you.

Others noted cultural expectations of caregiving for family. For instance, one woman cited the responsibility in an Italian family for the children to take care of the adults in their old age. She still works, and it is difficult to take care of her aunt and get ready for work each morning. When her aunt became ill, there was no question that the aunt would come to stay with a family member. Since she did not have children of her own, it fell to her niece to provide the care:

I’m the female, so it is my job. . . The way she took care of everybody, from her sister to her mother, to my father. It’s a consideration and it’s a respect.

For some, they couldn’t fathom accepting wages for what they do.

To me this is all part of life. . . we do what we do out of love.

A Burden, A Way of Life

The demands of the job, though, get to them. Most of the caregivers saw themselves as fairly stressed and working nearly 24 hours a day, at least to be on call.

Some were angry with brothers or sisters or other family members for not doing their share, but several also talked about getting to a stage of acceptance, where they gave up their resistance to what life has presented and settled into this as a way of life.

One woman told us,

There is no salary that could compensate a person for this job. No one would do this unless they had to. . . I meant it when I said that marriage is for better or for worse.

One of the biggest struggles are feelings of loneliness, perhaps particularly for those living with Alzheimer’s or dementia patients who were formerly their close companions.
One woman described the difficulty of not knowing other people who have spouses suffering from Alzheimer’s, saying “It is just not the same talking with someone whose mother has it.” Since her husband’s illness, she has found it much harder to enjoy socializing and talking with others who do not understand what she is going through.

Unpredictability is another trial. Each day can be different – “I wake up every day unsure of what the next will be.”

Being a part of an Italian family where the females are responsible for caregiving came up again when discussing males in the household helping out.

The hardest things about taking care of [her] are the little things at home... I don’t have time to sit down, and I’m always worried if [she] is taken care of.

My husband not helping is one of the more stressful parts of my life... Men aren’t always the most understanding.

The role as a caregiver restricts activities that were formerly possible. One woman spoke for many in saying that she would participate in a variety of activities, such as gardening, going out to lunch with friends, and going to church if she could. “I am a fairly social person, but that’s limited now,” she told us. “There just isn’t time.”

Changes in the Loved One and in the Relationship Are Hard

One caregiver describes the most difficult tasks of caregiving as watching her father’s condition deteriorate and communicating effectively with her mother, who is often confused about her father’s condition. And a wife laments the changes in her intelligent and accomplished husband, saying:

It is hard to see him change and no longer be the man that he used to be... difficult sometimes to see him struggle because he cannot understand why he no longer functions as he did before.

It’s difficult for her to accept that she is no longer in control of her body... I try to make jokes to lighten the mood, but... It’s hard to cope with the fact that my husband of 60 years is now wetting the bed.

Caregivers spoke about their fear of the future too and the possible need of putting their loved one into a nursing home if the burden became too great.

Support is Needed, Just a Break

The opportunity to get out for an afternoon or an overnight or a weekend occasionally was the most frequent wish after recommendations for more support. Many caregivers experienced being “homebound” and a loss of freedom for even the shortest errands.

One woman cited small trips out of the house to the grocery store or time to read as her support, and she considers her friends to be her family support. They don’t help with the
caregiving, but they make her feel loved and cared for. Another just wishes that she could have one week off in a year to take her children, who are still at home, camping.

_I wish that I had more time or just had a way to get a break without worrying about my mother._

One family, while having good support from family members, suggests that access to more funds to hire outside caregivers or cheaper rates for independent aides would allow the family more time to pursue their own interests. This family does not qualify for Medicaid or other governmental supports.

Visits from friends outside of the family and members of church communities can provide much-needed outside support. One family noted that they were able to take communion each week, as a friend from their church brings it to the house, calling it a “nice diversion.”

One woman lamented the lack of freedom for both herself and her husband. She misses the little things like going out to dinner as well as the big things like traveling that the two did in the past:

_He worked too hard to end up being homebound like he is today. I take it in stride and do what I can for him._

Another does everything for her mother without family support, raises two children, and works nights, using the time that her mother is at Ava Dorfman Center to sleep a few hours each day. She seemed to sum up a way of life for most caregivers, telling us at the end of the interview,

_I have to laugh . . . because if I didn’t laugh, I would cry._

Summary/Conclusion

Undergraduate students in Women’s Studies at Hamilton College found the perspectives of older women caregivers about their needs and gaps in services to be moving and inspirational, as well as informative. This summary of two years of interviews given to the Women’s Fund of Herkimer-Oneida Counties and the participating service agencies demonstrates the dedication of women to providing care for their loved ones. They struggle, however, with inconsistent services, lack of sleep and yearn for respite. It is difficult for the women to watch the deterioration and the change in their spouse, parent, or other relative, and there is a great deal of variation in their networks of support. The network of services will vary considerably from family to family and needs to move from a patched together system to one both individually and strategically designed.


