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EVERYDAY HEROES: FAMILY CAREGIVERS FACE INCREASING CHALLENGES IN AN AGING NATION

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BEFORE THE

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UNITED STATES SENATE

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EVERYDAY HEROES: FAMILY CAREGIVERS FACE INCREASING CHALLENGES IN AN AGING NATION

THURSDAY, SEPTEMBER 10, 1998

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 9:33 a.m., in room SD–628, Dirksen Senate Office Building, Hon. Charles E. Grassley, (chairman of the committee) presiding.

Present: Senators Grassley, Reid, and Reed.

OPENING STATEMENT OF SENATOR CHARLES E. GRASSLEY, CHAIRMAN

The CHAIRMAN. I am Chuck Grassley, and I am Chairman of the Special Committee on Aging. There will be other members coming in and out today. I think we will be fortunate enough not to have our hearing interrupted by any roll call votes, because I do not expect those to happen until early afternoon. That is one of the sad commentaries about a very important hearing being held, that sometimes, it is very erratic in attendance, or even in how we conduct it, because of those roll call votes. But I think we will be fortunate today.

Also, my practice is to give members an opportunity to make statements, so, if we get into Mrs. Carter's opening statement, I am going to have her finish and then call on other members to speak. If other members arrive before she starts to speak, I will follow the practice of letting each person give an opening statement.

I want to say thank you very much for the very fine turnout we have today. As chairman of this committee, it is my pleasure to welcome colleagues who will be here and, most importantly, to welcome our witnesses, particularly our very distinguished former First Lady, and of course, all of you in the public who are very much interested in this issue.

I want to especially extend a special welcome to those who have traveled here today with a special mission to gather useful information and carry it back to their States and communities—because it is an especially busy day of Senate business as we try to wrap up by October 9. So, for any colleagues who can come, like Senator Reid, who has just joined us, I appreciate it very much.

This committee has examined a number of important issues related to Federal programs, especially the Medicare and Social Security programs. Today's hearing is different in the respect that there is no Federal program that I am aware of for family caregiving; yet our witnesses will testify about the valuable contribution of more than 22 million family caregivers who are actively caring for an aging or ailing elderly family member.

To put this number in perspective, there are less than 2 million Americans living in nursing homes, so simply by looking at the numbers, we can conclude that the bulk of caring for our Nation's elderly is carried out by family and friends in the form of informal caregiving.

I said that we would learn about the contributions made by these individuals. I think you have to conclude that it is just enormous. We have not quantified that, and I do not know whether it can be quantified, but it has got to be just enormous. Economically, family caregiving could be and is worth billions of dollars. Emotionally and physically, caregiving is often an overwhelming task. Caregivers know what it entails to juggle personal and professional demands with the responsibilities that accompany caregiving.

Nearly 75 percent of caregivers are women, most of whom work and also care for children and a spouse. This group of caregivers, often referred as the "sandwich generation," faces particular challenges. The sacrifices made by these individuals not only improve the quality of life for those they care for, but save the public from what would be very expensive costs for caring for people who might otherwise require services in a hospital or a nursing home. In both of those settings, the Medicare and Medicaid programs pay heavily.

Today's hearing will more precisely examine the important and unique contributions of these caregivers. It is likely that many of you in this room are caring for a family member, in fact, I know that two of our witnesses today are caregivers. I would like to take a moment to share a unique story of family caregiving. I should say that each family has a unique story, since no two families are alike.

One story, I am familiar with is that of Marie Somers. She is a 93-year-old woman who lives close to my home in New Hartford, IA. Ms. Somers has a number of physical conditions which require special attention, including hypertension, macular degeneration and arthritis. She is also a breast cancer survivor. Despite busy lives of their own, including running a restaurant, her two daughters, Florence and Charlene Engalls, have made it possible for Ms. Somers to remain at home. They have arranged their schedules so that they take turns with the responsibility of caring for their mother.

I have tremendous respect and admiration for this family's commitment to caring for their mother. It is a huge effort. I look forward to more stories of caregiving from our witnesses. By sharing their insight and expertise, I am confident that today's witnesses will contribute greatly to the objective of raising awareness of the value and importance of family caregiving. It is particularly important for public policymakers to understand its importance in the long-term care delivery system, given the growing long-term care demands of our aging population, particularly as that is enhanced very much by the retirement of the baby boomers just 13 years away.

We are especially honored to have former First Lady Rosalynn Carter here with us today. Mrs. Carter has had first-hand experience as a caregiver which she will share with us today. She is the author of two books on caregiving. The most recent one offers help to those caring for someone with mental illness. I commend her for her leadership in this area and particularly for bringing attention to it through her writings and authorship.

I also welcome all of our other witnesses today and thank you for taking time out of your busy schedules to appear before the committee.

On a related matter, I would like to announce that today I am introducing a bill that will help Americans prepare for the day that they might need long-term care and find themselves without a family member who can be their caregiver. The bill, titled, "The Long-Term Care and Retirement Security Act," will be introduced today. This legislation would help people who do not have access to subsidized long-term care plans through their jobs. It would allow them to deduct the cost of long-term care insurance premiums from taxable income. The goal of this legislation is to help Americans plan responsibly for later years.

We would also hope to make sure that those plans would have flexibility in them for care that would cover this type of family caregiving as well.

Today's hearing will provide an in-depth look at the important policy issues related to family caregiving and provide an opportunity to look at innovative programs from around the country. With a growing number of older Americans, the demand for long-term care will increase dramatically. The role fulfilled by family caregivers, then, will also have new demands, and I look forward to learning more today about all of this.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR CHARLES GRASSLEY

Good morning. This hearing will come to order. As Chairman of the Special Committee on Aging it is my pleasure to welcome my colleagues, our witnesses, and members of the public to this important hearing. I extend a special welcome to those who traveled here today with a special mission to gather useful information and carry it back to their states and communities. Because it is an especially busy day of Senate business, I expect my colleagues to be coming and going.

This Committee has examined a number of important issues related to federal programs, especially the Medicare and Social Security programs. Today's hearing is different in the respect that there is no federal program for family caregiving. Yet, our witnesses will testify about the valuable contribution of more than 22 million family caregivers who are actively caring for an aging or ailing elderly family member. To put this number in perspective, there are less than 2 million Americans living in nursing homes. So, simply by looking at the numbers, we can conclude that the bulk of caring for our nation's elderly is carried out by family and friends in the form of informal caregiving.

I said that we would learn about the contributions made by these individuals. It is enormous. Economically, family caregiving is worth billions of dollars. Emotionally and physically, caregiving is often an overwhelming task. Caregivers know what it entails to juggle personal and professional demands with the responsibilities that accompany caregiving.

Nearly 75% of caregivers are women, most of whom work and also care for children and a spouse. This group of caregivers, often referred to as the 'sandwich generation', face particular challenges. The sacrifices made by these individuals not only improve the quality of life for those they care for, but save the public from what would be very expensive costs for caring for people who might otherwise require services in a hospital or nursing home. In both of these settings, the Medicare and Medicaid programs pay heavily. Today's hearing will more precisely examine the important and unique contributions of caregivers.

It is likely that many of you in the room here are caring for a family member. In fact, I know that two of the witnesses are caregivers. I'd like to take a minute to share a unique story of family caregiving. I should say that each family has a unique story since no two families are alike. One story I am familiar with is that of Marie Sommer. She is a 93 year old woman who lives close to my home in New Hartford, Iowa. Mrs. Sommer has a number of physical conditions which require special attention, including hypertension, macular degeneration, and arthritis. She is also a breast cancer survivor.

Despite busy lives of their own, including running a restaurant, her two daughters, Florence and Charlene Ingalls, have made it possible for Mrs. Sommers to remain at home. They have arranged their schedules so that they take turns with the responsibility of caring for their mother. I have tremendous respect and admiration for this family's commitment to caring for their mother. It is a huge effort.

I look forward to more stories of caregiving from our witnesses. By sharing their insight and expertise, I am confident that today's witnesses will contribute greatly to the objective of raising awareness of the value and importance of family caregiving. It is particularly important for policy makers to understand its importance in the long term care delivery system given the growing long-term care demands of our aging nation.

I am especially honored to have First Lady Rosalynn Carter here with us today. Mrs. Carter has had first-hand experience as a caregiver, which she will share with us today. She is the author of two books on caregiving. The most recent one offers help to those caring for someone with mental illness. I commend her for all her fine leadership in this area. I also want to welcome all the other witnesses here today and to thank you for taking time out of your busy schedules to appear before the committee.

On a related matter, I would like to announce that today I am introducing a bill that will help Americans prepare for the day that they might need long-term care and find themselves without a family member who can be their caregiver. This bill, titled "The Long Term Care and Retirement Security Act" will be introduced today. This legislation would help people who do not have access to subsidized long-term care plans through their jobs. It would allow them to deduct the cost of long-term care insurance premiums from their taxable income. The goal of this legislation is to help Americans plan responsibly for their later years.

Today's hearing will provide an in-depth look at the important policy issues related to family caregiving and provide an opportunity to look at innovative programs from around the country. With the growing number of older Americans, the demand for long term care services will increase drastically. The role fulfilled by family caregivers will also see new demands. I look forward to hearing from our witnesses.

I turn now to Senator Reid.

OPENING STATEMENT OF SENATOR HARRY REID

Senator REID. Mr. Chairman, I served on the Aging Committee during the time I was in the House, part of that time during the chairmanship of the great Claude Pepper. Since coming to the Senate, I have served on the Aging Committee, and the reason I mention that is that I think that you and Senator Breaux have done an outstanding job of holding very probative hearings, and I think the title of today's hearing says it all—it is entitled, "Everyday Heroes: Family Caregivers Face Increasing Challenges in an Aging Nation." That really, I repeat, does say it all.

I want to join with you in expressing appreciation to former First Lady Rosalynn Carter for all the work that she has done. I had the good fortunate of being able to be with her several months ago where we were able to talk about a number of issues related to mental health, including suicide, which I have been very heavily involved in, and I had the opportunity to read your book at that time—you gave me a copy of it—I have since done that, and I appreciate very much the great work that you have shared with the American public.

I certainly want to express, through you, to your great husband the appreciation we all have for his continued work to improve not only what is going on in America, but around the world.

Chairman Grassley has stated very clearly that this is a serious problem. We have an aging population, and we do have everyday heroes—people who work to keep their loved ones at home. Not only are they heroes because they are doing the right thing, but for us as a Nation, they are saving the taxpayers billions and billions of dollars.

So I think it is worth our time today to look at ways that we can give these caregivers some help. We certainly need to look at some type of respite for them so they can get away from the jobs that they have of 24-hour caregiving, for example, to an Alzheimer's patient or someone with Parkinson's disease, and we need to set up a program where we can give them some help, either with some kind of better tax break than they now have, or at least some program that will make their lives more bearable.

So I look forward to our reporting to the rest of the Senate as to things that can be done. This is a problem that is complex today but will be more so because the baby boom generation over the next 30 years will continue to make our problem more difficult.

I would ask unanimous consent, Mr. Chairman, that my statement that has been prepared be submitted in the record as if given here.

The CHAIRMAN. Thank you very much, and it will be.

[The prepared statement of Senator Reid follows along with prepared statements of Senator Enzi and Senator Snowe:]

PREPARED STATEMENT OF SENATOR HARRY REID

Good morning Mr. Chairman, members of the Committee, and distinguished panel of witnesses. I am pleased that the Committee has decided to devote this hearing to the challenges facing family caregivers, and I commend the Chairman for convening this distinguished panel.

I would like to take a moment to extend a special welcome to Former First Lady Rosalynn Carter. A few months ago, I had the privilege of meeting Mrs. Carter and she gave me an autographed copy of her book, *Helping Someone With Mental Illness*. This book provides some wonderful insights about the role of caregivers, and I encourage everyone to read it. Mrs. Carter, it is truly an honor to have you here today, and I look forward to hearing your remarks.

More than 22 million Americans—one in four households—are involved in caring for an aging or ailing family member, friend, or neighbor. Anyone who has ever cared for an elderly relative knows that the personal and financial demands that come with this task are tremendous. As we prepare for the aging of the babyboom generation over the next thirty years, and as Americans continue to live longer, it is imperative that we focus our attention to the challenges facing family caregivers.

While there is no doubt that caring for a sick or elderly relative is extremely rewarding, the emotional, physical and financial tolls associated with caregiving are significant. Caring for a sick or elderly relative is a full-time job, yet most caregivers already have a job. Many caregivers are professionals who spend their paychecks and savings on caring for a loved one, often with little outside assistance. Additionally, many caregivers have little or no medical training, yet they regularly administer treatments and medications to their loved ones at home.

Talk to any of these caregivers, and chances are they will tell you they are in desperate need of more personal time, more resources, and more technical and medical training. While the needs of individual family caregivers are unique, one thing is certain: it is time for us to start caring for our caregivers.

The demand for family caregiving will only increase with time. It is therefore critical that we began to examine ways we can help family caregivers meet the challenges they face every day. The first step we must take is to increase public awareness and recognize the value of family caregivers in our long term care system. We cannot afford to overlook the needs of the relatives, spouses, friends and loved ones who provide ongoing care at home to seriously ill and disabled patients. Today's hearing is a step in the right direction. I look forward to hearing from the distinguished panel of witnesses convened here today.

PREPARED STATEMENT OF SENATOR MICHAEL ENZI

Mr. Chairman, once again you have chosen an important and timely topic for this Aging Committee hearing—family caregiving. The focus of Congress has always been on the federal programs that assist our elderly, such as Social Security, Medicare, and Medicaid. This is certainly necessary and appropriate. However, we also need to remind ourselves and the nation that we have a personal responsibility to care for our own vulnerable senior citizens when possible. State-supported care should never, and could never, replace the love and attention that family caregivers can provide. I am pleased, therefore, that the Chairman is holding this hearing that will highlight the prevalence and importance of family caregiving in our nation, and more importantly, it will remind Americans of their responsibility to their elders.

I believe that encouraging and increasing the use of family caregiving will be essential to help shore up our federal programs and avoid a retirement crisis in our nation when the Baby Boom generation begins to retire. The Medicare Part A Trust Fund is already scheduled to go broke in 10 years, Medicare Part B expenditures from the government's general revenues are increasing dramatically every year, the cost of nursing homes exceeds $40,000 per year and will only increase, and the national savings rate has dropped to only 3.8 percent. These statistics certainly do not bode well for our nation's future retirees, and I did not even mention Social Security! As Congress and our society prepares for the retirement of the Baby Boom generation, the role of caregiving must be an important factor to include in the process.

I am pleased that many programs have been initiated at the state and local level to encourage the use of family caregiving and to ease the strain it places on caregivers. These programs are best developed and implemented at the local level, since the needs of caregivers and care recipients vary widely across the nation. It is vitally important, however, that Congress is aware of these programs, and of the need to facilitate their further development as we explore the best ways to ensure that affordable, reliable care is available to our elderly.

More importantly, family caregiving can provide the comfort and security that is often lacking in an institutional setting. This Committee has already highlighted the abuse and neglect that can occur in nursing homes. The encouragement of family caregiving is certainly one method to address this problem. In fact, it is heartening to learn that caregiving is so prevalent throughout our nation and our senior citizens are not becoming "wards of the state." In Wyoming, we don't have the same level of access to retirement facilities that exist in other states, and we also like to take care of things ourselves. Family caregiving therefore is extremely widespread in my state. Our terrestrial climate may not be hospitable for retirees, but our family climate is certainly welcoming. I applaud all of the people, in Wyoming and elsewhere, who take the time to help care for an elderly loved one.

Once again, I thank the Chair for holding this hearing to discuss family caregiving. Taking care of vulnerable individual, whether it is a child or a senior citizen, is an essential component of any healthy society. We have a responsibility to take care of our elders. It is safe to say that there is much work to be done to prepare our nation's elder care system for the retirement of the Baby Boomers. The promotion of family caregiving is not only the most practical way to help cope with this retirement surge, it is the best way.

PREPARED STATEMENT OF SENATOR OLYMPIA SNOWE

Thank you, Mr. Chairman, and thank you Members of the Committee for inviting me to participate in the "Day on Family Caregiving." I appreciate Chairman Grassley's invitation and his continued leadership on behalf of our seniors.

I would also like to welcome Former First Lady Rosalynn Carter, who has so deeply devoted herself to the issue of caregiving by providing information, hope and comfort to others through her books on the subject. Thank you, Mrs. Carter, for lending your eloquent voice to this significant cause, and for taking the time to share your thoughts with us on this issue that touches the lives of millions of Americans. From my own experiences talking to caregivers in the home, you are right on the mark.

I must admit that this hearing is like something of a homecoming for me. You see, in the House of Representatives, I served with two of my colleagues here today, Senators Grassley and Wyden, on the former Select Committee on Aging where we first began to really look at the issue of caregiving.

In fact, it was there on that committee that I requested a study on the subject entitled, "Exploding the Myths: Caregiving in America" and I introduced the first National Family Caregivers Resolution. Senator Glenn took the lead in the Senate, and I know it's not exactly a news flash to say that we are losing a great friend with his impending retirement.

Before I first started looking at the issue of caregiving, I had no idea how pervasive it is across this country. Today, there are an estimated 25 million people in this country who find themselves cast in the role of family caregiver.

In fact, I would be surprised if there is anyone in this room who couldn't think of at least one friend or family member who is a primary caregiver to a loved one. And the reality is, many of us may one day find ourselves in that role further down the road.

That's why our time and energies are so well-spent here today. The fact is, caregiving isn't some unusual phenomenon. It isn't limited to one social class, geographical region, political party, or gender. It is a major part of life for millions of Americans—and I again want to commend Chairman Grassley and this Committee for taking the initiative by holding this hearing.

Mr. Chairman, we all enjoy the time spent in the company of our family, our loved ones. But imagine being their primary caregiver in addition to working to meet the everyday needs of a family and career—that is an extraordinary challenge to say the least, and it is one which places incredible demands on those who undertake this task.

Sadly, then, it's not surprising that the most common response given by caregiver's in a survey conducted by the National Family Caregiver's Association was a "sense of isolation." Hopefully, they will find some comfort in today's hearing, which makes it very clear that they are not alone.

In that light, this hearing presents us with an ideal opportunity to consider ways in which the Federal Government may be able to provide some assistance; some relief. I have introduced legislation, over the years, to provide tax assistance and respite care to caregivers, and have asked the General Accounting Office to study the actions businesses are taking on behalf of caregivers.

I was pleased to learn from the study that businesses are beginning to understand that if they want to keep good employees, they need to provide flex time, information on resources, and other benefits in order to help their employees meet both their work and family responsibilities.

With that, I look forward to hearing from Mrs. Carter and our other witnesses on their ideas for other ways the Federal Government could provide assistance. Again, Mr. Chairman I appreciate the opportunity to join with you today.

The CHAIRMAN. I would like to take 60 seconds to once again introduce our former First Lady——

Senator REID. Mr. Chairman, if I could just say one brief word.

The CHAIRMAN. Yes, please do.

Senator REID. As has been recorded in all the press today, the Senate Democratic leadership has been invited to the White House this morning, so I am going to have to leave to go down there; but I am going to stay and hopefully be able to hear Mrs. Carter's testimony.

The CHAIRMAN. She will be starting in 60 seconds.

Senator REID. There are places I would rather go than the White House this morning.

The CHAIRMAN. I cannot think of a better place to be than here, to hear Mrs. Carter.

In the weekend Des Moines Register, an op ed writer who writes regularly for the Register by the name of Lavel Beaulieu wrote an article about the moral leadership of the Carters and particularly of former President Jimmy Carter, and I will quote only one sentence from that, leading up to Mrs. Carter's introduction.

He says, and I quote: "Carter, who with his wife Rosalynn, exemplifies the ideals of American love and family values. The question: Want morals? Jimmy Carter is ready."

I am very honored to have this opportunity to welcome our first distinguished witness, former First Lady Rosalynn Carter. Mrs. Carter has successfully worked for more than two decades to improve the quality of life of people of all ages around the world. Today she is a national leading advocate for many worthwhile causes, including promoting positive change in the mental health field.

The Rosalynn Carter Institute of Georgia Southwestern State University was established in her honor, with the mission of helping family and professional caregivers. Mrs. Carter is the author of two books on caregiving—*Helping Yourself Help Others: A Book for Caregivers* and *Helping Someone with Mental Illness: A Compassionate Guide for Families, Friends and Caregivers.* She brings first-hand experience to understanding the challenges facing family caregiving.

We are honored to have her testify today, and I am also glad to welcome Tom Bryant, director of the Carter Center Mental Health Task Force. I would also like to acknowledge Mr. Jack Nottingham, who is not testifying but is here today, and we welcome him. Mr. Nottingham is executive director of the Rosalynn Carter Institute.

Mrs. Carter, thank you very much for coming. Please proceed.

STATEMENT OF FORMER FIRST LADY ROSALYNN CARTER, ROSALYNN CARTER INSTITUTE, AMERICUS, GA; ACCOMPANIED BY TOM BRYANT, CHAIRMAN OF THE BOARD, ROSALYNN CARTER INSTITUTE

Mrs. CARTER. Thank you, Mr. Chairman and Senator Reid. It is very nice to be here, and I appreciate this opportunity to talk about caregiving, because it is an issue that is very close to my heart and one that I have worked on in various capacities for many years, in fact, for most of my life.

When I was very young, I helped my mother take care of my own ill and aging family members, and in more recent years, I have witnessed firsthand again the problems and needs of caregivers, as Jimmy's mother, his sister and his two brothers have struggled with terminal cancer; all of them have died since we came home from the White House.

I remain heavily involved in the issue in other ways. It has been an important part of my mental health work. We have worked closely with those who care for people with mental illness, and that is an interest that I have pursued since my husband was Governor.

I want to congratulate you, Senator Grassley, on your new legislation—it is very exciting for me to hear about that—and for the good things that both of you have done to help people and particularly families.

I serve as president of the Rosalynn Carter Institute. Tom Bryant is chairman of the board of the Rosalynn Carter Institute, and I am glad he is here with me, and as you said, Jack Nottingham is executive director of the Institute.

The Institute was established to work on mental health issues, but I have a really good mental health program at the Carter Center in Atlanta, so we began working with those caring for people with mental illnesses. Even before our first symposium though, the project had spread to take in all caregivers, whether caring for people who are elderly or physically disabled, suffering from any kind of illness or disability.

The Institute now is in its 10th year, and it is dedicated to improving the caregiving process by both professionals—we work, Mr. Chairman, with both professionals and family caregivers, trying to bring them together and trying to increase their skills in caring for people and in working together.

The Rosalynn Carter Institute has had a really positive impact on the community surrounding the university. We have created a model that I am going to be talking about more which could be replicated across the country.

My concerns about caregiving are also integral to my work as honorary chairperson of the Last Acts Coalition, which is a group of more than 180 organizations dedicated to improving care for the dying. Last Acts involves health professionals, health officials and consumers in fostering three major changes—better communication among dying patients, their families and the health professionals; more support for good end-of-life care from the medical community, and a cultural shift in our society. Mr. Chairman, physicians see dying as a failure when it should be a natural process, because it is inevitable for all of us.

I have shared this in my two books. We named my first one *Helping Yourself Help Others* because what we have learned is that many caregivers are so overwhelmed caring for a loved one that they neglect themselves, which leads to having to institutionalize loved ones. Also, caregivers become casualties themselves if they do not take care of themselves.

Through all of these efforts, I have learned that caregiving is not only a very complex, difficult, personal issue, but it is of great national concern. I first encountered the issue when I was 12 years old, and my father became terminally ill with leukemia. My mother was 34 years old. I was the oldest of four children, and as the oldest and the daughter, I helped out.

Caregiving affects the whole family when someone is ill or handicapped. My main responsibility, other than reading to my father and helping my mother, was to take care of the three younger children in the family—and for a 12-year-old, knowing that my father was not going to live, that was a horrible experience for me.

Less than a year after my father died, my mother's mother died. My mother is an only child, and my grandfather came to live with us. He was 70 years old, and he lived to be 95; so I have seen caregiving from all angles.

I knew how hard it was for my mother, but I did not realize the extent of the problem until we began the Rosalynn Carter Institute. We were charting new ground with the Institute. When we began, I called to all the organizations we could think of that dealt with health problems health organizations and groups and nobody was working on the issue, but everybody said that it was needed.

Then, we did a needs assessment in our community with students at the university, and we realized that we had struck on an issue that was very important. We found the problems overwhelming physically, emotionally and financially. Caregivers in our own small community felt isolated, lonely, trapped by their situation, frustrated, not knowing where to go for help, whom to turn to, or whether they were doing what was best and right for a loved one. Burnout was common. More than half of the people that we surveyed said they were suffering from burnout.

We heard many poignant stories. One man, for instance, said: "I cry, but I do not let her see me." He was caring for his wife who had Alzheimer's. Another one said: "Even when friends call, they ask how he is doing, but they never ask how I am doing." This is very sad.

National statistics have shown that caregivers, when compared with the general population, are three times more likely to be depressed, two to three times more likely to take psychotropic drugs like tranquilizers, and 12 percent more likely to use alcohol as a way to cope with stress. And yet almost all the caregivers we surveyed said they found something rewarding about the situation.

We had one woman say that she just wanted to run away, and she did. She left home. She left her father, whom she was taking care of, in a wheelchair, checked into a motel, and after a couple of hours, she said she felt so guilty that she went back home, and of course, he was right where she had left him. But as we were leaving the house, she said: "But nobody can take as good care of my father as I can." So there is something rewarding about the situation.

Caregiving is an issue that is not going away. One of my colleagues has said that there are four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregiving. That is how universal the problem is.

I think you know the scope of the problem; you have already talked about that and about how many Americans are family caregivers. One of the myths in our country is that the family does not care for its older members. The fact is that the family is the number one caregiver of older people even when the one cared for is impaired. Only 5 percent of the population over 65 lives in nursing homes, and most of that 5 percent have no family. And of those who do have a family, many of them spend only the final stages of illness in a nursing home. As you said, 75 percent of caregivers are women, and this raises another concern, because one-fourth of women caregivers in one study were between the ages of 65 and 74. People in their 70's are caring for parents in their 90's.

The number and age of elderly people providing and receiving care is going to be even greater in the future, as Senator Reid said, when baby boomers reach this age. So our population is aging rapidly, and at the same time, modern medicine keeps people alive for an extraordinary length of time.

Now, many people live for months and even years with severe illnesses that will result in their death, and that brings up another issue, Mr. Chairman, regarding the Last Acts Campaign. We have learned through the largest survey ever done on dying patients that most people die in hospitals. Often, they are left alone, in unrelieved pain, hooked up to machines. We need a renewed focus on caring for dying family members at home.

Those who are at home are more likely to receive palliative care, which is care that is focused on the comfort of the individual in those last stages of life rather than trying to cure the person who has a terminal illness. Here again, the signal points to the growing need to recognize and support caregiving for the role it plays in providing long-term care.

What can be done to provide pro-family support for caregivers? States can play a vital role. Pennsylvania has a good program for caring for elderly citizens in the home. The program assesses caregiver needs, counsels on ways to cope, trains family caregivers, provides information about other local, State and Federal support programs or resources, and offers one-time grants for home adaptations. Other States could replicate this, and some have—Oregon, for example, has a good program.

So much can be done in local communities. Educational, religious and other institutions can establish resource centers and provide consultants or volunteers to help family caregivers; they can help establish support groups, and they can make people more aware of the issue and the great service that caregivers provide. We have found that to be so important as we deal with caregivers, because many of them tell us that they feel underappreciated—and some of them even tell us they feel worthless, when they contribute so much.

These efforts can work in communities. We have seen what has happened with the Rosalynn Carter Institute, which serves as a resource center. We provide volunteers, and have courses for caregivers. We go into the small communities in our area and hold sessions for them, generic sessions on caregiving, but we also have sessions on how to deal with the different illnesses that people have.

Jimmy asked me once if he developed a serious illness, would there be anybody to train me how to care for him with just simple things like bedpans and how to turn the patient in bed and take blood pressure. Home caregivers do not understand or know how to deal with a lot of these issues.

Those are some of the things that can be done through the institutions, and there are, Mr. Chairman, also a number of policy areas that I hope you will explore that can be very helpful. We need to have the benefits of the Family and Medical Leave Act cover more employees in small businesses and be more flexible. This would help caregivers a lot. Respite care could be added to Medicare reimbursement. Having a substitute caregiver come in for a day, or even for just a few hours, can do so much to help lift the burden of the caregiver. We have seen it at home. It is important, and also economical in the long run, because as I have said, caregivers burn out, which results in their loved ones having to go to nursing homes and the caregivers themselves having to be cared for.

Third, the government could foster demonstration projects that build support systems for caregivers. At the Rosalynn Carter Institute, we have created a network called "CARENET," the caregivers' network. We actually have family caregivers, professional caregivers, representatives of local, State and Federal Government agencies—welfare, mental health agencies, etc. representatives of the religious community and advocates all meeting together. We have a CareNet committee, and it is fascinating to see the government agencies and other people meeting together, because there never before has been discussion among them. They come together regularly to talk about the needs of caregivers and try to come up with solutions to the problems. It has been very effective in our area.

CareNet serves a 16-county area, and we are just now beginning to replicate this in another 16-county area in our State. We are keeping very detailed records of what we are doing so that, hopefully, this can be replicated again and again.

On the national level, the Department of Health and Human Services may be able to use its regional structure to implement this idea or other similar ideas across the country. I can tell you that it has been very effective in helping caregivers in our area.

Government could also play a role in creating a program that makes a professional care manager—not a case manager, but a care manager—available to informal caregivers. We are experimenting with this at the Rosalynn Carter Institute. We have received a Robert Wood Johnson Foundation grant to develop a certification program for people to fill this role locally. Making a care manager available would be a significant way to alleviate caregivers' anxiety about where to go and what to do when a loved one becomes ill.

Finally, caregivers need better education and training to do their work well. Colleges and universities could be encouraged to offer courses for family caregivers. Our State university now offers a generic course, as I said before, and we have even developed a textbook for it from the Rosalynn Carter Institute—"Caring for You, Caring for Me"—and we take this program throughout the area.

Grants could be provided to schools of medicine, nursing, social work, to find new ways that health professionals and family caregivers can work together. It is a real problem with a lot of caregivers when the professional focuses on the patient and does not take into consideration what the caregiver, who is spending so much time with that family member, does.

I have focused mostly on what we are doing at the Rosalynn Carter Institute because that is what I know about, and I have seen how effective it is. I was also asked to talk about my own personal experiences. And I have summarized these things that I have talked about on a list that includes other recommendations that I hope the committee will consider. These come from people who are more knowledgeable about current legislation than I am.

There is one other issue that I would like to mention. I have not said anything about home care. I know that you are familiar with that issue, which is very complicated, and I know you are grappling with it now, and hopefully, something can be done because home care is critical to so many caregivers and to so many people who are ill and suffering.

I just want to point out a couple of other things on these recommendations that the Government can do. One is to provide Social Security credits allowing caregivers to accrue caregiving hours to their earnings record in Social Security. France does this, as well as some other countries. Germany tried direct payments to the families, but that has been very controversial. But I think it would be very helpful if we could work something into Social Security.

Also, what caregivers do is so significant, and it is not counted at all in the nation's gross domestic product. I think the Congressional Budget Office could develop a system to calculate the value of caregiving provided and count its contribution in the nation's gross domestic product. Canada does a good job of this, and I think that would recognize caregiving as being the important issue it is.

Those are some of the things I wanted to say, Mr. Chairman and Senator Reid. I thank you again for letting me be here.

[The prepared statement of Rosalynn Carter follows:]

ROSALYNN CARTER INSTITUTE
OF GEORGIA SOUTHWESTERN STATE UNIVERSITY
800 Wheatley Street
Americus, Ga. 31709-4693
(912) 928-1234

Rosalynn Carter's Testimony
Senate Special Committee on Aging
Hearing on Caregiving Issues
September 10, 1998

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE, I AM VERY PLEASED TO BE HERE THIS MORNING AND TO HAVE THIS OPPORTUNITY TO TALK ABOUT CAREGIVING. IT IS AN ISSUE ABOUT WHICH I CARE DEEPLY AND ONE I HAVE WORKED ON IN VARIOUS WAYS FOR MUCH OF MY LIFE. FROM AN EARLY AGE, I HELPED CARE FOR MY OWN ILL AND AGING FAMILY MEMBERS AT HOME. AND IN MORE RECENT YEARS I HAVE WITNESSED AGAIN FIRST-HAND THE NEEDS AND PROBLEMS OF CAREGIVING AS JIMMY'S MOTHER, BROTHER AND SISTERS HAVE EACH STRUGGLED WITH TERMINAL CANCER.

I ALSO SPEAK TODAY AS ONE WHO REMAINS HEAVILY INVOLVED IN CAREGIVING. IT HAS BEEN AN IMPORTANT PART OF MY COMMITMENT TO MENTAL HEALTH ISSUES, AN INTEREST I HAVE PURSUED SINCE MY HUSBAND WAS GOVERNOR OF GEORGIA IN THE EARLY 1970S. IN ADDITION, I SERVE AS PRESIDENT OF THE ROSALYNN CARTER INSTITUTE (RCI) OF OUR LOCAL STATE UNIVERSITY, GEORGIA SOUTHWESTERN, IN AMERICUS, GEORGIA. THE INSTITUTE WAS ESTABLISHED TO WORK ON MENTAL HEALTH ISSUES. SINCE I HAVE A GOOD MENTAL HEALTH PROGRAM AT THE CARTER CENTER IN ATLANTA, I DIDN'T WANT TO DUPLICATE THE WORK THERE, SO WE BEGAN WORKING WITH THOSE CARING FOR PEOPLE WITH MENTAL ILLNESSES. OUR EFFORTS QUICKLY EXPANDED TO INCLUDE ALL CAREGIVERS, WHETHER CARING FOR ELDERLY, DEVELOPMENTALLY DISABLED, OR THOSE SUFFERING FROM A PHYSICAL OR MENTAL ILLNESS. THE INSTITUTE, NOW IN ITS TENTH YEAR, IS DEDICATED TO IMPROVING THE CAREGIVING PROCESS BY BOTH PROFESSIONAL AND FAMILY CAREGIVERS. IT HAS HAD A VERY POSITIVE IMPACT IN THE COMMUNITIES SURROUNDING THE UNIVERSITY, CREATING A MODEL

THAT COULD BE REPLICATED ACROSS THE COUNTRY. IN ADDITION, THE INSTITUTE HAS SERVED AS A CONVENER FOR PEOPLE WHO ARE INTERESTED IN LEARNING MORE ABOUT THE OPPORTUNITIES AND CHALLENGES ASSOCIATED WITH CAREGIVING.

MY CONCERNS ABOUT CAREGIVING ALSO ARE INTEGRAL TO MY WORK AS HONORARY CHAIR OF THE LAST ACTS COALITION, A GROUP OF MORE THAN 180 ORGANIZATIONS DEDICATED TO IMPROVING CARE FOR THE DYING. LAST ACTS INVOLVES HEALTH PROFESSIONALS, HEALTH OFFICIALS AND CONSUMERS IN FOSTERING THREE MAJOR CHANGES: BETTER COMMUNICATION AMONG DYING PATIENTS, THEIR FAMILIES AND HEALTH PROFESSIONALS; MORE SUPPORT FOR GOOD END-OF-LIFE CARE IN THE MEDICAL COMMUNITY; AND A CULTURAL SHIFT THAT WOULD ALLOW AMERICANS TO BE MORE COMFORTABLE IN FACING DEATH AND DYING.

I HAVE SHARED MUCH OF WHAT I HAVE LEARNED ABOUT CAREGIVING IN TWO BOOKS – *HELPING YOURSELF HELP OTHERS* AND *HELPING SOMEONE WITH MENTAL ILLNESS.* THROUGH ALL OF MY PROJECTS I'VE BECOME MORE AND MORE CONVINCED THAT CAREGIVING IS NOT ONLY A COMPLEX PERSONAL CONCERN BUT ALSO AN IMPORTANT NATIONAL CONCERN.

I FIRST ENCOUNTERED THE ISSUE WHEN I WAS 12 YEARS OLD, WHEN MY FATHER BECAME TERMINALLY ILL WITH LEUKEMIA. MY MOTHER WORKED HARD TO CARE FOR HIM AT HOME. AS THE OLDEST OF FOUR CHILDREN, I HELPED OUT. LESS THAN A YEAR AFTER MY FATHER DIED, MY MOTHER'S MOTHER ALSO DIED, AND MY GRANDFATHER, WHO WAS 70 YEARS OLD, MOVED IN WITH US. HE LIVED TO BE 95. I WATCHED MY MOTHER WORK, CARE FOR 4 SMALL CHILDREN AND CARE FOR MY GRANDFATHER. I KNEW HOW HARD CAREGIVING WAS FOR HER, BUT I DID NOT KNOW THE EXTENT OF THE PROBLEM UNTIL THE RCI WAS ESTABLISHED. (TODAY, THE SITUATION OF MY MOTHER, WHO IS 92 YEARS OLD, IS NEVER FAR FROM MY MIND. I AM HER ELDEST DAUGHTER, AND I MAKE MY HOME IN PLAINS, SO SHE FEELS PARTICULARLY RELIANT ON ME. ALTHOUGH SHE RECEIVES CARE IN AN ASSISTED LIVING HOME, SHE WISHES MY WORK WOULD REQUIRE LESS TRAVEL.)

WE WERE REALLY CHARTING NEW GROUND WHEN THE RCI BEGAN IN 1987. WE CALLED MANY ORGANIZATIONS AND INDIVIDUALS INVOLVED WITH IMPORTANT HEALTH PROGRAMS AND FOUND NO ONE WORKING ON CAREGIVING, ALTHOUGH EVERYONE ASSURED US THAT IT WAS AN ISSUE WE SHOULD PURSUE. AND AFTER A NEEDS ASSESSMENT IN OUR AREA – A SURVEY DONE BY STUDENTS OF THE UNIVERSITY – WE REALIZED THAT WE WERE ON THE CUTTING EDGE OF AN ISSUE THAT GREATLY NEEDED ATTENTION. WE FOUND THE PROBLEMS OVERWHELMING – EMOTIONALLY, PHYSICALLY AND FINANCIALLY. CAREGIVERS IN OUR OWN SMALL COMMUNITY FELT ISOLATED, LONELY, TRAPPED BY THEIR SITUATION, FRUSTRATED, NOT KNOWING WHERE TO TURN FOR HELP OR WHETHER THEY WERE DOING WHAT WAS RIGHT AND BEST FOR THEIR LOVED ONE. BURNOUT WAS COMMON. MORE THAN HALF OF THOSE WE SURVEYED SAID THEY WERE SUFFERING FROM BURNOUT.

NATIONAL STATISTICS HAVE SHOWN THAT CAREGIVERS, WHEN COMPARED WITH THE GENERAL POPULATION, ARE THREE TIMES MORE LIKELY TO BE DEPRESSED, TWO OR THREE TIMES MORE LIKELY TO TAKE PSYCHOTROPIC DRUGS (SUCH AS TRANQUILIZERS), AND 12% MORE LIKELY TO USE ALCOHOL AS A WAY TO COPE WITH THE STRESS. AND YET ALMOST ALL THE CAREGIVERS WE SURVEYED FOUND SOMETHING ABOUT THE EXPERIENCE REWARDING. ONE WOMAN TOLD US SHE HAD JUST WANTED TO RUN AWAY -- AND DID. SHE CHECKED INTO A MOTEL, LEAVING HER FATHER HELPLESS IN A WHEEL CHAIR. SHE SAID THAT AFTER A FEW HOURS, SHE FELT SO GUILTY THAT SHE WENT BACK HOME AND OF COURSE, HER FATHER WAS JUST WHERE SHE HAD LEFT HIM. BUT EVEN SHE FELT A SENSE OF PRIDE IN HER TASK. AT THE END OF THE INTERVIEW, SHE COMMENTED, ".....BUT NOBODY CAN TAKE AS GOOD CARE OF HIM [HER FATHER] AS I CAN!"

OTHERS HAVE SAID THAT CAREGIVING DEEPENS THEIR COMPASSION, STRENGTHENS THEIR ABILITY TO LISTEN, BUILDS THEIR CONFIDENCE, AND DISPELS THEIR FEARS OF THE SICK OR DISABLED. FOR SOME, PROVIDING CARE HAS TURNED THEM INTO OUTSPOKEN CHAMPIONS OF THE NEEDS OF THE SICK AND DISABLED. CAREGIVING IS AN ISSUE THAT IS NOT GOING AWAY. ONE OF MY COLLEAGUES HAS SAID THERE ARE ONLY FOUR KINDS OF PEOPLE IN THIS WORLD: THOSE WHO HAVE BEEN CAREGIVERS; THOSE WHO CURRENTLY ARE CAREGIVERS; THOSE WHO WILL BE CAREGIVERS; AND THOSE WHO WILL NEED CAREGIVERS. THAT'S HOW UNIVERSAL THIS ISSUE IS.

LET'S LOOK AT THE SCOPE OF THE PROBLEM MORE SPECIFICALLY. TWENTY-FIVE MILLION AMERICANS HAVE IDENTIFIED THEMSELVES AS FAMILY CAREGIVERS. ONE OF THE MYTHS IN OUR COUNTRY IS THAT THE FAMILY DOES NOT CARE FOR ITS OLDER MEMBERS. IN FACT, STUDIES SHOW THAT THE FAMILY IS THE NUMBER ONE CAREGIVER OF OLDER PERSONS, EVEN WHEN THE ONE CARED FOR IS IMPAIRED. ONLY 5% OF THE POPULATION OVER 65 LIVE IN NURSING HOMES; NEARLY HALF OF THESE DO NOT HAVE A FAMILY AND MANY WHO DO ARE ONLY IN THE NURSING HOME DURING THE FINAL STAGES OF DISABLING STROKE, CANCER OR HEART DISEASE. THE NATIONAL ALLIANCE FOR CAREGIVING REPORTED IN 1997 THAT 75% OF CAREGIVERS ARE WOMEN. AND WHILE MALE CAREGIVERS TYPICALLY HANDLE LEGAL, FINANCIAL AND HOUSING MATTERS, WOMEN USUALLY PROVIDE PERSONAL CARE – BATHING, FEEDING, WASHING, TOILETING AND DRESSING. THESE ARE THE KINDS OF DEMANDING, CONTINUOUS AND RELATIVELY UNREWARDING TASKS THAT PUT THE CAREGIVER AT HIGH RISK OF BURNOUT.

THE PREPONDERANCE OF WOMEN CAREGIVERS RAISES ANOTHER CONCERN – 25% OF CAREGIVERS IN ONE STUDY WERE THEMSELVES BETWEEN THE AGES OF 65 AND 74, WITH MANY OF THEM RESPONSIBLE FOR THE NEEDS OF ELDERLY PARENTS OR SPOUSES. THESE CAREGIVERS PROVIDE ENORMOUSLY VALUABLE SERVICES, WHICH HAVE NOT BEEN MEASURED IN FINANCIAL TERMS AND ARE NOT COUNTED IN THE NATION'S GROSS DOMESTIC PRODUCT. MANY OPERATE, AS I HAVE ALREADY POINTED OUT, WITHOUT ADEQUATE SOCIAL AND EMOTIONAL SUPPORT AND RESPITE. AND NEARLY HALF OF THE FAMILY CAREGIVERS IN 1997 SAID THEY WERE EMPLOYED. THAT IS ABOVE AND BEYOND THEIR CAREGIVING ROLES. MANY, HOWEVER, HAVE HAD TO LEAVE THEIR JOBS AND THEREBY REDUCE OVERALL PRODUCTIVITY OF THE COUNTRY. THE NUMBER AND AGE OF ELDERLY PEOPLE PROVIDING AND RECEIVING CARE IS A GREAT CONCERN NOW AND WILL BE EVEN GREATER IN THE FUTURE AS THE BABY BOOMERS REACH THIS AGE. THE DEMOGRAPHIC TREND IN AMERICA SHOWS THAT OUR POPULATION IS AGING QUICKLY.

AT THE SAME TIME, MODERN MEDICINE HAS AN EXTRAORDINARY ABILITY TO KEEP PEOPLE ALIVE. AS A RESULT, MANY NOW MAY LIVE FOR MONTHS OR EVEN YEARS WITH THE SEVERE ILLNESSES THAT ONE DAY WILL CAUSE THEIR DEATHS. ANOTHER ISSUE, MR. CHAIRMAN, IS THAT WE KNOW FROM OUR LAST ACTS

INITIATIVE THAT MOST AMERICANS DIE IN HOSPITALS, WHERE THEY ARE ALL TOO OFTEN LEFT ALONE, IN UNRELIEVED PAIN, AND ATTACHED TO LIFE-SUSTAINING MACHINES THEY MAY NEVER HAVE WANTED. ONE ANSWER TO THIS PROBLEM IS A RENEWED FOCUS ON CARING FOR PATIENTS AT THE END OF LIFE AT HOME. THIS OFFERS THE ADVANTAGES OF FAMILIAR SURROUNDINGS AND PERMITS PATIENTS TO SPEND MORE TIME WITH THE PEOPLE WHO MEAN THE MOST TO THEM. THOSE CARED FOR AT HOME ARE MORE LIKELY TO RECEIVE PALLIATIVE CARE – AN APPROACH THAT AIMS PRIMARILY TO PROVIDE COMFORT, NOT CURE, IN THE FACE OF A TERMINAL ILLNESS. HERE AGAIN, THE SIGNALS POINT TO A GROWING NEED TO RECOGNIZE AND SUPPORT CAREGIVING FOR THE SIGNIFICANT ROLE IT PLAYS IN PROVIDING LONG-TERM CARE. WHAT CAN BE DONE TO PROVIDE PRO-FAMILY SUPPORT FOR AMERICA'S GENEROUS CAREGIVERS?

STATES AND COMMUNITIES CAN PLAY A VITAL ROLE IN PREVENTING THE DOWNWARD SPIRAL IN WHICH CAREGIVERS THEMSELVES BECOME PHYSICALLY OR MENTALLY ILL. THE STATE OF PENNSYLVANIA HAS DESIGNED THE FAMILY CAREGIVER SUPPORT PROGRAM TO HELP THOSE WHO WANT TO CARE FOR OLDER RELATIVES IN THEIR HOMES. THE PROGRAM ASSESSES CAREGIVER NEEDS; COUNSELS ON WAYS TO COPE; TRAINS FAMILY CAREGIVERS; PROVIDES INFORMATION ABOUT OTHER LOCAL, STATE, AND FEDERAL SUPPORT PROGRAMS OR RESOURCES, AND OFFERS ONE-TIME GRANTS FOR HOME ADAPTATIONS. OTHER STATES COULD REPLICATE THIS OR SIMILAR MODELS. MUCH CAN BE DONE IN LOCAL COMMUNITIES. EDUCATIONAL, RELIGIOUS AND OTHER INSTITUTIONS CAN ESTABLISH RESOURCE CENTERS, AND PROVIDE CONSULTANTS OR VOLUNTEERS TO HELP FAMILY CAREGIVERS CARE FOR THEIR DISABLED LOVED ONES. THEY CAN HELP ESTABLISH SUPPORT GROUPS AND MORE GENERALLY SEEK TO INCREASE AWARENESS OF INFORMAL CAREGIVING AND THE VALUE OF THEIR ROLE IN SOCIETY. EFFORTS SUCH AS THESE CAN BE VERY HELPFUL, AS DEMONSTRATED BY THE RCI. MR. CHAIRMAN, THERE ARE A NUMBER OF POLICY-MAKING AREAS I HOPE CONGRESS WILL EXPLORE SO THAT GOVERNMENT AND BUSINESS CAN HELP AMERICANS GIVE AND RECEIVE BETTER FAMILY CARE.

FIRST, THE FAMILY AND MEDICAL LEAVE ACT PROVIDES IMPORTANT BENEFITS FOR ELDER CARE AS WELL AS CHILD CARE. HOWEVER, WE NEED TO HAVE THESE BENEFITS COVER MORE EMPLOYEES IN SMALL BUSINESS AND TO HAVE

THE ACT AMENDED TO PROVIDE GREATER FLEXIBILITY FOR CAREGIVERS DURING THE COURSE OF THEIR WORKDAY AS WELL AS WITH JOB RETENTION AND OTHER SUPPORTS. AND BECAUSE EMPLOYERS CAN BE AN IMPORTANT SOURCE OF REFERRAL FOR THEIR EMPLOYEES SEEKING SOCIAL SERVICES, BUSINESSES COULD OFFER MORE INFORMATION ON HOW TO FIND HELP FOR THOSE WITH CAREGIVING DILEMMAS.

SECOND, RESPITE CARE COULD BE ADDED TO MEDICARE REIMBURSEMENT. RESPITE CARE MEANS HAVING A SUBSTITUTE CAREGIVER COME INTO THE HOME TEMPORARILY – PERHAPS FOR A DAY OR EVEN A FEW HOURS – SO THE PRIMARY CAREGIVER CAN GET RELIEF. APPROPRIATE RESPITE CARE, GIVING NECESSARY RELIEF TO THE BURDENED CAREGIVER, IS ECONOMICAL IN THE LONG RUN SINCE IT REDUCES THE EXHAUSTION WHICH MAY LEAD TO NURSING HOME ADMISSION OR OTHER EXPENSIVE FORMS OF CARE. ALSO, WITHOUT SUCH RELIEF, CAREGIVERS THEMSELVES OFTEN BECOME CASUALTIES. THIRD, GOVERNMENT COULD FOSTER DEMONSTRATION PROJECTS THAT BUILD EFFECTIVE SUPPORT SYSTEMS FOR CAREGIVERS. I AM PARTICULARLY PROUD OF THE SUCCESS THE ROSALYNN CARTER INSTITUTE HAS ACHIEVED IN CREATING A SUPPORT NETWORK FOR BOTH FAMILY AND PROFESSIONAL CAREGIVERS. THIS NETWORK INCLUDES CAREGIVERS, REPRESENTATIVES OF LOCAL, STATE AND FEDERAL GOVERNMENT AGENCIES (WELFARE, HEALTH, MENTAL HEALTH, ETC.), REPRESENTATIVES OF THE RELIGIOUS COMMUNITY, AND ADVOCATES WHO COME TOGETHER TO TALK ABOUT THE PROBLEMS INVOLVED AND TRY TO FIND WAYS TO RESOLVE THEM.

THE NETWORK SERVES CAREGIVERS IN A 16-COUNTY AREA OF SOUTHWEST GEORGIA, AND ITS FINDINGS HAVE BEEN INVALUABLE IN PLANNING PROGRAMS. WE ARE JUST NOW BEGINNING TO REPLICATE THIS MODEL ON AN EXPERIMENTAL BASIS IN ANOTHER 16-COUNTY REGION IN SOUTH GEORGIA. I HAVE HIGH HOPES THAT THE EXPERIMENT WILL BE SUCCESSFUL IN SHOWING OTHER COMMUNITIES THE WAY TO ENHANCE THEIR SUPPORT OF CAREGIVERS. ON THE NATIONAL LEVEL, THE DEPARTMENT OF HEALTH AND HUMAN SERVICES MAY BE ABLE TO USE ITS REGIONAL STRUCTURE TO IMPLEMENT THIS IDEA OR OTHER SIMILAR PROJECTS NATIONWIDE.

GOVERNMENT MAY ALSO PLAY A ROLE IN CREATING PROGRAMS THAT MAKE A PROFESSIONAL CARE MANAGER AVAILABLE TO INFORMAL CAREGIVERS. AGAIN, THE ROSALYNN CARTER INSTITUTE HAS TAKEN THE LEAD IN EXPERIMENTING WITH THIS CONCEPT. WE HAVE RECEIVED A ROBERT WOOD JOHNSON FOUNDATION GRANT TO DEVELOP A CERTIFICATION PROGRAM THAT PREPARES PROFESSIONALS TO FILL THIS ROLE LOCALLY. MAKING A CARE MANAGER AVAILABLE WOULD BE A SIGNIFICANT WAY OF ALLEVIATING CAREGIVERS' ANXIETY ABOUT HAVING NOWHERE TO TURN FOR SOLUTIONS. FINALLY, CAREGIVERS NEED BETTER EDUCATION AND TRAINING TO DO THEIR WORK WELL. COLLEGES AND UNIVERSITIES MAY BE ENCOURAGED TO OFFER COURSES FOR FAMILY CAREGIVERS. SUCH TRAINING WOULD NOT ONLY OFFER NEW SKILLS, BUT ALSO OPEN CHANNELS OF COMMUNICATION AND COOPERATION AMONG OTHER CAREGIVERS IN THE COMMUNITY.

GRANTS COULD ALSO BE PROVIDED TO SCHOOLS OF MEDICINE, NURSING (INCLUDING NURSE PRACTITIONERS) AND SOCIAL WORK TO FIND NEW WAYS THAT THE HEALTH PROFESSIONS CAN BETTER ASSIST THE INFORMAL CAREGIVING NETWORK. THIS WOULD HELP BREAK DOWN THE BARRIER OFTEN CREATED WHEN HEALTH PROFESSIONALS DEAL STRICTLY WITH THE PATIENT, OMITTING THE INSIGHTS THAT DAILY CAREGIVERS CAN PROVIDE – A VERY REAL PROBLEM FOR MANY CARING FOR A LOVED ONE. WE ARE TRYING TO OVERCOME THIS BARRIER, ORGANIZING 30 LEADING ORGANIZATIONS OF HEALTH CARE PROFESSIONALS AND CONSUMERS INTO THE NATIONAL QUALITY CAREGIVERS COALITION OF THE ROSALYNN CARTER INSTITUTE. FOR SEVERAL YEARS, MEMBERS OF THE COALITION HAVE COME TOGETHER IN AN EFFORT TO IMPROVE THE SKILLS THESE PROFESSIONALS AND OTHERS BRING TO THEIR WORK WITH FAMILY CAREGIVERS.

MR. CHAIRMAN, I AM VERY PLEASED THAT THIS COMMITTEE IS RECOGNIZING CAREGIVING AS AN IMPORTANT NATIONAL MATTER. CAREGIVERS DESERVE OUR PRAISE FOR THE ENORMOUS CONTRIBUTIONS THEY MAKE TO THE AMERICAN FAMILY AND TO OUR COUNTRY. BUT IT IS TIME TO GO BEYOND JUST RECOGNITION.

DIRECT CONGRESSIONAL ACTION IS NEEDED TO SUPPLEMENT THE ALREADY REMARKABLE ROLE THAT THE FAMILY, THE INDIVIDUAL AND THE VOLUNTARY SECTOR MAKE TO OUR NATIONAL LIFE. BUSINESS, TOO, MUST JOIN IN THIS COMMON ENDEAVOR WHICH AFFECTS EVERY AMERICAN FAMILY.

THANK YOU.

Recommendations for Congressional Action

1. Amend the Family and Medical Leave Act to provide greater flexibility for caregivers during the course of their workday as well as with respect to job retention and other supports; extend the Act to small business and consider expanding unpaid leave to paid leave for significant caregiving (as is done in many other countries).
2. Add reimbursement for respite care to Medicare.
3. Develop demonstration projects that build effective support systems for caregivers.
4. Create a program that makes a professional "care" manager available to family caregivers.
5. Assist colleges and universities in offering courses for family caregivers; provide grants to schools of medicine, nursing (including nurse practitioners), and social work to find new ways that the health professions can better assist the informal caregiving network.
6. Provide Social Security credits, allowing caregivers to accrue caregiving hours to their earnings record in Social Security. This follows the lead of France and other countries. (In Germany, direct payments are given to the family, but this has proven controversial.)
7. Provide specific tax credits for caregiving activities, including a refundable tax credit for low-income caregivers.
8. Have the Congressional Budget Office develop a system to calculate the value of caregiving provided and measure its contribution to the nation's gross domestic product.
9. Develop demonstration projects throughout the ten regions of the Department of Health and Human Services to study cultural, ethnic and regional differences to ensure effective support systems for caregivers.
10. Provide additional funding to the National Institutes of Health to undertake a National Institutes of Health/National Institute of Aging initiative against frailty and dementia.
11. The Geriatric Medical Education funds from Medicare, the Veterans Administration and the National Institutes of Health should function together to further the development of geriatrics to ensure high quality, cost effective solutions – oriented care for older persons including prevention and rehabilitation.

The CHAIRMAN. I will ask Senator Reid if he wants to say anything before he goes to the White House.

Senator REID. Thank you, Mr. Chairman.

Mrs. Carter, I very much appreciate your testimony. I am especially impressed with the ideas you have on Social Security hours of credit for caregivers. I would also like you to focus on another area. I also believe that women who stay home—or men, if that is the case, but of course, it is mostly women—and take care of their children should also receive some tax benefit. Think of the great savings they contribute to society. I think we have got to start looking at people who stay home to help the family unit.

Mrs. CARTER. That is right.

Senator REID. The other thing I would like you to focus your attention on is that every medical school in America teaches a course in pediatrics, a mandatory course in pediatrics, but out of the over 100 medical schools in America today, only a handful, less than 10, have mandatory courses in geriatrics. That is really too bad. I would like you to keep that in mind in the work you are doing, because I think that lending your authority to the fact that medical schools must become more involved in the training of physicians to be aware of the problems of the aging, which they have not kept up with, would be very valuable. When medical schools started, they wanted to make sure they had good programs to take care of kids, but they have not focused on seniors, and we have got to do a better job there.

Mrs. CARTER. That is very true, and I am familiar with that. I do not know if you are familiar with Robert Butler, who works with geriatrics, but he is a very close advisor of mine.

Another thing we have been working on—I have met with many people to try to get curricula changed in medical schools. This is very difficult, because each medical school determines its own curriculum. But also, medical students have no contact with dying patients, and they need that contact. Doctors are taught to heal and to cure, and if they cannot cure, they feel that they are a failure, and we need to change that and give palliative care.

Senator REID. I am glad you are aware of that, Mrs. Carter. Modern medicine does a great job of taking care of people who are sick; they do not do a very good job of taking care of people who are dying or taking care of people who are well so they do not get sick. So I am glad you are aware of this.

Mr. Chairman, as I have already said and will say again, I thank you very much for this panel. I apologize for having to leave to go to the White House.

The CHAIRMAN. You have a bill in—I think I am a cosponsor—to promote the geriatrics curriculum within the medical schools.

Senator REID. Yes. What Senator Grassley and I are working on is a bill to give medical schools more of an incentive to have programs in geriatrics.

Mrs. CARTER. That is great.

Senator REID. We have to make sure that Medicare is involved in that. They certainly should give incentives for people to be trained in geriatrics. I think we also have to look at loan forgiveness for medical students, or partially, at least, for those who are willing to go into geriatrics.

Mrs. CARTER. That is good, and to work with dying patients. We really need those curriculum changes.

Senator REID. And I will say that especially in today's environment, we do not hear a lot about bipartisan efforts. I say this—and I have told him personally, and I will say it publicly—Senator Grassley has been great. We are working on a bipartisan basis to solve the problems, to be aware of and to investigate the problems of our senior population. This committee is not a partisan committee, and certainly, Senator Grassley has set a great example.

The CHAIRMAN. Thank you very much.

Senator Reed of Rhode Island, is it OK if I go ahead and ask my questions, and then you can have time for your opening statement, plus questions?

Senator REED. That is perfectly fine, Mr. Chairman. Thank you.

The CHAIRMAN. First of all, thank you once again, and in fact, so many times, for taking time out of your busy schedule to come today. I commend you for your accomplishments and for blazing a trail, which I think the Rosalynn Carter Institute is doing under your leadership, particularly blazing a trail in the 16-county area that you are talking about in Georgia.

I understand it has been about a decade since your Institute was founded and began its work on caregiving. At that time, you noted that caregiving was very much an uncharted territory. In your estimation, have we come a long way since then, and could you tell us what you consider the biggest changes to be, or just give us an idea of what are the trends that you have been able to initiate and bring about, not only directly but indirectly, as a result of your work?

Mrs. CARTER. Well, I do not know whether I have brought them about or not, but I do think there is a trend among organizations and people who deal with health matters to recognize caregivers now. I think the trend is growing, because I think everybody now realizes how important the caregiver is, and in times of budget cuts caring for people at home is so much less expensive than putting them in nursing homes, and I think people are realizing that. But I also think the general public, because of the interest in it by the different organizations, is becoming more and more appreciative of caregivers and recognizing them more—not nearly as much as we want them to yet, but I think the trend is that way.

That is the reason I think it is so important to have resource centers like the Rosalynn Carter Institute in local communities that can bring more attention to the issue. What we have found at home, for instance, is that the religious community has gotten more involved, the library has a resource center for caregivers—things just happen when people realize the significance of the issue and how many people are really suffering and contributing so much, with no praise and no acknowledgment. So I think the trend is to recognize caregivers more.

The CHAIRMAN. Much of your work has focused on mental health issues and how they cross-cut areas such as caregiving, and in your most recent book, *Helping Someone with Mental Illness,* you devote an entire chapter to how the caregiving experience can be unique when a loved one has a mental illness.

Can you tell us more about what types of things make caring for someone with mental illness unique for a caregiver and then, conversely, are there any special challenges facing older adults who care for children or grandchildren with mental illness?

Mrs. CARTER. I think one of the main problems that makes caring for someone with a mental illness different is the stigma. The stigma affects the whole outlook of a family with a mentally ill person. It affects the mentally ill person, it affects the person who is trying to get help for him or her, and it makes it very, very difficult.

I wrote my book on mental illness because I want people to know that we have learned so much in the last decade and even in the last 5 years about the brain. Mental illnesses can now be diagnosed, they can be treated, and the overwhelming majority of people with mental illness can live full and productive lives. I do not think people know that, and if we can get that message out, when people learn that, the stigma goes away. Also mental illnesses should be treated just like physical illnesses. If you are sick, you are sick; you should be able to get care without being stigmatized. When the stigma goes away—we are not close to that yet—then, it will be a burden lifted from the caregiver in trying to get help for a family member with mental illness.

Just as with physical illnesses, those caregivers of a person who develops a mental illness—and it happens suddenly, sometimes, in families—have no idea where to go to get help, or the difference between a psychiatrist and a psychologist, and what a social worker can do, and so forth. So I do have a chapter in my book on those issues, and I also explain the research on the brain—and I hope it is a book of hope, because there is hope now in the mental health community for people who are suffering from mental illnesses and for their families.

The CHAIRMAN. Is there any particular, special thing we should know about caring for elderly people with mental illness versus children with mental illness, as a caregiver?

Mrs. CARTER. I think the problems are very similar as far as stigma goes, but I am not sure there is a lot of difference for the caregiver, except that the caregiver has got to live with that situation and try to get help for that person.

What we do know is that the earlier a mental illness is detected, the better the treatment can be, and that if you catch it early, it is easier to control, and it sometimes does not develop into a situation where someone has to have long-term care.

The CHAIRMAN. We obviously have got to be very concerned here in Congress in the next 13 years to make sure we are ready for the baby boom generation going into retirement. What do you see in the future for a generation that will live much longer and likely experience higher incidence of dementia? Should we be concerned about decreasing numbers of family caregivers to care for the baby boomers, since we know they have fewer children?

Mrs. CARTER. It is going to be a major problem in the coming years. I was reading in the newspaper yesterday that the incidence of Alzheimer's disease is going to increase threefold in the next 50 years. It is a major problem for more reasons than one. Baby boomers have not saved as some other generations have, and I think home care is going to be more and more important. I think Congress is going to have to look into the issue, because it is a serious issue even now in our country. The major reason is because we are living longer, and with so many more people reaching an older age, it is going to have to take a lot of thought. I think it is going to take congressional action. Right now, there are more and more people requiring care and fewer and fewer people to care for them, and the baby boomer generation is going to add to that dramatically.

The CHAIRMAN. Let us look at the practice of medicine and the public policies that affect it. We are going to have some written testimony of one of our witnesses today which contains this interesting observation. The witness is going to touch on this in his testimony, but maybe I could get your comments. That is, in the current environment of trying to reduce spending on government health programs, what has resulted is a cost shift, adding to the responsibilities or burdens of individuals and families. It is suggested that fewer hospital admissions, shorter length of stay, higher-tech medical procedures being done at home, are some of the manifestations of the trend. Do you agree with that trend, and if so, that is going to have some impact on family caregiving in the future, if you agree that it is going to have an impact.

Mrs. CARTER. I hope I will be able to hear that testimony, because I do agree that it is going to have an impact. I have real problems with a lot of it, because it bothersome particularly being involved with mental health for so long, that people do not get nearly enough time with the doctor they would like to see, who cares about them. I do not have any patience with people other than professionals in the health field saying on the telephone, "You tell me what your symptoms are, and I will tell you whether or not you need a doctor." Those kinds of things bother me tremendously, and I do not know what we are going to do about it.

The CHAIRMAN. Well, hopefully, we are going to legislate in that area yet this year.

Mrs. CARTER. I hope you work out some good solutions, because it is a major, major problem. I hear that all the time. I work so closely with people who care for those with mental illness, and with what we know now that can be done to help them, to have them shortchanged by some of the HMOs and managed care organizations is really devastating to me. I have seen it happen so much. I have had people call me, and I have called these companies on many occasions and said look after this one particular person. One of them I found who could not get care I just happened to call I couldn't get him so I had a friend go to see him. He was trying to commit suicide, and we just saved his life. These things are major and drastic, and because I have worked in this field for so long, I see so much of this happening because people tell me about it and bring their problems to me. It is a very, very difficult issue.

I think the original purpose or the idea of managed care is good—focusing on the whole person, on prevention and those kinds of things. That is good. But I think we have taken it a bit too far in many instances.

The CHAIRMAN. My last question deals with a recommendation that you have made, and I am only going to ask you to expand on it. That is your recommendation to make a professional care manager available to family caregivers. You have had some experience with that professional person in your area.

Mrs. CARTER. We have a grant to set up a certification system for people to be care managers in our area. I think it is so important, because most communities do not have a resource center for people who are caregivers, and they do not know where to go. A care manager could be situated in the Office on Aging or some government office, or university, or hospital—we have not worked that out yet, because we have our center, which is a resource center—somebody who could interact with the caregiver. The caregivers, as I said before, sometimes have no idea where to go, and this person could be a resource for them, to get them in touch and let them know what is in the community. There are lots of things available in the community and lots of organizations that will help. I have listed many of them in my book. People do not know about them, and they do not know where to go. Of course, some people need more than that, but a care manager could put them in touch with the resources.

Also, it would make it so much easier for caregivers to know they had someone to call on when something happened, one who could tell them where to go in a crisis situation and so on.

We just think it is a good idea and needed in every community in our country. I would like, of course, to have a Rosalynn Carter Institute—not my institute—but a center similar to ours in every community. If we could have a care manager in every community who would be familiar with people who are sick, that person could be in touch with the health department, the welfare department, the mental health department, and they would know people who needed help and care and could interact with them. We just think it is a really needed effort in all communities.

The CHAIRMAN. Thank you.

This Senator Reed is from Rhode Island.

Mrs. CARTER. Yes, Senator.

Senator REED. Thank you, Mr. Chairman.

First, let me salute you, Mrs. Carter, for your great, great work in an area that is very important, and of increasing importance, as our society ages. I would also ask you to convey my regards to President Carter for his great work.

Mrs. CARTER. I will. Thank you.

Senator REED. One of the points that Senator Harry Reid, my wiser and more senior colleague, made was in regard to geriatric medical education. We had a forum here several weeks ago, and we are trying—and I know Senator Grassley in his position as chairman of this committee is trying very hard—to impress upon medical education the need to develop good geriatric programs, and I would under score Senator Reid's and Chairman Grassley's point in that regard.

Also, I would ask if you were appearing again, if you could add to your list of States that are doing something Rhode Island, because we have developed a Family Caregiver Resources Network there——

Mrs. CARTER. Great.

Senator REED [continuing]. And one of the young State Senators, Charles Fogerty, has been very active and has managed to allocate resources. They are actually providing respite care and up to $2,000 a year in benefits for many people who are involved with giving care to seniors.

Mrs. CARTER. That is wonderful.

Senator REED. So if you could add that to your list, I would appreciate it, Mrs. Carter.

Mrs. CARTER. Certainly.

Senator REED. Now, because the chairman was so thorough, as usual, in his questions, and Senator Reid was also thorough, I just have one question, and that is, I wonder if, in your experience, you have had the opportunity to make an assessment on whether there are unique caregiver needs in rural environments versus urban environments, and if you might comment on that.

Mrs. CARTER. I do not know whether it is unique or not. I do not know whether people in urban centers know where to go for help, and we have not tried to expand. The Rosalynn Carter Institute and the caregiving networks to the urban centers yet. We do have Columbus, GA, in our network.

Senator REED. I lived in Columbus, GA.

Mrs. CARTER. Probably at Fort Benning.

Senator REED. Yes, ma'am.

Mrs. CARTER [continuing]. which, compared to Plains, is an urban center. And we want to do that; once we get the other 16-county area, which has Valdosta State University—we are working out of Valdosta State University for another 16-county area—then we hope to try to take this to an urban area to see if it works there—to see if there is a difference. There will be differences. I am sure, with issues of how to get people together and so forth.

But the fact is that we have all of these people from local, State, Federal agencies working together who have never met or spoken with each other before and getting caregivers with them. We sometimes get upset because professional caregivers do not work very closely with family caregivers, but it is not their fault. They are over burdened, too. One social worker told us she had 108 clients, and if she worked with the clients, she did not have time to work with the family caregivers. Well, out of our CARENET, for instance, came a real solution to that. Now, she invites the caregivers to come to where she works, the agency, and talks with them all together. She have them come in groups, which she had never done before, and it lets the caregivers know better how to work with the ones they are caring for, and it helps the professionals know what the caregivers are thinking. These kinds of things can go on anywhere, we believe, and we want to try it in an urban community.

As far as working with the curricula in medical schools, there is one other thing that I think is important that is not done. We have a book—I did one for the family caregiver and others on the Rosalynn Carter Institute board did one for professional caregivers—to teach professional caregivers how important it is to work with the family caregiver. There is often no interaction, and that is another thing that I think should be done in medical schools, particularly now, with the cutbacks. Sometimes professional caregivers are given only a short time with a patient, but if the family caregiver could be involved in that—they are actually with them 24 hours a day sometimes, and they know so much about them—it could be a great help to professional caregivers, and that does not usually happen.

Senator REED. Thank you. Again, I thank you for your leadership and also for your example.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Reed.

Mrs. Carter, we have concluded with our questions, and you are welcome to remain here. I know you have other things you have to do, and when you have to leave, I understand that.

Also, for you and the following panels, because some members could not be here, we would like to have you expect that there may be some questions submitted to you by other members or even myself for answers in writing, and if you and the other panelists could do that—I guess there is no urgency——

Mrs. CARTER. I can stay here until 11:30. I hope I am here for the whole session.

There is one other thing that I would like to mention. We have brought together 30 national organizations dealing with caregiving and health problems, like the American Nurses Association, the American Medical Association, the American Psychiatric Association, the Psychological Association, among others to try to break down this barrier between professionals and family caregivers and actually get them to see the value. We meet once a year to work on the problems and also to get these different organizations, which all have newsletters, to let people in the community, their members and other people know how important it is to recognize caregiving at the local level. That is another thing that we are doing from the Rosalynn Carter Institute that I think is becoming more and more important.

Thank you.

The CHAIRMAN. To use those other organizations to get the word out.

Mrs. CARTER. That is right, but also to see how these people who are also interested in these illnesses can get family caregivers and professional caregivers together. This is going to have to happen with managed care and with so many more people being cared for at home.

Thank you.

The CHAIRMAN. Thank you very much.

We have a 6-minute video that I want to show now before we go to our second panel, which shows three caregivers telling their stories. The video is a project of the United Hospital Fund, and I want to express my appreciation to that organization for allowing us to show the video.

[Videotape shown.]

The CHAIRMAN. Now I would like to call our second panel to the witness table. Our first witness is Gail Gibson Hunt, who is executive director of the National Alliance for Caregiving, a nonprofit organization dedicated to conducting research and to developing national programs for family caregiving for the elderly.

Then, we will hear from Dr. Peter Arno. Dr. Arno is professor of health economics in the Department of Epidemiology and Social

Medicine at Albert Einstein College of Medicine. He has conducted extensive research on the economics of family caregiving and long-term care. I believe his testimony will provide us a clear understanding of what previously has not been acknowledged in economic terms. I spoke about that in my opening statement and the extent to which we could get a picture of the economic contribution of home health care would be very important.

We will start with Ms. Hunt. Welcome.

STATEMENT OF GAIL GIBSON HUNT, EXECUTIVE DIRECTOR, NATIONAL ALLIANCE FOR CAREGIVING, BETHESDA, MD

Ms. HUNT. Good morning. I am executive director of the National Alliance for Caregiving, which is a nonprofit coalition of 14 national aging groups which came together to focus on family caregiving of the elderly.

Thank you for allowing me to come and provide a demographic picture of family caregiving of the elderly in the U.S. These numbers help to put family caregiving into the larger perspective of long-term care and illustrate the incredibly important role that caregivers play in keeping older people in the community longer.

The 1997 National Alliance for Caregiving/AARP National Caregiver Survey, which was funded by Glaxo Wellcome, revealed that 22.4 million households—which is nearly one-quarter of U.S. households—contain someone caring for an older relative or friend. Whether it includes intensive personal care such as bathing, dressing and feeding a parent or grandparent, or less intensive, everyday tasks such as grocery shopping, sorting out bills and insurance forms and transporting them to doctors' appointments, caregiving obviously involves a great many Americans.

On average, caregivers spend 18 hours a week caring for elderly relatives, and close to one in five provide what we call "constant care;" that is 4.1 million caregivers doing at least 40 hours a week of caregiving, unpaid. Nearly one-third care for more than one person—perhaps a grandparent, a parent, and a close neighbor—and the average length of time spent caregiving for each person is 4½ years.

As we have heard this morning, the vast majority of family caregivers are women—daughters, wives, sisters, daughters-in-law. In addition to caregiving for family members and friends, two-thirds of them work full- or part-time, and 40 percent are also caring for children at home who are under 18.

What about work issues? Two-thirds of family caregivers work, and half of these workers report having to make some adjustments to their work schedule to accommodate their elder caregiving. Adjustments range from coming in late, leaving early, taking time off from work—for half of the caregivers—to taking a leave of absence (11 percent), dropping back to part-time, or taking a less demanding job (7 percent) to giving up work entirely, which is 6½ percent.

A study commissioned by MetLife using data from the national caregiver survey estimates that for U.S. employers, the loss in productivity from caregiving employees ranges between $11.4 billion and $29 billion a year.

What about the financial impact of caregiving on family members? We do not know how much long-term care is paid for by caregivers versus comes from the older person's income and assets, but we do know that caregivers on average report out-of-pocket expenditures of $171 a month for special food, home modifications, clothing, and so on for their care recipient. This amounts to about $2,000 a year or the equivalent of an IRA.

What about the physical and emotional toll of caregiving? About 15 percent of caregivers say they have experienced physical or mental health problems due to caregiving, but this number doubles to 31 percent for those doing the most intense caregiving. One in four caregivers say that the experience is emotionally stressful, and a majority of caregivers use positive words like "rewarding", "loving" and "grateful" to describe the experience.

When asked what kinds of help, information or support they would use, nearly 40 percent of caregivers said they did not know. This points up the issue of lack of knowledge of what is available and how it could help. "Free time/time for oneself" was mentioned most often by those who could identify something they need.

Given that caregivers clearly understand some of the toll that caregiving can take, what are they doing to plan for their own long-term care? A study that we have just completed—actually, we are releasing it today—for the Equitable Foundation called, "The Caregiving Boom: Baby Boomer Women Giving Care," concluded that nearly two-thirds of middle-aged women caregivers do not plan adequately for their own long-term care. This was a follow-up survey of 267 women age 33 to 51 who participated in the original national survey. We found that despite recognizing the financial implications of long-term care, 62 percent have taken no action to prepare themselves.

This high incidence of insufficient financial planning held true regardless of their age, income or level of caregiving burden. It held true even though the percentage of women who said that caregiving represents "some" or "a great deal" of hardship financially rose from 27 percent to nearly 50 percent in the 2 years.

It is well-known that Americans in general have not done much long-term care planning, and boomers in particular have been criticized for not engaging in saving, investing or retirement planning. However, since the women in our survey have themselves been caring for an older person, we expected that they would have begun to plan for their own futures—but this does not appear to be true—although at 37 percent, these women are taking steps to plan at a higher rate than the 25 percent for the general public, shown in the 1995 Harvard School of Public Health Study.

Steps the women mentioned taking include saving more money, obtaining more insurance, indicating to others their preference for care, and writing wills.

How well-prepared do these caregivers think they are for their own possible long-term care? Very few feel they are "well-prepared." Over half report "a little or not at all." Nearly all respondents believe their own future long-term care will be paid for by one of three means—private long-term care insurance, which is OK; their own savings and investments—I do not think that is going to work unless you are a millionaire; or Government insurance.

The belief that Medicare and Medicaid will pay for future long-term care probably reflects the common lack of knowledge about the financial and medical conditions required to qualify for Government coverage of long-term care. When asked what information they would like to help prepare for their future needs, a third of them did not know. Topics mentioned in priority by others were financial planning information—information about how much their care and general living needs will cost, long-term care insurance, and Government assistance.

What are a few of the implications of all these data about caregivers? I am just going to mention three areas.

Unquestionably, family caregivers provide an enormous proportion of the long-term care of older people in this country. As a matter of fact, 80 percent of the care of the elderly is provided by family and friends. In terms of time, intensity of task, private dollars spent out-of-pocket, and impact on productivity at work, caregivers bear far more than their share of the burden for caring for older people, especially given the incorrect perception that older people in this country are warehoused by their families in nursing homes.

It is amazing and heartening to see how much families do, even as expectations of their dealing with medical technology increases, as we have seen from the video, and even with as little preparation as they have. So greater public awareness and recognition of the value of their role in long-term care are the first steps we can take.

Second, caregivers need information and education. They need to know where to turn for disease-specific information on their older relatives and information about older adult resources available in the community, including financial, legal and paperwork assistance, transportation and other services. They need information about caregiver support programs within the workplace. They need education, not just from the acute care system on specific medical devices, but hands-on, everyday caregiving education—how to transfer somebody from bed to chair, how to bathe them and oversee medications. They need information about how to plan for their own long-term care, long-term care insurance, planning for long-term care as part of retirement, and other options.

Parenthetically, we support the long-term care insurance support in the form of tax deductions such as you are planning on submitting.

Employers need incentives to provide greater access for their employees to eldercare information and services.

Third, caregivers need respite. They need to have flexible time off from caregiving for a few hours to run errands, have time for themselves, and for longer periods, to attend family functions, take vacations and continue working. Respite can be purchased from a number of different sources, but however it is provided, caregivers need some time for themselves and the other parts of their lives in order to continue doing the job that is such an essential part of our long-term care system.

As our population lives longer, but with chronic illness, the role of the family caregiver becomes more and more important in keeping the older person in the community. Adequate support for caregivers now means fewer proportional outlays of public dollars for institutional care in the future.

Thank you.

The CHAIRMAN. Thank you.

[The prepared statement of Ms. Hunt follows:]

NATIONAL ALLIANCE FOR CAREGIVING
A NATIONAL RESOURCE FOR CAREGIVERS OF OLDER AMERICANS

Testimony before the Senate Special Committee on Aging

Prepared by

Gail Gibson Hunt
Executive Director, National Alliance for Caregiving

September 10, 1998

I am Gail Hunt, executive director of the National Alliance for Caregiving, a new nonprofit coalition of 14 national aging groups which came together to focus on family caregiving of the elderly. We conduct research, develop national programs, and work to increase public awareness of caregiving issues. Thank you for allowing me to come and provide a demographic picture of family caregiving of the elderly in the U.S.. These numbers help to put family caregiving into the larger perspective of long term care and illustrate the incredibly important role that caregivers play in keeping older people in the community longer.

The 1997 National Alliance for Caregiving/AARP national caregiver survey (funded by Glaxo Wellcome) revealed that 22.4 million households - nearly one-quarter of U.S. households - contain someone caring for an older relative or friend. Whether it includes intensive personal care such as bathing, dressing and feeding a parent or grandparent, or less intensive, everyday tasks such as grocery shopping, sorting out bills and insurance forms, and transporting them to doctors' appointments — caregiving involves a great many Americans. On average, caregivers spend 18 hours per week caring for elderly relatives; and close to one in five provides "constant" care - that's 4.1 million caregivers providing at least 40 hours per week of unpaid care. Nearly one-third care for more than one person, perhaps a parent, grandparent and a close neighbor. And the average length of time spent caregiving for each person is 4 ½ years.

Fifteen percent of those being cared for are not blood relatives, but friends and neighbors. In the Black community especially, the survey revealed extensive caregiver connections to friends and neighbors who are treated as family. Pre-survey focus groups described to us that: "growing up as children, we were taught to check in on Mrs. Jones everyday and do the shopping for Old Mr. Smith across the way, as part of taking care of our own."

The vast majority — 73 percent — of family caregivers are women — daughters, wives, sisters, daughters-in-law. In addition to caregiving for family members and friends, two-thirds of them work full or part time and 40 percent are also caring for children at home under 18.

What is the profile of the family caregiver? A 46-year-old Baby Boomer woman who is working and caring for her 77-year-old mother who lives nearby. The mother suffers from chronic illness, such as arthritis or heart disease or dementia. Often another family member, usually the caregiver's sister or brother, helps with the caregiving. Around 40 percent of our respondents said that they were the primary or only caregiver, which means that they are doing the vast majority of the work. When you combine that with the fact that half are doing hands-on personal care — bathing, dressing, feeding — you can begin to understand some of the burden.

What about work issues? Two-thirds of family caregivers work and half of these workers report having to make some adjustment to their work schedule to accommodate their elder caregiving. These adjustments range from coming in late, leaving early and taking time off from work (49%), to taking a leave of absence (11%), dropping back to part-time or taking a less demanding job (7%), to giving up work entirely (6.4%). A study commissioned by MetLife using data from the national caregiver survey estimates that for U.S. employers the loss in productivity from caregiving employees ranges between $11.4 billion and $29 billion per year.

What about the financial impact of caregiving on family members? We do not know how much long term care is paid for by caregivers versus coming from the older person's income and assets, but we do know that caregivers on average report out-of -pocket expenditures of $171 per month for special food, home modifications, clothing, etc., for their care recipient. This amounts to $2,000/year or the equivalent of an IRA.

What about the physical and emotional toll of caregiving? About 15% of all caregivers say they have experienced physical or mental health problems due to caregiving, but this number doubles to 31% for those doing the most intense caregiving. One in four caregivers say that the experience is emotionally stressful, and a majority of caregivers use positive words, like "rewarding," "loving," and "grateful" to describe the experience.

When asked that kinds of help, information, or support they would use, nearly 40% of caregivers said they didn't know - this points up the issue of lack of knowledge of what is available and how it could help. "Free time/time for oneself" was mentioned most often (17%) by those who could identify something they need.

Given that caregivers clearly understand some of the toll that caregiving can take, what are they doing in planning for their own long term care? A study that we have just completed for the Equitable Foundation, called "The Caregiving Boom: Baby Boomer Women Giving Care," concludes that nearly two-thirds of middle-aged women caregivers do not plan adequately for their own long term care. In this follow-up survey of 267 women ages 33 to 51 who participated in the original national survey, we found that, despite recognizing the financial implications of long term care, 62% have taken no action to prepare themselves.

This high incidence of insufficient financial planning held true regardless of their age, income, or the level of caregiving burden. It held true even though the percentage of women who said that caregiving represents "some" to "a great deal of hardship" financially rose from 27% to 49% in two years. It is well known that Americans in general have not done much long term care planning and that boomers in particular have been criticized for not engaging in saving, investing or retirement planning. However, since the women in our survey have themselves been caring for an older person, we expected that they would have begun to plan for their own futures. This does not appear to be true, although at 37% these caregiving women are taking steps to plan at a higher rate than the 25% for the general public 50 and older, as shown in the 1995 Harvard School of Public Health "Long Term Care Awareness" Study. Steps the women mentioned taking include saving more money (52%), obtaining more insurance (36%) indicating to others their preferences for care (9%), and writing a will (7%).

How well prepared do these caregivers think they are for their own possible long term care? Very few feel they are "well" prepared. Over half report feeling "a little or not at all" prepared. Nearly all of the respondents believe that their own future long term care will be paid for by one of three means: private long term care insurance (31%), their own savings and investments (31%), or government insurance (34%). The belief that Medicare and Medicaid will pay for future long term care probably reflects the common lack of knowledge about the financial and medical conditions required to qualify for government coverage of long term care.

When asked what information they would like to help prepare for their future needs, one-third of the caregivers do not know. Topics mentioned in priority by others were financial planning information, information about how much their care and general living needs will cost, long term care insurance, and government assistance.

What the implications of these data about caregivers?

Unquestionably, family caregivers provide an enormous proportion of the long term care of older persons in this country -- as a matter of fact, 80% of the care of the elderly as provided by family and friends. In terms of time, intensity of tasks, private dollars spent out-of-pocket and impact on productivity at work, caregivers bear far more than their share of the burden of caring for older people, given the incorrect perception that older people in this country are "warehoused" by their families in nursing homes. It is amazing and heartening to see how much families do -- even as expectations of their dealing with medical technology increases and even with as little preparation as they have. Greater public awareness and recognition of the value of their role in long term care are the first steps we can take.

Secondly, caregivers need information and education. They need to know where to turn for disease - specific information on their older relatives; information about older adult resources available in the community, including financial, legal and paperwork assistance, transportation, and other services; information about caregiver support programs within the workplace. They need education -- not just from the acute care system on specific medical devices -- but hands-on everyday caregiving education -- how to transfer someone from bed to chair, how to bathe them, help with exercise, and oversee medications. They need information about how to plan for their own long term care: long term care insurance; planning for long term care as part of retirement; and housing and service options and how much they cost. Employers need incentives to provide greater access for their employees to eldercare information and services.

Thirdly, caregivers need respite. They need to have flexible time off from caregiving for a few hours, to run errands and have time for themselves, and for longer periods, to attend family functions, take vacations, continue working. Respite can be purchased from a paid caregiver or provided through a county social service program or by volunteers through a local church group, or as a regular part of adult day care, or through other means. But, however it is provided, caregivers need to have some time for themselves and the other parts of their lives in order to continue doing the job that is such an essential part of our long term care system.

As our population lives longer but with chronic illness, the role of the family caregiver becomes more and more important in keeping older people in the community. Adequate support for caregivers now means fewer proportional outlays of public dollars for institutional care now and in the future.

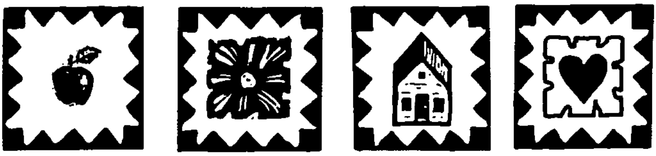
FAMILY CAREGIVING IN THE U.S.

Findings from a National Survey

FINAL REPORT

NAC NATIONAL ALLIANCE FOR CAREGIVING
A National Resource for Caregivers of Older Americans

AARP American Association
of Retired Persons



The NAC, located in the Washington, DC, area, is a non-profit joint venture of several national aging organizations that have allied themselves to focus attention on the issue of family caregiving of the elderly through research, program development, and public awareness activities.

AARP is the nation's leading organization for people age 50 and over. It serves their needs and interests through legislative advocacy, research, informative programs and community services provided by a network of local chapters and experienced volunteers throughout the country. The organization also offers members a wide range of special membership benefits, including *Modern Maturity* magazine and the monthly *Bulletin*.

FAMILY CAREGIVING IN THE U.S.
Findings from a National Survey

Sponsored by

The National Alliance for Caregiving
Bethesda, MD

and

The American Association of Retired Persons
Washington, DC

Funded by

Glaxo Wellcome, Inc.

Additional Funding by

The Archstone Foundation, ManorCare Health Services
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FAMILY CAREGIVING IN THE U.S.:
Findings from a National Survey
FINAL REPORT

Introduction and Background

Numerous studies have been conducted on various aspects of informal (unpaid) or family caregiving of older adults. Nationwide information on the magnitude, intensity, and types of informal caregiving provided, however, together with its physical, emotional and financial repercussions, has been lacking. In particular, similarities and differences among racial/ethnic groups with respect to caregiving practices and the impact of informal caregiving on caregivers' lives have not been systematically studied on a nationwide basis.

This study attempts to identify and profile the various impacts of family caregiving in today's society. Using a broad definition of caregiving, the survey documents for corporate America, policymakers, and the general public the experiences and attitudes of persons who provide care to older Americans. A broad definition was used in order to determine the type of care family and friends provide to older persons, ranging from light, occasional tasks, to round-the-clock care, including care provided from a distance.

The present study is the first of its kind to address these issues systematically, using survey methodology, across four racial/ethnic groups within the United States: Whites, Blacks, Hispanics, and Asians[1]. It was sponsored and designed by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP), with funding provided by a grant from Glaxo Wellcome, Inc.[2] Additional funding was provided by the Archstone Foundation, ManorCare Health Services, and Metropolitan Life Insurance Company.

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[1] These designations are adapted from OMB's "Directive No. 15." Race and Ethnic Standards for Federal Statistics and Administrative Reporting (as adopted on May 12, 1977). The term "White" refers to persons self-identified as White and having origins in any of the original peoples of Europe, North Africa, or the Middle East, but in this case exclusive of persons who designate themselves as of Hispanic origin. The term "Black" refers to persons who identify themselves as Black (having origins in any of the black racial groups of Africa), but in this case not of Hispanic origin. The term "Hispanic" refers to persons who identify themselves as of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture of origin, regardless of race. The term "Asian" refers to persons who identify themselves as having origins in any of the peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands.

[2] Funding for this survey was provided by a grant from Glaxo Wellcome, Inc., a research based company whose people are committed to fighting disease by bringing innovative medicines and services to patients, their families, and the healthcare providers who serve them.

Overview of Methodology

The study was designed as a telephone survey to be used with a nationwide random sample of caregivers aged 18 and over, with oversamples of Black, Hispanic, and Asian caregivers to ensure adequate numbers of each of these groups for analytic purposes. NAC contracted with the ICR Survey Research Group, Inc., of Media, PA, to generate the samples, conduct the survey, and prepare a topline report.

The survey was conducted between August 13 and September 20, 1996 with respondents capable of answering questions in English by telephone. (Funds were not available to conduct the survey in languages other than English.) See the Appendix for a detailed description of the methodology used to generate the samples.

A total of 1,509 English-speaking family caregivers participated in this telephone survey: 623 Whites, 306 Blacks, 307 Hispanics, and 264 Asians.

Limitations of This Study

Although this is the first U.S. study of its kind to include large enough oversamples of caregivers drawn from three racial/ethnic minority groups, these samples underrepresent recent immigrant or first generation caregivers who speak little or no English, such as Hispanics who are fluent only in Spanish or Portuguese, or Asians who speak only Chinese, Japanese, Korean, or Vietnamese, or other Far Eastern language. It is also possible that the respondents, being of diverse cultural and linguistic backgrounds, may not have interpreted all questions identically.

Additionally, because this was a survey conducted by telephone, it underrepresents households that do not have a telephone (6% of households nationwide).

This Report and Its Companion Volumes

This report summarizes the findings from the survey and their implications. It does not contain the survey instrument.

Also available are, a copy of the survey instrument (D16476), and a report entitled Caregiving Among American Indians: A Review of the Literature (D16690)[3], which highlights caregiving issues among American Indians. A report on implications for employers is also available.[4]

Caregiving, Caregiver: Definitions Used for This Study

What is informal or family caregiving, and who is an informal or family caregiver? These terms are used inconsistently in the literature; there are no universally accepted criteria for designating an activity as caregiving or a person as a caregiver among scholars, policymakers or advocates.

Informal or family caregiving is typically performed by relatives and close friends for a person who is no longer able to manage all aspects of his or her daily life and/or personal care. It generally involves everyday activities related

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[3] Additional copies of this report and of any of its companion volumes may be obtained by writing the National Alliance for Caregiving, 4720 Montgomery Lane, Suite 642, Bethesda, MD 20814-3425, or the AARP Fulfillment, 601 E Street, NW, Washington, DC 20049. Please use the order number when requesting reports.

[4] Order a copy of the report on the Metlife Study of Employer Costs for Working Caregivers based on data from Family Caregiving in the U.S.: Findings from a National Survey from Metlife Mature Market Group, 57 Green Farms Road, Westport, CT 06880, Phone (203) 221-6580.

to managing a household, or to performing personal care, such as dressing, bathing, toileting, and feeding. By providing unpaid assistance and support to older family members or friends who need it, informal or family caregivers may help avoid or delay institutional placement of the older person, or the need for paid caregiving services.

For purposes of this study, the term caregiving was defined to prospective respondents in the following words:

> "By caregiving, I mean providing unpaid care to a relative or friend who is aged 50 or older to help them take care of themselves."
>
> "Caregiving may include help with personal needs or household chores. It might be taking care of a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you."

To be included in this study, a caregiver had to be at least 18 years old and either currently providing informal care to a relative or friend aged 50 or older, or to have provided informal care to such a person at some point during the past 12 months. *No stipulations were placed on the amount, frequency, or duration of care provided, or on where the care recipient resided.*

The decision to use a broad definition of caregiving and caregiver was based on focus group discussions conducted with members of the target racial/ethnic groups prior to designing the survey instrument.

Illustrative comments made by focus group participants are interspersed throughout this report to provide glimpses into the experience of caregiving.

> **"It's like when I was growing up, my mother cared for others. She would send me to deliver food to a sick neighbor so I learned it from my mother. I've been like this all my life."**

Intensity of Care:
The Level of Care Index

A major purpose of this study was to understand how the level of demand presented by the caregiving situation (i.e., the difficulty of the tasks caregivers perform and the amount of time they devote to caregiving) impacts caregivers' lives and attitudes. To measure the intensity of caregiving, a Level of Care Index was developed which classifies caregivers into different levels of care according to the kinds and numbers of assistive activities they perform and the number of hours per week they devote to caring for their principal care recipient. (How the Level of Care Index was developed is discussed in detail in the Appendix to this report.)

Each caregiver was classified into one of five levels, with Level 1 being the lowest in caregiving demand or intensity, and Level 5 being highest. Within each level, there is a range of activities and number

TABLE 1
CAREGIVERS BY LEVEL OF CARE

	Number of Caregivers	Percent of All Caregivers
Total	1,509	100.0
Level 1	389	25.8
Level 2	208	13.8
Level 3	287	19.0
Level 4	355	23.5
Level 5	185	12.3
Missing	85	5.6

of hours of care provided per week. Each successive level involves a higher degree of caregiving responsibility or demand. Level 1 caregivers, for example, provide no assistance with personal care activities such as dressing or bathing their care recipient, and typically provide care for a maximum of eight hours per week. Level 5 caregivers, in contrast, assist with at least two personal care activities and provide care for more than 40 hours per week. (See the Appendix for additional information.) Table 1 shows the distribution of caregivers in this survey by level of care provided.

Presentation of Findings

All findings presented in this report refer to caregiving and caregivers as defined above. For ease of reporting, caregiving statistics are typically expressed in the present tense, whether or not the caregivers in question are currently providing care. Noteworthy findings, or key differences between subgroups, may be bulleted and/or italicized.

While some caregivers report that they care or cared for more than one person, the survey inquired only about relationships with and activities pertaining to the recipient for whom the caregiver provides the most care.

In addition, all percentages cited in this report refer to proportions of the entire U.S. population of informal caregivers, and not to the sample of caregivers included in this study. That is, the findings from this sample of caregivers have been adjusted or weighted to reflect accurately the distribution of U.S. telephone households with a caregiver, based on sampling techniques used by the contractor in combination with U.S. Census projections and estimates. (For a more complete discussion of weighting, see the Appendix.)

When percentages are cited and compared across subgroups, the differences are statistically significant at the .05 level or better, unless otherwise indicated. This means that no more than five times in 100 would the particular finding be expected to occur by chance, and that there is a 95 percent probability that the difference is a true difference between groups. When "no differences" are reported, it means that percentage differences found across comparison groups did not reach statistical significance at the .05 level and thus could have been due to chance.

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Survey Findings

Prevalence of Caregiving in the United States

- Just over 23% of all U.S. households with a telephone contain at least one caregiver[5], of whom more than three-fourths (76%) are currently caring for a relative or friend who is at least 50 years old. The remaining 24% report having provided informal care to a relative or friend within the past 12 months, but are not currently doing so. Higher proportions of Level 1 and 2 caregivers are currently providing care than Level 4 and 5 caregivers.
- This translates into an estimated 22,411,200 caregiving households nationwide with English speaking caregivers[6], of which there are approximately:
  - 18,290,000 White, non-Hispanic households
  - 2,380,000 Black, non-Hispanic households
  - 1,050,000 Hispanic households and
  - 400,000 Asian households.

  The remaining caregiving households are of other races.
- *The prevalence of informal caregiving is higher among Asian and Black households (31.7% and 29.4%, respectively) than among Hispanic households (26.8%) or White households (24%).*

Demographic Profile of Caregivers

As shown in Table 2, (page 10), the typical caregiver is a married woman in her mid-forties who works full-time, is a high school graduate, and has an annual household income of $35,000. Highlights of findings by race/ethnicity and other characteristics are presented below.

Age

- The average age of caregivers is 46.
- More than one in five caregivers is under age 35 (22%), close to four in 10 are 35 to 49 (39%), about one in four is 50 to 64 (24%), and 12 percent are 65 and older.
- *Asian and Hispanic caregivers are significantly younger than Whites, with average ages of 39 and 40, respectively,* compared with 47 for Whites. More than one-third of Asian and Hispanic caregivers are under 35, compared with just over one in five White caregivers.
- *Level 5 caregivers are much more likely to be at least 65 years than any other caregivers:* 30 percent, in contrast with only 10 percent of Level 1 caregivers, for example.

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[5] In a 1988 study of caregivers, 7.8 percent of U.S. households were identified as having a caregiver when a more restrictive definition of caregiving was used than in the present study. In the 1988 study, to be defined as a caregiver, a person must have been helping with at least two Instrumental Activities of Daily Living (IADLs) or one Activity of Daily Living (ADL). See A National Survey of Caregivers: Final Report (D13203) conducted by Opinion Research Corporation of Washington, DC, for the American Association of Retired Persons of Washington, DC, and The Travelers Foundation of Hartford, CT, September 1988.

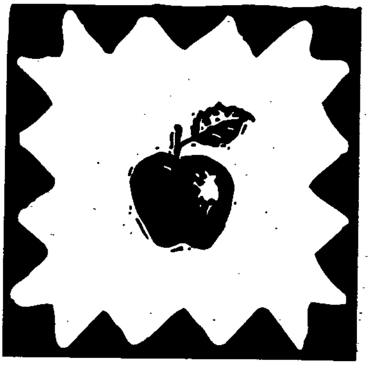
[6] The 1988 report estimated that there were seven million U.S. caregiving households at that time, based on the definition of a caregiver used for that study. Applying the same definition of a caregiver as used in the 1988 study to the current study (i.e., the caregiver must be providing assistance with at least two Instrumental Activities of Daily Living or one Activity of Daily Living), the number of caregivers providing this level of care as of 1996 is 21,290,000, or triple the number in 1988.

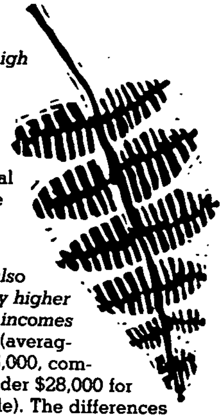
Gender

- *More than seven in 10 caregivers (73%) are female and 27 percent are male.*
- *Asian caregivers are most evenly split among female and male caregivers:* 52 percent of Asian caregivers are women (in contrast with 77% of Blacks, 74% of Whites, and 67% of Hispanics) and 48 percent are men.

Education and Income

- Thirty five percent of caregivers are high school graduates, 23 percent have some college education, and 29 percent are college graduates or have post graduate education. Nine percent have less than a high school education.
- *Asian caregivers in the sample are more highly educated than caregivers of other racial/ethnic groups, with 39 percent being college graduates and 21 percent having had graduate education. In contrast, only 15 percent of Blacks and 18 percent of Hispanics are college graduates, and fewer than seven percent of either group have had graduate education. Sixteen percent of Black caregivers have less than a high school education, compared with only two percent of Asians.*





- The median annual household income of caregivers is $35,000.
- *Asian caregivers also report considerably higher annual household incomes than other groups* (averaging more than $45,000, compared with just under $28,000 for Blacks, for example). The differences may reflect, in part, the fact that more recent Asian immigrants, whose incomes might be expected to be lower, were not included in the sample because they do not speak English.

Marital Status and Presence of Children under 18

- Close to two-thirds of caregivers nationwide are married (66%), 13 percent are single, 13 percent are separated or divorced, and eight percent are widowed.
- Black caregivers are the least likely to be married or living with a partner—just over half (51%) are, compared with two-thirds of Asians and Whites (68%), and 64 percent of Hispanics.
- While 41 percent of caregivers have one or more children under age 18 living in their households, more than half of all Black, Hispanic, and Asian caregivers report having one or more children under age 18 in their households, in contrast with 39 percent of White caregivers.

TABLE 2
CAREGIVER PROFILE
(Base = Total Caregivers)

Number interviewed (unweighted)	n=1,509	n= 623	n=306	n=307	n=264
Number in U.S. population (weighted)*	n=2,241	n=1,829	n=238	n=105	n= 40
GENDER					
Female	72.5%	73.5%	76.8%	67.4%	52.3%
Male	27.5	26.5	23.2	32.6	47.7
AGE OF CAREGIVER					
Under 35	22.3%	20.5%	23.5%	37.1%	38.6%
35-49	39.4	39.0	44.4	37.5	43.6
50-64	26.0	26.8	22.5	21.2	14.4
65 or Older	12.4	13.6	9.5	4.2	3.4
Mean (years)	46.15	46.93	44.75	40.01	39.01
MARITAL STATUS					
Married or living with partner	65.7%	67.8%	50.9%	63.8%	64.4%
Single, never married	12.6	11.1	19.3	18.2	26.1
Separated or divorced	13.0	12.1	19.0	15.7	6.0
Widowed	8.0	8.3	9.8	2.0	3.0
CHILDREN UNDER AGE 18 IN HOUSEHOLD					
Yes	41.3%	38.8%	51.0%	58.3%	51.1%
No	57.8	60.2	48.4	41.7	48.1
EDUCATIONAL ATTAINMENT					
Less than high school	9.0%	8.2%	16.3%	11.1%	2.3%
High school graduate	35.3	36.0	32.0	35.2	18.2
Some college	22.5	22.2	26.8	26.7	17.0
College graduate	20.1	20.4	15.4	18.2	39.0
Graduate School +	8.8	8.8	5.6	6.5	20.8
Technical school	3.5	3.5	3.3	2.3	1.9
EVER ON ACTIVE DUTY/ U.S. ARMED FORCES	**11.5%**	**11.1%**	**11.1%**	**11.4%**	**7.2%**

	TOTAL	WHITE	BLACK	HISPANIC	ASIAN
Number interviewed (unweighted)	n=1,509	n= 623	n=306	n=307	n=264
Number in U.S. population (weighted)*	n=2,241	n=1,829	n=238	n=105	n= 40
CURRENT EMPLOYMENT					
Employed full-time	51.8%	51.0%	55.6%	51.8%	63.3%
Employed part-time	12.3	12.7	10.5	13.4	14.0
Retired	15.9	17.0	13.7	6.8	4.2
Not employed	19.7	18.9	20.3	28.0	18.2
HOUSEHOLD INCOME					
Under $15,000	14.0%	11.7%	29.1%	21.1%	8.3%
$15K-24.9K	18.0	17.3	24.8	22.5	11.0
$25K-29.9K	9.3	9.5	9.8	7.8	8.0
$30K-39.9K	14.0	14.0	12.4	16.3	13.3
$40K-49.9K	10.3	10.4	7.8	11.1	14.0
$50K-74.9K	14.0	14.4	9.5	10.4	15.5
$75K or higher	10.9	12.1	3.0	6.2	19.7
Median	$35K	$35K	$22.5K	$27.5K	$45K

Note: Column percentages may not total 100% because of refusals.

*Weighted numbers refer to numbers of caregiving households in the U.S. population. Each number must be multiplied by 10,000 to determine the U.S. population prevalence for that cell. For example, 2,241 means 22,410,000 (i.e., there are an estimated 22,410,000 caregiving households in the U.S.). All percentages are based on weighted data.

Employment Status

- Close to two in three caregivers (64%) are working, 52 percent full-time and 12 percent part-time; and 16 percent are retired. One in five (20%) say they are "not employed." Table 3 shows the percentages of working caregivers by age and other key characteristics.
- Of those not currently employed (36% of caregivers), about one in three (34%) said they had even been employed while taking care of their care recipient.
- Asian caregivers are more likely to be employed full- or part-time (77%) than Whites (65%), Blacks (66%), or Hispanics (65%), and also more likely to be employed full-time. This may reflect the fact that, in general, their caregiving demands are lower than those of all other racial/ethnic groups.
- On the other hand, both White and Black caregivers are more likely to be retired than either Hispanics or Asians.

TABLE 3
EMPLOYMENT STATUS BY AGE AND OTHER CHARACTERISTICS
(percentages)

	Employed Full or Part-Time
Total	64.2
18-34	77.2
35-49	75.8
50-64	60.3
65+	12.1
Asians	77.3
Women	60.5
HH income < $15,000	36.5
HH income > $50,000	77.8
R is primary caregiver	54.5
Care recipient has dementia	59.8
Level 1 caregivers	70.1
Level 5 caregivers	40.5

- Hispanic caregivers are more likely to report they are not working (28%) than either Asians (19%) or Whites (18%).
- Those providing Level 5 care are more likely to be retired (32%) than caregivers of any other level, which suggests that the persons they provide care for (including spouses) may themselves be older and require more care.

> **"I miss the office, the people, the socializing. I don't get out, can't get away."**

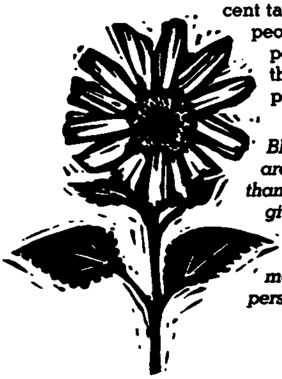
Military Status

- Eleven and a half percent of all caregivers and 38.9 percent of male caregivers have been on active duty in the U.S. Armed Forces. Fewer Asian caregivers (7.2%) than White (11.1%), Black (11.1%) or Hispanic caregivers (11.4%) had served in the military.

Characteristics of the Caregiving Situation

Number of Persons Cared For

- Close to seven in 10 caregivers (69%) provide care to just one person, 23 percent take care of two people, and eight percent care for three or more people.
- *Asian and Black caregivers are more likely than White caregivers to be involved in caring for more than one person.*



> **"We were raised in our culture to take care of each other"**

- *Level 5 caregivers are more likely than Level 1, 2, and 4 caregivers to be taking care of only one person.*

Duration of Caregiving

- The average duration of caregiving is 4.5 years.
- Close to two-thirds of caregivers (64%) have provided care to their primary care recipient for less than five years, while 21 percent have done so for five to nine years, and 10 percent for 10 years or more. There are no differences by caregiver level, except that Level 3, 4, and 5 caregivers are more likely to have been providing care for less than six months than are Level 1 caregivers.

Recipients of Care: To Whom Do Caregivers Provide Care?

Relationship between Caregiver and Care Recipient

- Overall, more than eight in 10 caregivers (85%) take care of a relative, and 15 percent take care of a friend or neighbor. Level 5 caregivers are more likely than other caregivers to be taking care of a relative and less likely to be taking care of a friend.
- *Care recipients are typically female relatives:* 31 percent of caregivers take care of their own mothers, nine percent care for their mother-in-law, and 12 percent take care of a grandmother. There are no differences by level of care.

> **"I would say 80 percent of the people I associate with, it's the daughter who comes every weekend—rain or shine. I don't see sons come in."**

- *While only five percent of caregivers report taking care of a spouse*[7], *23 percent of Level 5 caregivers take care of a spouse* (in contrast with less than one percent for Level 1 and Level 2 caregivers).

> **"When they asked me at the adult day care center to come to this meeting, I didn't know why. I don't consider myself a caregiver. I take care of my wife."**

- *Spousal caregivers are also much more common among caregivers aged 65+ (23%), when compared with all other age groups*[8].
- Of all racial/ethnic groups, Asians are the least likely to be caring for a spouse (only 1%) and the most likely to be assisting a father (18%).
- *Hispanic caregivers are more likely to be caring for a grandparent* (22%) than other caregivers (15%).
- *Black caregivers are the most likely to be taking care of a relative other than an immediate family member or grandparent*—14 percent, in contrast with nine percent of White, seven percent of Hispanic, and six percent of Asian caregivers.

Age of Care Recipient

- The average age of care recipients is 77 years.
- About two in three care recipients (64%) are over age 75, and almost one in four (24%) is over age 85. There are no differences in the ages of care recipients by caregiver level.
- White caregivers, on average, care for persons who are older than those cared for by caregivers of other racial/ethnic groups: the mean age of care recipients of White caregivers is 77.6 years, compared with 75.2 for Blacks, 74.7 for Hispanics, and 74.4 for Asians.
- Asian caregivers provide care to persons *least* likely to be 85+ (only 15% are). The comparable figures for White and Black caregivers are 25 percent and 24 percent.

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[7] A 1995 survey of caregivers aged 18 and older that used a very similar definition of caregiving found almost the same low percentage of caregivers taking care of a spouse (4%). (See Findings from an Excel Omnibus Survey of Caregivers Conducted May 19-28, 1995, prepared for AARP's Long-term Care Team/Health Advocacy Services/Programs Division by Jane Takeuchi, Evaluation Research Services/Research Division/AARP, August 28, 1995.)

[8] This finding is consistent with the 1995 survey, in which 14 percent of caregivers aged 65+ were caring for a spouse.

Health Status of Care Recipients

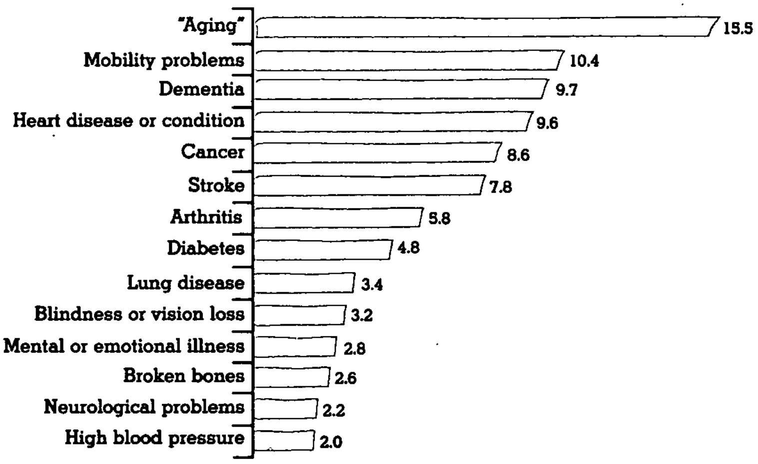
- Better than seven in 10 caregivers (71%) report that their care recipient's illness or condition is long-term or chronic in nature, and an additional 11 percent say the conditions/illnesses are both chronic and short-term. Twelve percent say their care recipient's illness or condition is short-term (expected to last up to three months); and six percent say they do not know. There are no differences by level of care.

Figure 1 shows the main illnesses or problem of care recipients, as reported by their caregivers.

Presence of Dementia, Stroke and Diabetes

- *More than one in five caregivers (22.4%) say they take care of someone with Alzheimer's disease, confusion, dementia, or forgetfulness (hereafter referred to as dementia) as the primary or a secondary illness or condition. This finding translates into an estimated 5,020,000 caregiving households nationwide that provide care for someone with dementia.*
- Black caregivers are more likely than any other group to report dementia in their care recipient (28%, in contrast with 22% of White, 20% of Hispanic, and only 3% of Asian caregivers). Asian caregivers also are less likely than other racial/ethnic groups to report dementia as the main illness or problem.

FIGURE 1
MAIN ILLNESS OR PROBLEM OF CARE RECIPIENTS
(percentages)

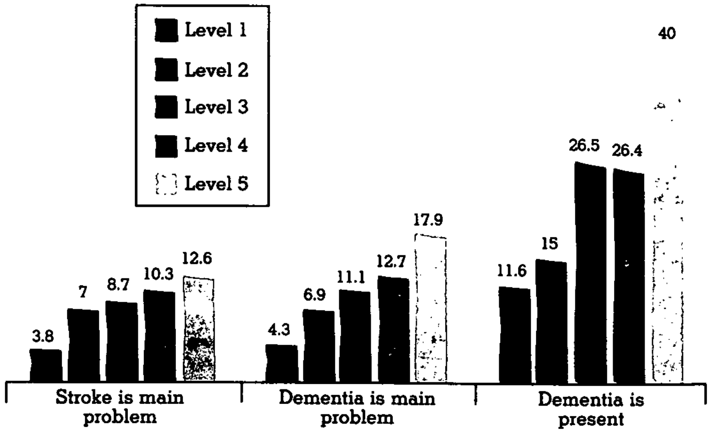


- Black caregivers also report a higher incidence of stroke (12%, in contrast with 7% for each other group.)
- *Not surprisingly, higher percentages of Level 4 and 5 caregivers than Level 1 caregivers report that the main illness or problem of their care recipient is dementia. This is also the case for stroke. (See Figure 2.)*
- Higher proportions of Level 3, 4, and 5 caregivers report caring for someone with dementia as either the main or secondary problem. (See Figure 2.)
- Both Hispanic and Black caregivers are more likely than Whites to report diabetes as the care recipient's main illness (9.4% and 9.2% vs. 3.7%).

Living Arrangements

Despite the frequency of chronic and long-term illnesses or conditions necessitating care, very few caregivers said their care recipient resides in a nursing home, assisted living facility, or group home. One-fifth of care recipients live in the same household as their caregiver, and this living arrangement was established in most cases (69%) because of the recipient's need for care. Slightly more than half of all care recipients live alone, either in their own home (37%) or in an apartment or retirement community (17%). The remaining 37 percent live with another family member or friend.

FIGURE 2
PREVALENCE OF STROKE AND DEMENTIA BY LEVEL OF CARE
(percentages)



> **"Even if she is in a facility, I am a caregiver just because I try to be there for her when she needs me, to lighten her days, to give back a little of the love she showed me as I was growing up."**

No matter where the care recipient lives, most caregivers and care recipients live in close proximity to each other. Not counting the 21 percent of care recipients who live with their caregiver, more than half of all care recipients (55%) live within a 20-minute commute of their caregiver, 69 percent live between 20 minutes and one hour away, and 94 percent live within two hours' commuting distance of their caregiver. *Only six percent of care recipients live further than two hours away from their caregiver.*

- *While just over one in five care recipients (21%) live in the caregiver's home, 70 percent of those who receive Level 5 care live in the caregiver's home.*
- Asian caregivers are more likely to live in the same household with their care recipient (36%) than Blacks (26%) or Whites (19%).
- Care recipients of Asian, Hispanic, and Black caregivers are more likely than those of White caregivers to live with another family member or friend if they do not live with the caregiver.

Intensity of Caregiving: Hours of Care Provided and Activities Performed

As discussed in the introduction to this report, and further elaborated on in the Appendix, a Level of Care Index was created to categorize caregivers according to the amount of time they devote to caregiving and the number and types of activities they assist with when caring for the person to whom they provide the most care. This section addresses these aspects of caregiving.

Estimated Hours per Week of Care Provided

Caregivers in this survey provide anywhere from less than one hour of care per week to "constant care." Table 4 shows the mean number of hours of per week that caregivers estimate they provide, by level of care. Table 4 shows that the increases for Level 4 and 5 caregivers are dramatic.

TABLE 4
MEAN HOURS OF CARE PROVIDED PER WEEK BY CAREGIVER LEVEL

	Number in Sample	Hours Per Week
All Caregivers	1,509	17.9
Level 1	389	3.6
Level 2	208	8.2
Level 3	287	9.1
Level 4	355	27.3
Level 5	185	56.5

- *All Level 5 caregivers, by definition, provide "constant care" of 40 or more hours of care per week (an estimated 2,910,000 caregiver households nation-*

wide), and 25 percent of Level 4 caregivers (or 1,200,000 caregiving households nationwide) also provide this amount of care. This means that a total of at least 4,110,000 caregiving households have a caregiver who provides at least 40 hours of care per week.

- On the other hand, close to all Level 1 (N=389) caregivers surveyed (99%), by definition, spend eight or fewer hours per week providing care.
- Almost half of all caregivers perform care for at least 8 hours per week, and 21% report spending between nine and 20 hours on caregiving per week.
- While the average caregiver provides care for 18 hours per week, close to one in five (19%) provides either "constant care" or at least 40 hours of care per week.
- *Women spend significantly more time caregiving than men—an average of 18.8 hours per week, in contrast with 15.5 hours per week for men.*
- While women constitute 73% of all caregivers, they are 79% of the constant/40-hour-per-week caregivers.
- *Asian caregivers spend significantly less time providing care per week, on average, than other minority caregivers: 15.1 hours, in contrast with 20.6 hours for Blacks and 19.8 hours for Hispanics.* (Whites average 17.5 hours of caregiving per week.)

Types of Assistance Caregivers Provide

1. INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs):[9] Managing Everyday Living

Close to all caregivers surveyed (98%) say they assist their care recipient with at least one IADL, and more than four in five (81%) assist with three or more IADLs.

- Almost eight in 10 caregivers (79%) say they help with transportation, 77 percent do grocery shopping, 74 percent do household chores, 60 percent prepare meals, and more than half manage finances (56%) and/or arrange or supervise the provision of outside services (54%).
- More than one in three caregivers (37%), or 8,370,000 caregiving households nationwide, give medications, pills, or injections to the person they care for. Black caregivers are more likely than either White or Asian caregivers to report that they give medications (51% vs. 35% and 38%); and Hispanic caregivers are more likely to give medications (45%) than Asian caregivers (38%). (Issues concerning the management of medications are discussed in a separate section beginning on page 20.)
- While men and women perform most IADLs in equal proportions, women are more likely than men to do housework (77% vs. 65%) and to prepare meals (65% vs. 47%).
- There are no differences in the incidence of assisting with IADLs by employment status (working compared with non-working caregivers).
- *Income, however, does make a difference in the kinds of IADLs performed. For example, caregivers with household incomes under $15,000 are more likely than high-income caregivers (with household incomes of $50,000 or more) to provide assistance with housework (84% vs. 73%) and meal preparation (69% vs. 55%). Similarly, caregivers with*

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[9] Instrumental Activities of Daily Living (IADLs) are activities performed to manage one's daily life or maintain a household and live independently, such as preparing meals, grocery shopping, driving or using transportation systems, doing light housework, taking medications, managing finances and paying bills and using the telephone.

household incomes over $50,000 are more likely than caregivers with household incomes under $15,000 to arrange for or supervise outside services (61% vs. 48%) and to manage finances (61% vs. 46%).

There are no differences by race/ethnicity in the extent to which caregivers provide help with IADLs, though there are differences by level of care, as shown in Table 5, which highlights differences between Level 1 and Level 5 caregivers. Level 5 caregivers (and in most cases Level 4 caregivers, as well) are more likely than caregivers of any other level to provide assistance with *each* IADL.

"I do all the laundry for my sister. I help her bathe. I cook her all her favorite foods. I play cards with her an hour a day to keep her mind active. I do literally everything for her."

TABLE 5
PERFORMANCE OF IADLS: TOTAL AND BY LEVELS 1 AND 5
(percentages)

	Total	Level 1	Level 5
Transportation	79.3	72.0	89.6*
Grocery shopping	77.3	67.9	93.7*
Housework	73.6	53.2	96.0*
Preparing meals	60.0	28.9	94.6*
Managing finances	55.6	48.3	74.4*
Arranging/supervising outside services	53.9	42.9	74.6*
Giving medicine	37.3	0.0	86.6*
No IADLs	2.0	2.6	—

*Differences between Level 5 and Level 1 caregivers are statistically significant at the .05 level

2. Activities of Daily Living (ADLs):[10] Personal Care such as Bathing or Eating

More than half of all caregivers (51%) help with at least one ADL, and 29 percent help with at least three.

- *Overall, women are more likely than men to assist with ADLs (54% vs. 45%), and higher proportions of women than men assist with dressing, bathing or showering, and with continence or diapers.*
- Black caregivers are more likely to help with at least one ADL (60%) than Whites (50%) or Asians (44%); half of all White caregivers and 56 percent of Asian caregivers do not assist with any ADLs. Higher proportions of Blacks than Asians report assisting with each ADL, except for feeding.
- A higher percentage of Hispanic caregivers assist with at least one ADL (58%) than Asians (44%); and Hispanics are more likely than Whites to assist with dressing, bathing, toileting, and continence.
- Non-working caregivers are more likely to perform ADLs than employed caregivers (59% vs. 48%).
- While employed caregivers are as likely as those not employed to provide assistance with IADLs, a significantly smaller percentage provide assistance with any ADLs (48%, as compared with 59% of non-working caregivers).

While, by definition, Level 1 caregivers provide no help with ADLs, high proportions of Level 4 and 5 caregivers do, as shown in Table 6.

TABLE 6
PERFORMANCE OF ADLS:
TOTAL AND BY LEVELS 4 AND 5
(percentages)

	Total	Level 4	Level 5
Getting in/out of chairs	36.8	56.7	77.8*
Dressing	31.4	56.2	79.9*
Bathing	26.6	47.4	77.5*
Toileting	26.2	47.8	63.2
Feeding	19.2	29.5	43.9
Continence/diapers	13.6	20.2	44.6*
No ADLS	48.5	15.9	—

*Differences between Level 5 and Level 4 are significant at the .05 level.

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[10] Activities of Daily Living (ADLs) are activities involving personal care, such as eating, toileting, getting in and out of bed and chairs, bathing, dressing and grooming, and managing continence or changing adult diapers/briefs.

Receipt of Instruction in How to Perform Caregiving Activities

- Just over two in five caregivers (41%) report that someone taught them how to perform at least one of the activities they assist with, while 59 percent have received no instruction. There are no differences by level of care, gender, income, education, or employment status.

That fewer than half of all caregivers have received any instruction in providing care may reflect the fact that many activities they assist with, such as providing transportation or grocery shopping, require no additional skill to be performed satisfactorily.

- There are differences, however, by race/ethnicity. *Asian caregivers are the least likely to have been taught how to perform any of the tasks they assist with—only 32% have received any training*. This figure is significantly lower than for Black caregivers (46%).

> **"I was scared of the IV. I had to keep the wounds clean, then there was an abscess in her knee. I asked a lot of questions of the nurse until I understood what I was supposed to do."**

Medication Management

More than seven in 10 caregivers say their care recipients take their own medications as directed—on time, in the right amount, and with no problem. Fewer than one in four caregivers (23%) report that their care recipient has trouble taking medicines, and six percent say their care recipient takes no medicines. There are no differences by race/ethnicity.

- *Level 3, 4, and 5 caregivers are more likely than Level 1 caregivers to say their care recipient has trouble taking medications as directed (at least 30%, compared to 9% for Level 1 caregivers).*

Of those who do help with medications, a very high percentage (96%) say they know how to administer them as prescribed (on time and in the right amount). Again, there are no differences by race/ethnicity or by level of care.

High proportions also report knowing what each medication is for (90%), the possible side effects of each medication (78%), and how medicines may react with each other (69%).

- *Asians are less likely to know these things than caregivers of other racial/ethnic groups.*
- Level 4 and 5 caregivers are more likely to be well-informed about these issues than Level 2 caregivers. (Level 1 caregivers do not administer medications.)

More than three in four caregivers who help with medications (77%) say they have asked someone about a medication that was prescribed. Asian caregivers who help with medications are less likely than either Whites or Hispanics to have consulted anyone about them (63% vs. 80% and 78%). There are no differences by level of care.

The person most frequently consulted is a doctor (61%), pharmacist (24%), or a nurse (9%). Four percent report having consulted a family member.

Caregiver Support: Who Also Helps Provide Care?

Almost three in four caregivers (73%) report that someone else also helps provide care to the care recipient. Typically the other helpers are the care recipient's daughter (34%), son (25%), spouse (9%), daughter-in-law (6%), grandson (6%), "the whole family" (5%), or son-in-law (5%). Sisters and nieces of the care recipient were each mentioned by four percent of caregivers. Thirteen percent of caregivers report that a friend or other unpaid non-relative also helps in providing care.

- Hispanic caregivers are more likely than Asians to report that a daughter of the care recipient also provides care (45% vs. 33%); and a higher proportion of Asians (11%) than any other racial/ethnic group report that daughters-in-law also provide care.
- Level 1 caregivers are more likely to say that a relative of the care recipient also helps provide care than are Level 5 caregivers (78% vs. 64%), and that person is less likely to be the care recipient's spouse for Level 5 caregivers than for Levels 2, 3, and 4 caregivers. (This latter finding reflects the fact that Level 5 caregivers are more likely to be caring for a spouse than lower level caregivers.)

Primary vs. Secondary Caregivers

Just over two in five caregivers (41%) say they provide most of the care or that no one else helps, while an equal percentage say someone else provides most of the care. This means that 41 percent of caregivers can be considered primary caregivers and an equal percentage can be considered secondary caregivers. Seventeen percent say the care is split equally between themselves and another person.

- A higher percentage of Black than Asian caregivers report that they themselves provide most of the care or that no one else helps (49% vs. 36%).
- *While only 18 percent of caregivers report that no one else helps them with the caregiving, more than one in three Level 5 caregivers (34%) say no one else helps them (which amounts to 980,000 caregiving households), more than for caregivers of any other level.*

Are Others Doing Their "Fair Share" of the Caregiving?

Just under half of all caregivers (49%) feel that other relatives are doing their "fair share" of the caregiving. One in five say their relatives are not doing their fair share, and just over three in 10 (31%) say no one else helps or they get help from a non-relative.

- Asian and Hispanic caregivers are more likely to feel that other relatives are doing their fair share of the caregiving (61% and 54%) than Blacks (43%), and Asians are also more likely to feel that way than Whites (49%).
- A higher proportion of Level 4 and 5 caregivers than Level 1 caregivers feel that other relatives are not doing their fair share (26% and 28% vs. 13%).

> **"My brothers would provide just as much assistance to my father as I do, if I called them to do so. My brothers do help with bathing my father, as does my son. If I call them at any time, I know they will come."**

Perceptions of Family Conflict Over Caregiving

Only five percent of all caregivers report that they experience a lot of family conflict over caregiving, just over one-fifth (21%) report some conflict, and 73 percent report no family conflict at all. There are no differences by race/ethnicity, but there are differences by level of care, by age, and by employment status.

- Level 1 caregivers are more likely to report no family conflict (80%) than either Level 4 or Level 5 caregivers (67% and 68%); and Level 3 caregivers are almost twice as likely as Level 1 caregivers to say they experience some family conflict (30% vs. 16%).
- Caregivers aged 18-34 are more likely than those over 65 to say they experience some family conflict over caregiving (27% vs. only 8%), and are less likely than caregivers aged 50-64 and 65+ to say there is no family conflict at all.
- Employed caregivers are more likely to report family conflict over caregiving (24%) than caregivers who are not working (16%).

> **"I'm really angry because there's no reason why they can't come and sit a couple of hours or a day where we can get away."**

Physical, Emotional, and Financial Strain and Stress of Caregiving

While relatively small percentages of all caregivers say their caregiving responsibilities have seriously interfered with their usual activities, caused them physical or mental health problems, been highly stressful physically or emotionally, or posed a serious financial hardship, there is considerable variation in the responses of caregivers by the level of care they provide, by race/ethnicity, and by other demographic variables.

Impact of Caregiving on Time for Family and Leisure Activities

More than four in 10 caregivers (43%) report that their caregiving responsibilities have caused them to have less time for other family members than before, and an equal proportion say that caregiving has necessitated giving up vacations, hobbies, or other activities. More than half of all caregivers (55%) have experienced one or both of these.

- *Not surprisingly, Level 3, 4 and 5 caregivers are more likely to report either of these situations than Level 1 or 2 caregivers.* For example, two-thirds of Level 5 caregivers (68%) report having less time for family, in contrast with 22 percent of Level 1 caregivers and 35 percent of Level 2 caregivers; and almost three in four Level 5 caregivers (73%) have had to give up vacations, hobbies, or their own activities (as compared with 25% of Level 1 caregivers and 33% of Level 2 caregivers).

> **"Sometimes it's not good for the caregiver to have to split her time between young children and an aging parent. He or she can't do justice to either."**

- *Those caring for someone with dementia are more likely than other caregivers to have had less time for other family members or leisure activities (66%).*
- *Asian caregivers are less likely than caregivers of other racial/ethnic groups to say they have less time for other family members due to caregiving (only 31%, compared with 42%-44% of other caregivers).* There are no other differences by racial/ethnic group.
- *A higher percentage of caregivers with at least some college education report both less time for family and less time for leisure activities than those with a high school education or less.*

Experience of Physical or Mental Health Problems

Fifteen percent of all caregivers report that they have suffered any physical or mental health problems as a result of caregiving, and 85 percent say they have not.

- *Among Level 5 caregivers, however, more than three in 10 (31%) say they have experienced physical or mental health problems due to caregiving (compared with seven percent of Level 1 caregivers, 13 percent of Level 2 caregivers, and 12 percent of Level 3 caregivers.)*
- A higher proportion of Black than Asian caregivers report having suffered physical or mental health problems as a result of caregiving (19% vs. 10%).
- Women are more likely than men to have experienced physical or mental health problems as a result of caregiving (17% vs. 9%), and non-working caregivers are more likely than working caregivers to have experienced such problems (19% vs. 12%).
- A higher proportion of caregivers aged 50-64 report having experienced physical or mental health problems (21%) than those aged 18-34 (9%) or 35-49 (13%).

Experience of Physical Strain

More than half of all caregivers (56%) report that their caregiving activities cause no physical strain at all (a rating of 1 on scale of 1 to 5, where 1 is low and 5 is high), and only six percent say that caregiving has been very much of a physical strain for them.

- Level 5 caregivers, however, experience more physical strain than caregivers of any other level. One in three (33%) rank their physical strain as a 4 or a 5 on the five-point scale.
- A higher proportion of Blacks (19%) report experiencing high levels of physical strain (a rating of 4 or 5) than either Whites or Asians (10% apiece).
- A higher percentage of women than men report experiencing physical strain (13% vs. 5%); and those with annual household incomes under $30,000 are more likely than those with incomes of at least $50,000 to experience high physical strain (17% vs. 6%).

Experience of Emotional Stress

One in four caregivers experience caregiving as emotionally stressful (a rating of 4 or 5 on a scale of 1 to 5), while more than half (55%) find it not very stressful (a rating of 1 or 2). *In contrast, more than half of Level 5 caregivers (53%) find caregiving emotionally stressful.*

- Of the racial/ethnic groups, Asians report the least amount of emotional stress.

- *Women are more likely than men to experience their caregiving as stressful (30% vs. 13%), and a still higher percentage of those caring for a person with dementia say that caregiving is stressful (43%).*

Experience of Financial Hardship

Only a small percentage of all caregivers (7%) report that caregiving is a financial hardship for them (a rating of 4 or 5 on a scale of 1 to 5), and more than three in four caregivers (76%) say that caregiving is not a financial hardship at all (a rating of 1).

- *A higher percentage of Level 5 caregivers than caregivers of any other level say their caregiving responsibilities pose a financial hardship (21%).*
- *Whites are more likely than caregivers of any other racial/ethnic group to say that caregiving poses no financial hardship for them at all (78% vs. 70% of Hispanics, 66% of Asians, and 63% of Blacks).*
- Black and Hispanic caregivers are more likely than Whites or Asians to say that caregiving is a financial hardship for them (a rating of 4 or 5): 13% and 11%, compared with 6% of White and Asian caregivers.
- *Not surprisingly, those with annual household incomes under $15,000 are more likely than those with higher incomes to say that caregiving poses a financial hardship* (16% vs. only 1% for those with incomes of at least $50,000, for example). *Similarly, those who have not graduated from college are more likely to say that caregiving poses a financial hardship than those who have.*
- Non-working caregivers are more likely to find caregiving a financial hardship (10%) than working caregivers (5%).

Estimated Out-of-pocket Expenditures on Caregiving Other than for a Spouse

For the 41 percent of caregivers who report that they know how much they spend of their own money on caregiving during a typical month, the average amount spent is $171, which totals approximately $1.5 billion per month spent out-of-pocket on caregiving nationwide.

Nine percent say they do not know how much they spend, and just under half of all caregivers (49%) say they spend no money of their own on caregiving during a typical month.

- *Minority caregivers are more likely to have out-of-pocket expenditures for caregiving than Whites. Only 27 percent of Asians, 35 percent of Hispanics, and 37 percent of Blacks report no monthly personal expenditures on caregiving, in contrast with 53 percent of White caregivers.*
- *About twice as many Level 1 caregivers (67%) report no out-of-pocket expenditures for caregiving than Level 4 or Level 5 caregivers (31% and 34%).*
- Excluding those who say they have no out-of-pocket expenses for caregiving, Level 5 caregivers spend considerably more than Level 1, 2, or 3 caregivers, averaging $357 per month, as compared with $95.42 for Level 1 caregivers, for example.

"We have just enough money to make ends meet. There is very little left. It goes for medicines, drugs, transportation."

Caregiving Expenditures for Other than a Spouse, as a Percentage of Monthly Income

More than three in four caregivers (77%) not involved in spousal caregiving report that they spend 10 percent or less of their own monthly income on caregiving, and fewer than one percent of all caregivers providing non-spousal care report that they spend more than 50 percent of their income on caregiving. Seventeen percent of all caregivers, and 26 percent of Level 5 caregivers, cannot estimate how much they spend per month.

- *Of caregivers who can estimate how much they spend out-of-pocket on caregiving, Level 5 caregivers spend an average of 24 percent of their own monthly income on caregiving—a much higher percentage than for caregivers of any other level.*
- Of those who spend any money out-of-pocket on caregiving, both Black and Asian caregivers report spending higher proportions of their income on caregiving (averaging 15% and 13%) than White caregivers (6%).

Dealing with Stress: Coping Mechanisms

Caregivers cope with the strains and stresses of caregiving principally through their personal resources or informal networks. The most common coping mechanisms are prayer (74%), talking with friends or relatives (66%), exercising (38%), and hobbies (36%). Relatively small percentages get help from counselors or other professionals (16%), use medications (7%), or resort to alcohol (3%).

> **"I try to be optimistic. Sometimes I bend over backwards to take what might be an unpleasant situation and turn it around to something that could be pleasant just by attitude."**

- Prayer is the most common way of coping with the stresses and strains of caregiving—almost three in four caregivers (74%) use this method, but 88% of Black caregivers use prayer.

> **"Prayer elevates your mind. God is doing this. I am here physically, and He's instilling strength in me to do it."**

- Whites and Blacks are more likely than Hispanics or Asians to talk with friends and relatives to relieve stress.
- Asian caregivers are less likely to get help from a counselor or professional than either Whites or Blacks (6% vs. 17% and 14%).

Biggest Difficulty and Greatest Reward of Caregiving

Biggest Difficulty

One in five caregivers (20%) say the biggest difficulty they face in providing care is the demand on their time or not being able to do what they want; 15 percent say it is watching or worrying about their care recipient's deterioration; 10 percent say it is the care recipient's attitude (uncooperative, "demanding"); and four percent mention a problem with location, distance, or inconvenience. There were no differences by race/ethnicity.

More than one in four caregivers (26%) say they have no difficulty providing care, though this response was more frequent among Level 1 and 2 caregivers than among Level 4 and 5 caregivers.

- Perhaps not surprisingly, Level 3, 4, and 5 caregivers are more likely to say that watching or worrying about their care recipient's deterioration is their biggest concern (17-21%) than are Level 1 caregivers (just under 8%).
- Blacks are more likely than Whites to mention the physical demands of caregiving as their biggest difficulty (6% vs. 2%).

> **"It's a strain on you physically and mentally. You don't have a life because you neglect a lot of your own personal needs because you're so wrapped up with taking care of their needs."**

Biggest Reward

The biggest rewards of caregiving are knowing that the care recipient is well cared for, personal satisfaction in knowing one is doing a good deed, and the care recipient's appreciation or happiness. Each of these was mentioned by 16 percent of caregivers. Also mentioned are watching the care recipient's health improve (by 11%), family loyalty, "giving back," fulfilling family obligations (by 11%), and spending time together (by 10%). There are no differences by race/ethnicity.

- Level 2 caregivers are more likely to mention family loyalty or obligation as the biggest reward of caregiving (18%) than Level 4 or 5 caregivers (6%-7%).

> **"There's still a lot of happiness. My mother comes alive when she interacts with the grandchildren."**

Words Caregivers Use to Describe the Caregiving Experience

Positive Words

A majority of caregivers (57%) use positive words to describe the caregiving experience; and there are no differences in the overall positiveness of their comments by race/ethnicity or level of care.

Words used to describe the experience of caregiving by more than a handful of caregivers include "rewarded"/"rewarding" (mentioned by 19%); "happy," "helpful" (each by 7%); and "thankful"/"grateful," "enjoyable," and "love"/"loving" (each by 4%). Interestingly, Level 5 caregivers are more likely to report that they feel good, comfortable, content, or "OK" about caregiving than Level 1 or Level 2 caregivers (9% vs. 1%).

Negative Words

Just over one-third of caregivers (34%) use negative words to describe their experience as a caregiver. There are no differences by level of care provided or by racial/ethnic group.

The negative words caregivers most frequently use to summarize how they feel about caregiving are "stressful" (12%), "obligation"/"duty" (9%), "burdened" (3%), and "tired"/"exhausting" (3%). There are no differences by level of care.

- Hispanics are more likely than Whites to use the word "stressful" in describing their caregiving experiences (18% vs. 10%).

Eight percent of caregivers say they don't know how they feel about caregiving.

Utilization of Supportive Services Available in the Community

Almost three in four caregivers (74%) report having used one or more services or devices shown in Table 7. Not surprisingly, Level 3, 4, and 5 caregivers are more apt to have used wheelchairs or walkers, personal or nursing care services, home modification, and respite care (identified during the interviews as "temporary care services") than Level 1 or 2 caregivers. The number of such services and devices used also varies by level of care provided. For example, the average number of services used by Level 1 caregivers is 1.36, while for Level 5 caregivers it is 2.94.

- Caregivers who report that their care recipient has dementia are more likely to report the use of at least one of these services (83%) than caregivers overall (74%).
- *Asian caregivers are the least likely of the racial/ethnic groups to report having used any of these services—only 62 percent, compared with 72-76 percent of caregivers of other racial/ethnic groups. This finding holds for wheelchairs and other devices, personal or nursing care services, and home-delivered meal services.*
- White, Black, and Hispanic caregivers were more than twice as likely as Asian caregivers to have used personal or nursing care services (32% to 44% vs. only 15% of Asians), and Blacks were the most likely to have done so (44%).

TABLE 7
UTILIZATION OF SERVICES
(Base = Total Caregivers)
(percentages)

Acquiring a wheelchair, walker, or other device	46.7
Personal or nursing care services	37.8
Home modification	28.1
Home-delivered meal services	15.6
Assistance with housework	15.6
Financial information service	15.5
Transportation service	14.9
Respite care	14.1
Adult day care/senior center	9.5
Support group	6.6

It is not clear whether the lower rates of service utilization among Asian caregivers are a result of the overall lower level of care they provide, cultural factors, or something else.

- Both White and Hispanic caregivers were more likely to say they have made home modifications than Black caregivers (29% and 26% vs. 17%).

- Blacks and Hispanics are more likely to have used transportation services (more than 20% each) than Whites (only 14%), and Blacks are more likely than Whites to have used adult day care or senior centers (14% vs. 9%).
- Asians are the least likely to have used respite care services—only 8 percent have done so, compared with 15 percent of Whites, for example.
- Among Level 5 caregivers, use of respite care (by 23%), adult day care (by 16%), and support groups (by 15%) is modest, even though significantly higher than for caregivers providing lower levels of care. There were no differences by level of care in the extent to which meal services, help with housework, or transportation services are used.
- Female caregivers are more likely than male caregivers to have used a device such as a wheelchair or personal or nursing care services, and caregivers aged 65+ are more likely than caregivers of younger ages to have used a support group (14% vs. 4 to 8%).
- Not surprisingly, college graduates are more likely than caregivers of lower educational attainment to have used housework assistance or adult day care or a senior center to assist with care.

"I don't know what I would do without the adult day care center. My mother is busy during the day and I get a break. It helps me keep going."

Sixteen percent of caregivers reported they had sought information on how to get financial assistance for the person(s) to whom they provide care. Use of financial information services is more common among Level 4 and 5 caregivers than among Level 1 and 2 caregivers, but does not differ by race/ethnicity (except that Hispanics are more likely to have used them than Asians) or other demographic variables.

More than one in four caregivers (27%) say they have used none of the services or devices. Not surprisingly, this is more typically the case among Levels 1 and 2 caregivers than among Levels 3, 4, and 5 caregivers, and also among Asian caregivers.

Service Providers

Almost half the caregivers who use any of these services or devices (49%) say they are or were provided by an individual or private commercial agency, paid for by the caregiver. Community or government agencies were a source of services or devices for 45% of the caregivers. Other sources include health care providers (used by 43% of caregivers using any services) and family, friends, and volunteers (used by 23%). Ten percent say the services are or were provided by a church or synagogue.

Level of Satisfaction with Providers of Assistive Services and Devices

As Table 8 shows, satisfaction with services and devices is relatively high, with more than four in five caregivers reporting that the devices/services they have used either fully or partially met their needs, except in the area of financial information services.

Caregivers who have used wheelchairs or other devices, home modifications, and transportation services are the most apt to say the service fully met their needs, and those who have used financial information services are least likely to say the services fully met their needs.

TABLE 8
SATISFACTION WITH SERVICES AND INFORMATION
(Base = Total Caregivers)
(percentages)

	Met Need Fully	Met Need Partly
Wheelchair, walker, or other device	81.4	14.1
Home modification	77.9	17.6
Transportation Service	71.8	24.8
Home-delivered meal service	61.0	25.3
Housework	61.9	30.5
Personal care, nursing service	69.6	23.8
Adult day care/ senior center	53.6	30.7
Respite care service	62.9	32.4
Support Group	53.4	37.8
Financial information service	33.5	40.7

Reasons for Non-Utilization of Assistive Services and Devices

For each of the 10 services inquired about, caregivers who said they did not use it were asked why. In the great majority of cases, the reason caregivers did not use a service is that they had no need for it, ranging from 61 percent for support groups to 96 percent for assistive devices.

Lack of Awareness of the Service

The second most frequent reason for not using a service was not being aware of it, mentioned by 18 percent of all caregivers, but by 30 percent of Level 5 caregivers (a higher percentage than for caregivers of any other level). This reason was cited by higher percentages of Blacks and Hispanics (27% and 29%) than Whites (17%), and by a higher percentage of primary caregivers (22%) than secondary or co-equal caregivers (16%).

"Too Proud" to Use It

An unusually high percentage of caregivers (15%) said they or their care recipient were too proud to use adult day care or a senior center—a much higher percentage than for any other service/device inquired about (two percent or fewer). There is probably also some confusion as to what adult day care is, because five percent of caregivers mentioned that they didn't use it because they didn't want an outsider coming in to their home. "Too proud" may also reflect resistance to services by the older person.

- This reason was more often cited by caregivers aged 50-64 (23%) than those aged 18-34 (12%), and by primary caregivers (25%) than secondary/co-equal caregivers (12%).

No Special Reason/Never Thought about It

Seventeen percent of caregivers who don't use a particular service said they had no special reason for not using it, or that they had never thought about it. Higher proportions of Level 4 and 5 caregivers mentioned this reason than Level 1 caregivers (23% vs. 12%), and so did higher percentages of Black and Hispanic caregivers (29% and 26%) than White caregivers (15%).

Too Busy

Ten percent of caregivers said they were too busy to use the service, with a higher percentage of Hispanic caregivers (21%) citing this reason than caregivers of any other race/ethnicity (10-11%). A higher percentage of primary caregivers than secondary caregivers also said that they were too busy.

Service Is Not Available

The perception or knowledge that a service is not available also contributes to its non-utilization. Interestingly, 17 percent of Level 5 caregivers and 13 percent of level 4 caregivers mentioned this as a barrier, in contrast with only four percent of Level 1 caregivers. Those with incomes of less than $15,000 were more likely to cite this reason (15%) than those with incomes between $30,000 and $50,000 (only 4%).

Cost

Surprisingly, very few caregivers cited cost as a barrier to obtaining needed services. Factors influencing whether cost is mentioned include intensity of care, race/ethnicity, income, living arrangements, and primary vs. secondary/co-equal caregiver status.

- Although all percentages are small, higher percentages of Level 4 and Level 5 caregivers (9% and 11%, respectively) mention cost as a barrier to service utilization than Level 1 caregivers (1%), and a higher percentage of Hispanic caregivers (10%) cite this reason than Asians (2%).
- Not surprisingly, those with incomes under $15,000 were more likely to mention cost as a factor than those with incomes of at least $30,000. A higher proportion of caregivers whose care recipient lives with them cite cost as a reason for non-utilization of services (12%) than those whose care recipient lives up to an hour away (4%). Primary caregivers also are more apt to mention cost as a barrier than secondary/co-equal caregivers (8% vs. 4%).

Unmet Needs for Help, Information, or Support in Caregiver Role

Table 9 shows the kinds of assistance most frequently mentioned in response to a question concerning the kinds of help, information, or support caregivers would use, or would have used, in providing care.

While 38 percent said they didn't know what additional assistance they would use, or would have used, this figure escalates to 49 percent of Asian caregivers—higher than for all other racial/ethnic groups—and to 44 percent for those with a high school education or less (compared with about one-third of more highly educated groups).

Black caregivers were more likely than Whites or Asians to name at least one type of assistance they would use (51%, vs. 43% and 36%, respectively).

Those who have not used any services are more likely not to know what they would use, or would have used, than those who have (48% vs. 35%), and secondary/co-equal caregivers are less likely to know than primary caregivers (43% vs. 31%). This is also the case for higher percentages of Level 1 and 2 caregivers than for Level 5 caregivers.

While 19 percent of all caregivers said there was nothing they needed, those who had never used any services were more likely to say they didn't need any (25%) than those who had (16%).

TABLE 9
KINDS OF HELP, INFORMATION, OR SUPPORT CAREGIVERS WOULD USE/WOULD HAVE USED
(Base = Total Caregivers*)
(percentages)

Don't know	38.1
None/nothing/no help	18.5
Free time/time for self/a break	16.9
Help with housekeeping	9.8
Extra money/financial support	9.5
Central source of information	9.0
Information about paying for services such as nursing homes, adult day care	7.6
Someone to talk with/counseling/support group	6.0
Sitting services/someone to check up on care recipient	5.6
Help with ADLs/personal care	4.9
Help with shopping	4.3
Help with medications	3.2
Information about care recipient's condition	2.7

*Up to two responses per caregiver were coded.

Free Time/A Break from Caregiving

As expected, caregivers who provide the most intense and difficult kinds of care are the ones most likely to report needing more free time or a break from caregiving. There are no differences by race/ethnicity.

- *While 17 percent of all caregivers say they could use more free time or a break from caregiving, Level 5 caregivers are more likely to say they need it (33%) than Level 1, 2, or 3 caregivers. Primary caregivers also are more likely to report needing a break than secondary/co-equal caregivers (21% vs. 14%).*
- *Caregivers taking care of someone with dementia also are more likely to mention needing more free time or a break from caregiving: 24%.*

Caregivers who have used formal services are more likely to mention needing a break than those who have not (19% vs.10%).

Assistance with Housekeeping and Meal Preparation

Ten percent of caregivers say they could use help with housekeeping. Women are more likely to say this than men (11% vs. 7%). Both low- and high-income caregivers are more likely than middle-income caregivers to need help with housekeeping, as are primary caregivers compared with secondary/co-equal caregivers (13% vs. 8%), and those who have used formal services as compared with those who have not (12% vs. 5%).

Though the percentages are small, Black and Hispanic caregivers are more likely to report needing help with meal preparation than Whites (7% vs. 3%), as are spouse caregivers (9%) when compared to all caregivers (3%).

Needs for Financial Help

Very small numbers of caregivers mentioned needing money. Higher percentages of Blacks and Hispanics than Whites report needing extra money or financial support because of their caregiving responsibilities (14% vs. 9%).

Those caring for someone with dementia are also more likely to say they need extra money or financial support than the average caregiver (14% vs. 10%).

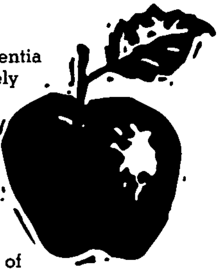
- Understanding how to pay for nursing homes, adult day care, or other services was more often mentioned by Hispanic caregivers (13%) than by Whites (7%), by caregivers with household incomes under $15,000 (16%) than by those with incomes above $15,000 (5% to 9%), by persons who have used formal services (9%) than by those who have not (3%).
- Not surprisingly, caregivers assisting persons with dementia were more likely than the typical caregiver to say they could use, or could have used, help in understanding how to pay for long-term care services such as nursing homes and adult day care (12% vs. 8%).

Central Source of Information

Having a central place to go to or to call to find out what help is available was mentioned by nine percent of caregivers as a need or service they would use, or could have used. Interestingly, this was mentioned more frequently by those with household incomes over $50,000 (15%) than by those with lower incomes (8%-10%), and more often by those with at least some college education (11-14%) than by those with a high school education or less (5%). It was also more frequently mentioned by those who had used services than those who had not.

Someone to Talk with, Counseling, Support Group

While only six percent of caregivers say they could use someone to talk with, counseling, or a support group, a higher percentage of Level 5 caregivers (25%) than all other groups say they could use this kind of assistance. Those caring for someone with dementia were also more likely than the average caregiver to say they could benefit from talking with someone (11%).



Women are more likely to say they could use this type of assistance than men (7% vs. 3%), and caregivers aged 50-64 and 65+ are more likely to say they need it than those aged 18-34 (9% and 10% vs. 2%). Those whose care recipient lives with them are more likely to need someone to talk with than those who do not live with their care recipient (13% vs. 4%).

- *Caregivers taking care of someone with dementia also are more likely to mention needing someone to talk with, counseling, or a support group (11%).*

Impact of Caregiving on Work

Since the majority of caregivers are employed (64%), most of them full-time (52%), the impact of caregiving responsibilities on work life can be important.

While relatively few caregivers who ever worked while providing care to their care recipient (79% of caregivers) report having given up working entirely as a result of caregiving (6%), caregiving responsibilities do have a significant impact on caregivers' work life. For example, more than half the caregivers employed while caregiving for the care recipient (54%) have made changes at work to accommodate caregiving.

- *Making changes in daily work schedule (going in late, leaving early, or taking time off during the day) are the changes most frequently reported: by 49% of caregivers who ever worked while caring for this care recipient.*

- One-fifth of all caregivers ever employed while caring for this care recipient gave up work either temporarily or permanently: 11 percent took or have taken a leave of absence, four percent took early retirement, and six percent gave up working entirely.
- Seven percent report having changed from full-time to part-time work or taken a less demanding job.
- Relatively few report having lost their benefits (4%) or having turned down a promotion (3%) because of caregiving responsibilities.
- Hispanic and Asian caregivers are more likely to have had to take a leave of absence from work (18% and 22%) than Whites (10%).

As Table 10 shows, there is a correlation between the level of care provided and the likelihood of altering one's daily work schedule, taking a leave of absence, switching to part-time work, or giving up work entirely. For example, three in four Level 5 caregivers, in contrast with 41 percent of Level 1 caregivers, have made at least one of the work-related adjustments shown in Table 10.

- Thirty percent of Level 5 caregivers report having had to give up work entirely, and 26 percent say they took a leave of absence because of their caregiving responsibilities—much higher percentages than for Level 1, 2 or 3 caregivers.

TABLE 10
WORK-RELATED ADJUSTMENTS BY LEVEL OF CARE

(Base = Caregivers Ever Employed while Providing Care to This Care Recipient)
(percentages)

	Total	Level 1	Level 2	Level 3	Level 4	Level 5
Total unweighted+	(N=1,193)	(n=330)	(n=174)	(n=240)	(n=277)	(n=113)
Total weighted+	(N=1,716)	(n=530)	(n=245)	(n=331)	(n=363)	(n=166)
Made any changes listed below	**54.2**	**40.8**	**45.1**	**58.2***	**66.5***	**75.0***
Changed daily schedule: go in late, leave early, take time off during work	49.4	36.3	44.0	54.0*	61.5*	64.0*
Took leave of absence	10.9	5.5	5.9	9.1	17.8*	26.0*
Worked fewer hours, took less demanding job	7.3	2.0	3.8	6.5	11.7*	25.0*
Lost any job benefits	4.2	2.4	3.4	1.7	7.5	11.0*
Turned down a promotion	3.1	1.2	2.1	0.7	6.0	10.4*
Chose early retirement	3.6	1.2	0.3	3.0	5.1	14.8*
Gave up work entirely	6.4	1.3	0.2	4.4	10.2*	30.3*

+Unweighted numbers refer to numbers of caregivers in the sample, while weighted numbers refer to numbers of caregiving households in the U.S. population nationwide.

*Differences in percentages are significant at the .05 level.

Other factors associated with higher levels of care or more intense caregiving include caring for a person with dementia, living in the same household as the care recipient, helping with two or more ADLs, and being a primary caregiver. Table 11 below shows the percentages of these types of caregivers who have made work-related adjustments as a result of caregiving.

> **"I have things set up. He goes to day care three days a week. I'm a supervisor. I got my unit together and explained the situation to them so if I have to go anytime during the day, I go."**

Attitude of Employer toward Caregiver

More than four in five caregivers who have experienced any of these problems (81%) have found their employer's attitude toward the demands of caregiving

TABLE 11
Conditions Increasing the Likelihood of Work-Related Adjustments

(Base = Caregivers Ever Employed while Providing Care to The Care Recipient)
(percentages)

	Alzheimer's or Confusion	**Live in Same Household**	**Help with 2+ ADLs**	**Primary Caregiver**
Total unweighted+	(n=239)	(n=270)	(n=426)	(n=460)
Total weighted+	(n=363)	(n=317)	(n=601)	(n=641)
Made any changes listed below	**62.7**	**64.9**	**68.2**	**65.7**
Changed daily schedule: go in late, leave early, take time off during work	57.5	57.3	62.1	61.5
Took leave of absence	9.9	15.1	18.5	15.8
Worked fewer hours, took less demanding job	13.7	14.0	14.0	9.6
Lost any job benefits	5.7	7.9	7.4	6.3
Turned down a promotion	5.8	7.4	5.3	4.5
Chose early retirement	6.9	10.2	6.2	6.6
Gave up work entirely	9.8	16.1	13.1	10.0

+Unweighted numbers refer to numbers of caregivers in the sample, while weighted numbers refer to numbers of caregiving households in the U.S. population nationwide.

to be either very understanding (63%) or somewhat understanding (18%). Seven percent said their employer was not very understanding, and 7% said their employer was not aware of their caregiving activities. There are no significant differences by level of care provided.

> **"Sometimes I go to work and get called right back. I get a lot of support at work. If I need to be off, there's no problem giving me time."**

Summary and Conclusions

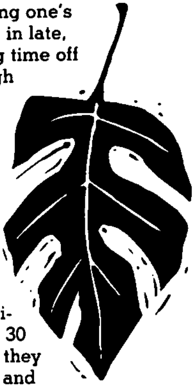
Family caregiving to persons aged 50 and older is widespread among the U. S. population. In close to one in four households there is at least one person aged 18 or older who presently provides care, or who has been a caregiver, to an older person at some point during the past 12 months. This person is typically a female and typically provided care to a female relative. About one in four caregivers is under 35 and more than one in three are age 50 or older, with the bulk of caregivers ranging in age from 35 to 49. The majority of caregivers have provided care to their primary care recipient for less than five years, while about one in five has done so for five to 10 years, and 10 percent have been providing care for at least 10 years.

Not only are family caregivers diverse in age and the length of time they have been providing care, they are also diverse with respect to the types of care and the number of hours of care they provide in a typical week, which range from very modest and non-taxing to heavy-duty, round-the-clock care involving assistance with multiple tasks and personal care. About half of all caregivers provide assistance with at least one personal care activity, and almost every caregiver provides assistance with some aspect of managing a household or coping with the demands of daily living. In general, caregivers and their care recipients live in close proximity to each other. About one in five lives in the same household with his or her care recipient(s)—typically the case with Level 5 caregivers—and of the remainder, almost seven in 10 caregivers live within an hour's commuting distance from their care recipient.

While a high percentage of caregivers use positive words to describe their feelings about caregiving, and relatively few say they experience family conflict over caregiving, the responsibilities involved in providing care do have an impact on family life, leisure time, work life, personal finances, and in some cases on physical and mental health. More than half of all caregivers report that their caregiving responsibilities cause them to have less time for other family members or have necessitated giving up vacations, hobbies, or other activities. Not surprisingly, those whose caregiving activities are more intense and require a heavier investment of time are more likely to report these impacts.

Though relatively few caregivers who have ever worked while providing care

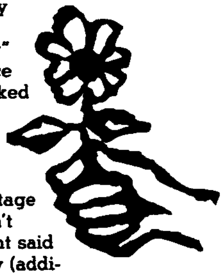
to their care recipient(s) report that they have had to quit work entirely, more than half have made at least some work-related changes to accommodate the demands of caregiving. Most typically, these changes have involved modifying one's work schedule—going in late, leaving early, or taking time off during the day—though 11 percent report having had to take a leave of absence due to caregiving responsibilities. Level 5 caregivers, however, are much more likely than Level 1 or 2 caregivers to have made work-related changes of a more serious nature, more than 30 percent reporting that they gave up work entirely and 15 percent saying they took early retirement.

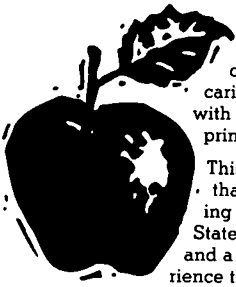


Among those caregivers who take care of someone other than a spouse and who report having out-of-pocket expenditures associated with caregiving, the average monthly outlay is $171. This estimate may be conservative, in that nine percent of all caregivers say they do not know how much they spend out-of-pocket on caregiving. Some caregivers experience considerable financial hardship due to caregiving responsibilities. For example, Level 5 caregivers, whose monthly outlay for caregiving averages $357, report out-of-pocket expenses constituting, on average, almost one-fourth of their monthly income. While a relatively small percentage of caregivers overall say that caregiving poses a financial hardship for them, Black and Hispanic caregivers are more likely than either Whites or Asians to say so, as are caregivers with annual household incomes under $15,000.

Again, while overall only a modest percentage of all caregivers report that they have suffered any physical or mental health problems as a result of caregiving, such problems are cited much more frequently by Level 5 caregivers than by persons providing lower levels of care, by women than by men, and by caregivers aged 50-64 than by younger caregivers. Additionally, more than half of Level 5 caregivers find caregiving emotionally stressful, in contrast with one in four caregivers overall. Women are more likely to experience emotional stress than men, and persons caring for someone with dementia are more likely to report that caregiving is emotionally stressful for them than those who are not.

Not surprisingly, utilization of supportive services available in the community, such as home-delivered meals, adult day care, or personal care/nursing services, is correlated with need, with Level 5 caregivers more likely to be using such services than Level 1 caregivers. Service utilization rates are lowest among Asian caregivers, for reasons that are unclear. Very few caregivers cited cost or "bureaucracy" as a barrier to service utilization. When asked what kinds of help, information, or support they would use, or would have used, a high percentage (38%) said they didn't know, and 19 percent said they didn't need any (additional) help. The most frequently cited need, however, was for free time, a "break" from caregiving, or time for one-

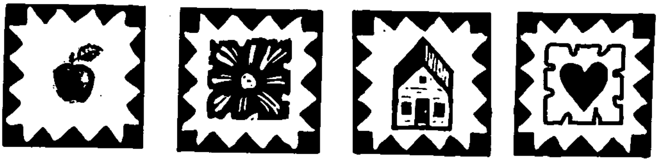




self—particularly among Level 5 caregivers, those caring for someone with dementia, and primary caregivers.

This study suggests that family caregiving in the United States is prevalent and a normative experience that caregivers by and large accept as a necessary responsibility, and that they provide such care for the most part without many complaints or a perception that they lack access to services they might need. The findings also suggest, however, that the impact of caregiving on caregivers' lives varies considerably by the type and amount of care required and provided, by race/ethnicity, and also by other demographic factors such as age. More research is needed on the direct and indirect financial contributions of caregivers, and on how services provided are paid for. With the projected increase in the minority elderly population in the future, it will also be increasingly important to better understand the needs and experiences of minority caregivers. The present study has made a start in this direction.

Clearly, there is a segment of the caregiving population that provides very intense care that can involve extensive personal and financial sacrifice, as well as physical and/or emotional stress. Providing an average of more than 56 hours of care per week and assisting extensively with both IADLs and ADLs, Level 5 caregivers report spending more out-of-pocket on caregiving than caregivers of any other level, and close to one-third of them say they have experienced physical or mental health problems as a result of caregiving. These caregivers have also made more extensive work-related adjustments than caregivers providing less intense care. Three in four of them have made at least some change in their work life, 30 percent have had to give up work entirely, and 26 percent report having had to take a leave of absence due to caregiving responsibilities. Though a relatively small proportion of all caregivers, Level 5 caregivers would be appropriate candidates for intervention.



Appendix/Methodology

The Samples

Two samples were used to conduct the survey. The first was a fully-replicated, stratified, single-stage random-digit-dial (RDD) sample of U.S. telephone households generated in-house by ICR. The supplemental sample was extracted from ICR's EXCEL Omnibus Service, and included individuals who had previously identified themselves as Hispanic, Black, or Other Race. All respondents were known to be English-speaking because they had been previously so identified by ICR. (Resources to conduct telephone interviews with non-English speaking Americans were not available.) The supplemental sample was used to oversample by race for Black, Hispanic, and Asian caregivers. Because the EXCEL Omnibus Service uses a sampling model that is similar to the one in the RDD sampling model, the racial/ethnic oversamples extracted from that source are similarly representative of U.S. telephone households within these racial/ethnic groups.

In total (both samples), 1,509 telephone interviews were conducted, all in English and averaging 20 minutes in length. The statistical margin of error for a sample of this size is plus or minus 2.52% at the 95% confidence level. This means that on a question answered by all 1,509 people, it is 95% certain that the total population would fall within 2.52 percentage points of the actual finding. The sampling error widens on questions answered by smaller groups of respondents.

The RDD sample yielded 754 interviews (consisting principally of interviews with Whites) that can be said to be accurate to within +/- 3.58% at the 95% confidence level. By race/ethnicity, the samples, and the 95% confidence interval for each, break out as follows:

Racial/Ethnic Category	Sample Size n	95% Confidence Level
White (non-Hispanic)	623	+/-3.93%
Black (non-Hispanic)	306	+/-5.60%
Asian	264	+/-6.03%
Hispanic	307	+/-5.59%
Other	9	
Total	1,509	

Weighting of the Findings

To reflect the actual proportion of racial/ethnic groups in the U.S. population, all survey data were weighted using incidence levels derived from the RDD sample and U.S. Census projections. All findings reported are weighted so that they can be projected to U.S. telephone households with an informal caregiver, as defined for purposes of this survey.

Of an estimated 96,600,000 U.S. telephone households, the incidence of caregiver households was determined to be 23.2%, or 22,411,200 households. Frequencies shown in the tables in this report refer not to sampled caregivers, but to the U.S. population of caregivers, and must be multiplied by 10,000 to obtain accurate household projections nationwide. For example, the number 2,241 (the estimated number of U.S. caregiving households) is equivalent to 22.4 million households.

Weighted estimates of caregiver households by racial/ethnic group, together with their population percentage of all caregiver households, are as follows:

Racial/Ethnic Category	Weighted n	Population Percentage
White (non-Hispanic)	18,287,539	81.6
Black (non-Hispanic)	2,375,587	10.6
Asian	403,402	1.8
Hispanic	1,053,326	4.7
Other	291,346	1.3

Factor Analysis

A factor analysis was conducted to determine which variables are most closely associated with the intensity, level of difficulty, or amount of wear and tear involved in informal caregiving.

Factor analysis is a statistical technique used to identify the underlying structure within a set of variables. It is used to reduce a large number of variables to a smaller set of factors that greatly simplify the description of the data and aid in its interpretation. Factor analytic techniques generate a smaller set of variables, called "factors," that represent the underlying dimensions of the original (larger) set of variables, based on the degree of association (or correlation) among them. Each factor is not a single, directly measurable entity, but rather a construct derived from the relationships among the original set of variables.

In this study, five questions were asked to assess different aspects of the amount of care, intensity of care, or degree of difficulty involved in informal caregiving, based on caregivers' reported experiences. These five questions concerned (1) the caregiver's estimate of the number of hours of care he/she provides per week; (2) the type of care he/she provides (the numbers of IADLs and ADLs he/she assists with); (3) the amount of physical strain experienced by the caregiver (a subjective measure); (4) the amount of emotional stress experienced by the caregiver (a subjective measure); and (5) the amount of financial hardship experienced by the caregiver (a subjective measure). Coding of these questions is described as follows:

Variables	Response Categories
Hours of care per week	1 = 0 to 8 hours 2 = 9 to 20 hours 3 = 21 to 40 hours 4 = 41 or more hours
Types of care provided	1 = 0 IADLs/0 ADLs 2 = 1 IADL/0 ADLs 3 = 2+ IADLs/0 ADLs 4 = 1 ADL (with or without IADLs) 5 = 2+ ADLs (with or without IADLs)
Physical Strain	1 Not at all a strain 2 3 4 5 Very much of a strain
Emotional Stress	1 Not at all stressful 2 3 4 5 Very stressful
Financial Hardship	1 No hardship at all 2 3 4 5 A great deal of hardship

Only a single factor emerged from a factor analysis of these five items. It can be interpreted as a measure of intensity of care, which consists of the number of hours of care provided per week coupled with the type of care provided. (Physical strain, emotional stress, and financial hardship do not load on this factor.)

Level of Care Index

Based on the outcome of the factor analysis, a Level of Care Index consisting of five points was created. This enabled each caregiver to be assigned for analytic purposes to one of the five levels, based on the intensity of caregiving provided.

The two variables on which the Index is based are "hours of care per week" (four levels, as shown above) and "types of care" (collapsed into four levels), as shown below:

Variables	Response Categories
Hours of care per week	1 = 0 to 8 hours 2 = 9 to 20 hours 3 = 21 to 40 hours 4 = 41 or more hours, or "constant care"
Types of care provided	1 = 0 IADLs/0 ADLs or 1 IADL/0 ADLs 2 = 2+ IADLs/0 ADLs 3 = 1 ADL (with or without IADLs) 4 = 2+ ADLs (with or without IADLs)

Each caregiver's score on the two variables was summed, resulting in his/her assignment to one of seven levels (2, 3, 4, 5, 6, 7, or 8). Examination of the frequencies suggested that collapsing the seven levels into five, as shown below, would result in a useful and not very skewed distribution of caregivers across levels, with Level 1 being the least intense level of caregiving, and Level 5 being the most intense.

	Combined Score	Resulting # of Caregivers (unweighted)	Percent of Sample
Level 1	2, 3	389	25.8%
Level 2	4	208	13.8%
Level 3	5	287	19.0%
Level 4	6, 7	355	23.5%
Level 5	8	185	12.3%
Missing		85	5.6%

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The CHAIRMAN. Dr. Arno, please proceed. I am going to step out for 90 seconds, but Senator Reed will remain, and I will come right back.

Please proceed.

STATEMENT OF PETER S. ARNO, PROFESSOR, ALBERT EINSTEIN COLLEGE OF MEDICINE, MONTEFIORE MEDICAL CENTER, BRONX, NY

Mr. ARNO. Good morning, Mr. Chairman and members of the committee. My name is Peter Arno, and I am health economist and professor in the Department of Epidemiology and Social Medicine at Montefiore Medical Center and Albert Einstein College of Medicine in the Bronx. It is a privilege to be here today.

The work that I will present this morning has been done in collaboration with Carol Levine, who is the director of the Families and Health Care Project at the United Hospital Fund of New York, whose video you saw a few moments ago.

I am sure that most people here are aware of the fact that more than a year ago, we surpassed the $1 trillion mark in health care spending in the United States. Because of the vast scope of health care and its political as well as personal importance, more intense scrutiny has probably been devoted to this sector of the economy than any other.

Yet a vital dimension of this far-reaching enterprise has never been calculated in economic terms. This is the contribution made by unpaid family members and friends to the care of ill or disabled persons, especially in cases of chronic or terminal illness or serious disability.

To fill this gap, we have engaged in a study which I will describe which estimates the economic value of informal, unpaid caregiving. But before I do that, let me just say a few words about why we did this study.

First, informal caregiving is generally not acknowledged to be of economic value in part because the burden is borne mainly by family members and friends outside the market economy. Personal bonds and familial obligations lead people to become and remain caregivers despite the sacrifices they may have to make. The costs and the value provided thus remain socially invisible. Imputing a value to the extraordinary level of caregiving described in this study may be novel, but it provides a tangible and crucial measures of the massive and vulnerable base on which America's chronic health care system rests.

In the current economic environment, Government programs, private insurers, managed care organizations and other payers are trying to reduce formal, paid services. Cost-cutting in many instances is really just cost-shifting, adding to the responsibilities of individuals and families. Fewer hospital admissions, shorter lengths of stay and high-tech medical procedures done at home are only the most obvious manifestations of this trend.

The major question we posed in this study was what is the annual dollar value of unpaid caregiving provided by family members, friends and relatives to the chronically or terminally ill. In other words, what would this care cost if it were treated as employment paid for by health and social service programs?

In Figure 1, which is the figure in the center here, there are two sets of estimates on the number of caregivers on the left-hand side. We have estimates of 9.5 million recipients of caregiving as measured by the SIPP survey, which is the Survey of Income and Program Participation, and 9.2 million based on the Health Interview Survey. On the right-hand side of the chart, we have three separate estimates of the number of caregivers, ranging from 23.6 million to 27.4 million caregivers. Thus, the mid-range estimate would be 25.5 million caregivers in 1996.

Because our estimate of caregiving prevalence is crucial to this study, I would like to spend just a moment on how we derived this figure. In Figure 2, we have illustrated one approach we used to estimate the current number of caregivers. If you make the reasonable assumption that the ratio of caregivers to care recipients was the same in 1996 as in 1986, the number of caregivers in 1996 is easily derived. As illustrated here, for 1996, there were 24.1 million.

In the next figure, we used an entirely different dataset, the National Survey of Families and Households, which was also a national probability sample of the U.S. population. This survey, conducted in 1987–88 asked specifically about the number of persons who were caregivers. By making the assumption that the proportion of caregiving in the population, by gender was the same in 1996 as it was in 1987–88, we can again derive reasonable estimates for the number of caregivers in 1996. This gave us our upper-bound estimate of 27.4 million, in the bottom right-hand corner, for 1996.

Let me just make a brief footnote. If you look at the breakdown of male and female, in the right-hand column, 11.3 million caregivers were men, 16 million were women, totaling 27.4 million caregivers in 1996. This suggests that approximately 40 percent of caregivers are men, contrary to the popular notion that the vast majority of all caregiving is done by women.

Basically, using a variety of different datasets and very conservative assumptions, we produced estimates of caregiving that fall within a very narrow range, from 23.6 million to 27.4 million caregivers in 1996.

Our second task was to determine how many hours of caregiving is performed by these caregivers. The best estimate we had, which we heard from Ms. Hunt, came from the National Family Caregiving Survey. This survey found than on average, caregivers provided 17.9 hours per week, which was a very conservative figure which we used.

In Figure 4, we can see the distribution of hours per week in this study, with an average of 17.9 hours per week. And if we used our mid-range estimate of the number of caregivers and 17.9 hours per week, this would yield approximately 24 billion hours of caregiving nationwide.

The final task in deriving the economic value of caregiving would be to determine what would be an appropriate wage rate to be used to replace informal caregiving, and again, to be as conservative as possible, we used the lowest legal wage rate, the minimum wage, which is currently $5.15 per hour. For an upper bound estimate, we used the national wage rate for home health aides, which is

$11.20 an hour. Averaging these together, we came up with $8.18 per hour. If we apply this wage rate to 17.9 hours per week, this yields the economic value of informal caregiving, the figure in the center, which ranges from $113 billion to $286 billion per year, with our best mid-range estimate of $194 billion per year. From another perspective, these figures suggest the average care recipient received informal caregiving services worth approximately $21,000 per year.

In the final figure, Figure 6, just to put a little perspective on this, the $194 billion in yellow is our mid-range estimate, and it dwarfs the $30 billion in paid home care on the left; it is about 2–1/2 times the size of nursing home care, the next column over, and in fact, the $194 billion is equivalent to nearly 20 percent of total national health care spending, making family caregivers the largest providers of long-term care.

In conclusion, focusing on the economic value of caregiving, especially in a market-driven health care system, we hope will raise professional and policymakers' awareness of the importance of family caregiving to the smooth functioning of the system, especially as more care moves from hospitals and institutions to homes and communities. Political pressures are mounting to curb the growth of formal home care expenditures, which have grown dramatically in recent years. However, efforts to constrain home care expenditures can only exacerbate the burden already felt among informal caregivers. We should be seeking ways to support and strengthen informal caregivers, rather than adding new and overwhelming responsibilities to the burdens they have already assumed.

Finally, I would like to commend this committee for its willingness to open up the public discourse on this vulnerable and neglected pillar of our Nation's chronic health care system. By taking leadership on this issue, the committee can help to reframe the issue of family caregiving, which has generally been understood only at the micro level, where individual caregivers attempt to cope with the stresses and responsibilities of caregiving to the macro level of the health care system, which must find more effective and meaningful ways to support and sustain the family caregivers of our country.

Thank you.

[The prepared statement of Mr. Arno follows:]

Statement of Peter S. Arno, Ph.D.

Professor
Department of Epidemiology and Social Medicine
Montefiore Medical Center/Albert Einstein College of Medicine
111 East 210 Street
Bronx, New York 10467
Tel: (212) 652 4631
parno@montefiore.org

before the

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Washington D.C.
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Introduction

Good morning, Mr. Chairman and members of the Committee. My name is Peter Arno and I am a health economist and Professor in the Department of Epidemiology and Social Medicine at Montefiore Medical Center and Albert Einstein College of Medicine in the Bronx. It is a privilege to be here today.

The work that I will present this morning has been done in collaboration with Carol Levine, who is the Director of the Families and Health Care Project at the United Hospital Fund of New York.

I am sure that most people here are aware of the fact that more than a year ago we surpassed the $1 trillion dollar mark in health care spending in the United States. Because of the vast scope of health care and its political, as well as personal, importance, more intense scrutiny has probably been devoted to this sector of the economy than any other.

Yet a vital dimension of this far-reaching enterprise has never been calculated in economic terms. And this is the contribution made by unpaid family members and friends to the care of ill or disabled persons, especially in cases of chronic or terminal illness or serious disability. To fill that gap, we have engaged in a study which I will describe, which estimates the economic value of informal, unpaid caregiving. But before I do let me just say a few words about why we did this study:

Firstly, informal caregiving is generally not acknowledged to be of economic value in part because the burden is borne mainly by family members and friends outside the market economy. Personal bonds and familial obligations lead people to become and remain caregivers, despite the sacrifices they may have to make. The costs – and the value provided – thus remain socially invisible. Imputing a value to the extraordinary level of caregiving described in this study may be novel, but it provides a tangible and crucial measure of the massive and vulnerable base on which America's chronic health care system rests.

In the current economic environment, government programs, private insurers, managed care organizations, and other payers are trying to reduce formal, paid services. Cost cutting is in many instances really just cost shifting, adding to the responsibilities of individuals and families. Fewer hospital admissions, shorter lengths of stay and high-tech medical procedures done at home are only the most obvious manifestation of this trend.

Clearly, some aspects of families' contributions to patient care are impossible to measure such as the comfort of the patient cared for by intimates rather than strangers or the value of care provided at home rather than in a hospital or nursing home. However, other aspects of caregiving can be expressed quantitatively, which I will now describe.

Methodology

The major question that we posed is what is the annual dollar value of the unpaid caregiving provided by family members to relatives who are chronically or terminally ill or seriously disabled? In other words, what would this care cost if it were treated as employment paid for by health and social service programs?

In order to answer this question reliably, two key questions were analyzed with information available in large-scale national data sets.

1) What is the national prevalence of informal caregiving?
2) What is a reasonable market wage that would have to be paid to replace informal caregiving?

What is the national prevalence of informal caregiving? We probably spent the most time trying to answer this question. We reviewed a number of different datasets looking for the answer to this question. Perhaps the most well-known source of data and published studies on the prevalence of disability and homecare in the U.S. comes from National Long Term Care Survey. Unfortunately, this survey is confined to the elderly Medicare-enrolled (>65) population. Due to its focus on the chronically disabled elderly, we chose to use more general samples of the U.S. population found in the Survey of Income and Program Participation (SIPP), conducted by Census Bureau and the National Survey of Families and Households (NSFH) for this analysis.

Figure 1: Estimated Number of Care Recipients and Informal Caregivers, U.S., 1996

Here we see two sets of estimates of the number of caregivers and care recipients. On the left, we have recent estimates on the number of persons with serious disabilities who are the recipients of caregiving — 9.5 million persons as measured by the SIPP and 9.2 million based on the Health Interview Survey. On the right hand side of Figure 1 we have three separate estimates of the number of caregivers ranging from 23.6 million to 27.4 million caregivers. Thus, the mid-range estimate would be 25.5 million caregivers in 1996. Because our estimate of caregiving prevalence is crucial for this study I would like to show you how we derived these figures.

Figure 2: Projected Number of Caregivers (Based on SIPP)

In Figure 2 we have illustrated one approach to estimating the current number of caregivers. The SIPP survey asked about both care recipients and caregiving only in 1986. The more recent survey asked only about the number of persons who needed personal assistance, defined as needing assistance with >1ADL or IADL over an extended period of time. If you make the reasonable assumption that the ratio of caregivers to care recipients was the same in 1996 as in 1986 then the number of caregivers in 1996 is easily derived. As illustrated here the number for 1996 is 24.1 million.

Figure 3: **Projected Number of Informal Caregivers (Based on the National Survey of Families and Households)**

In Figure 3 we used an entirely different data source, the National Survey of Families and Households, which was also a national probability sample of the US population. This survey was conducted in 1987-88 and asked specifically about the number of persons who were caregivers. By making the assumption that the proportion of caregiving in the population by gender was the same in 1996 as it was 1987-88, we can again derive reasonable estimates for the number of caregivers in 1996. This gave us our upward bound estimate of 27.4 million caregivers for 1996.

Thus, we felt satisfied that with entirely different datasets and conservative assumptions we produced estimates of caregiving prevalence that fell within a fairly narrow range — from 23.6 million to 27.4 million caregivers in 1996.

Our second task was to determine the number of hours of weekly care provided by informal caregivers. Here again we looked at a number of different studies, but these were mostly small studies of specific diseases such as Alzheimer's or Parkinson's Disease. The best overall estimate was found in the 1996 National Family Caregiving Survey conducted by the National Alliance for Caregiving and the American Association of Retired Persons. This survey found that on average, caregivers provided 17.9 hours of caregiving per week.

Figure 4: **Distribution of Caregiving Hours Per Week**

In Figure 4 you can see the distribution of hours per week in this study. In part we chose the average figure of 17.9 hours per week, because it was based on a nationally representative sample and to be conservative, it was lower than almost every other study we examined. Applying this weekly figure to our mid-range estimate of the number of estimated caregivers yields approximately 24 billion hours of caregiving per year, nationwide.

Figure 5: **Economic Value of Informal Caregiving, US 1996**

Our final task was to determine what is the appropriate wage rate that would have to be paid to replace informal caregiving. Again, to be as conservative as possible we used the lowest legal wage rate, the minimum wage, which is currently $5.15/hour. For our upper bound estimate we used the national wage rate for home health aides which is $11.20/hour according to the Bureau of Labor Statistics. And averaging these rates together, our mid-range estimate is $8.18 per hour. In this figure we applied these three different wage rates to our lower, middle and upper estimates for the number of caregivers, holding the number of hours of caregiving constant at 17.9 hours per week. This yields a range of economic value of informal caregiving from $113 billion to $286 billion dollars per year, with our best, mid-range value at $194 billion dollars per year. From another perspective, these figures suggest that the average care recipient receives informal caregiving services worth approximately $21,000 per year.

Figure 6: **Paid Home Care, Nursing Home Care, Informal Caregiving and National Health Expenditures**

In Figure 6 we have tried to put our best, mid-range estimate of the economic value of caregiving into some perspective. The $194 billion for caregiving dwarfs the $30 billion in paid home care and is about 2 1/2 times as large as the $79 billion that what we spend on nursing home care. In fact, our estimate of $194 billion for caregiving is equivalent to approximately 19% of total national health care expenditures. Informal caregiving is not counted as part of national health care expenditures, but if it were, the trillion-dollar figure would rise by nearly $200 billion.

Conclusion

Families have been undervalued as contributors to the health care economy for many reasons. They do not see themselves primarily as caregivers but as parents, spouses, partners, or daughters or sons. They do not expect to be paid for their work, which they provide out of love, duty, obligation, or lack of alternatives. If they find their tasks rewarding it is because they develop new strengths and skills or deepen their relationship to the care recipient. There are serious costs in terms of physical and emotional strain on caregivers, in addition to financial costs.

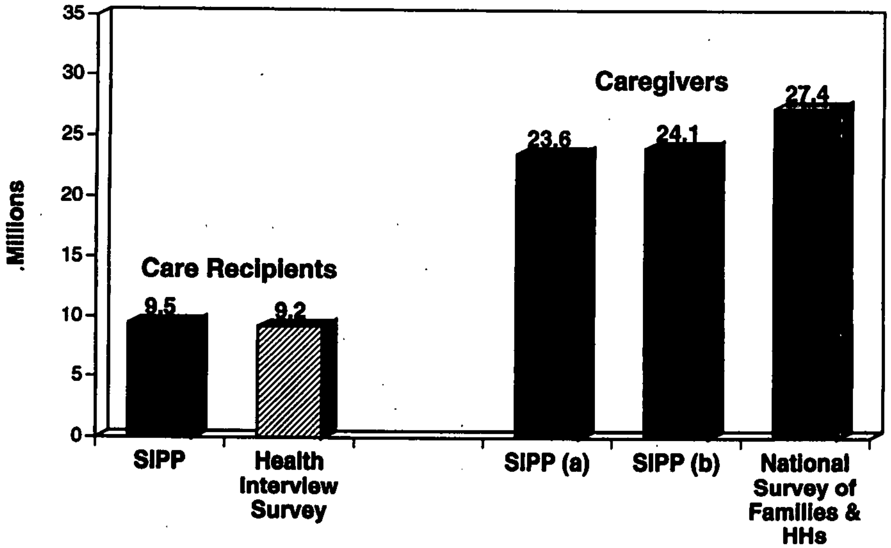
Focusing on the economic value of caregiving, especially in a market-driven health care system, we hope will help raise professional and policy makers' awareness of the importance of family caregiving to the smooth functioning of the system, especially as more care moves from hospitals and institutions to homes and communities. Political pressures are mounting to curb the growth of formal (paid) home health care expenditures which have grown dramatically in recent years. Between 1990 and 1996 total homecare expenditures rose more than three times faster than for hospital or physician services, for example. However, efforts to constrain homecare expenditures can only exacerbate the burden already felt among informal caregivers. We should be seeking ways to support and strengthen informal caregivers rather than adding new and overwhelming responsibilities to the burdens they have already assumed.

Finally, I would like to commend this Committee for its willingness to open up the public discourse on this vulnerable and neglected pillar of our nation's chronic health care system. By taking leadership on this issue the Committee can help to re-frame the issue of family caregiving, which has generally been understood only at the micro level, where individual caregivers attempt to cope with the stresses and responsibilities of caregiving to the macro level of the health care system which must find more effective and meaningful ways to support and sustain the family caregivers of our country.

Thank you.

Figure 1.

Estimated Number of Care Recipients and Informal Caregivers, U.S. 1996



Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1998

Figure 2.

Projected Number of Caregivers, 1996
(Based on SIPP, 1986 & 1994-95)

	1986 (thous.)	1996 (thous.)
No. Caregivers (>15 years)	20,891	24,117
Persons Needing Assistance with >1 ADL or IADL	8,206	9,473

Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1998

Figure 3.

Projected Number of Informal Caregivers to >18 Population, 1996
Based on Data from the National Survey of Families and Households, (Millions)

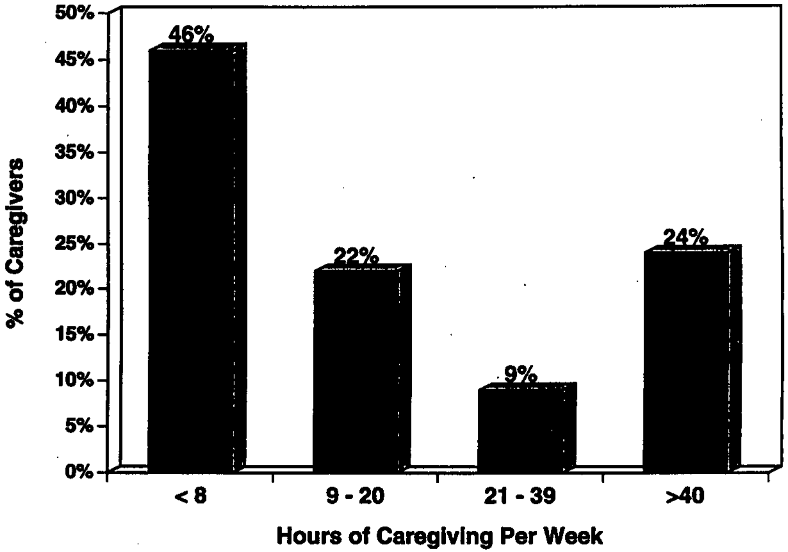
	Number of Caregivers 1987-88	U.S. Population 1987-88	Caregivers/ U.S.Population 1987-88	U.S. Population 1996	Projected Number of Caregivers 1996
Male	10.3	82.7	0.125	90.7	11.3
Female	14.8	90.2	0.164	98	16
Total	25.1	172.9	0.145	188.8	27.4

Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1996

Figure 4.

Distribution of Caregiving Hours Per Week

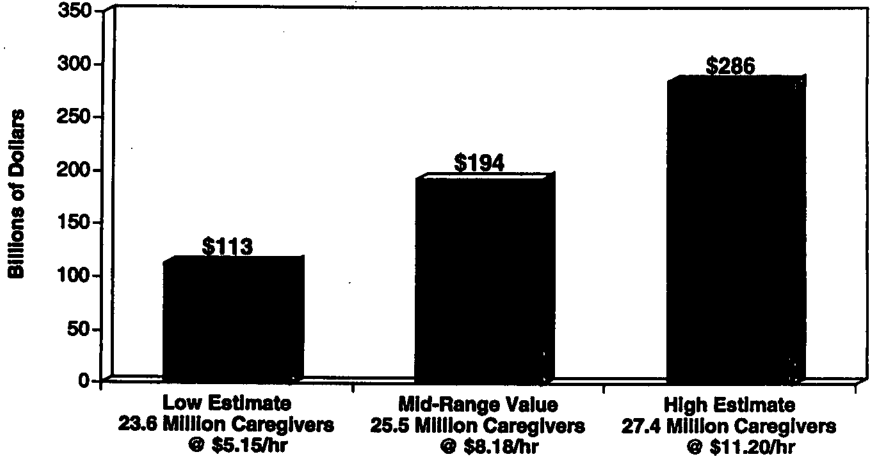
National Family Caregiving Survey
Average Hours Per Week = 17.9; N = 1,509



Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1998

Figure 5.

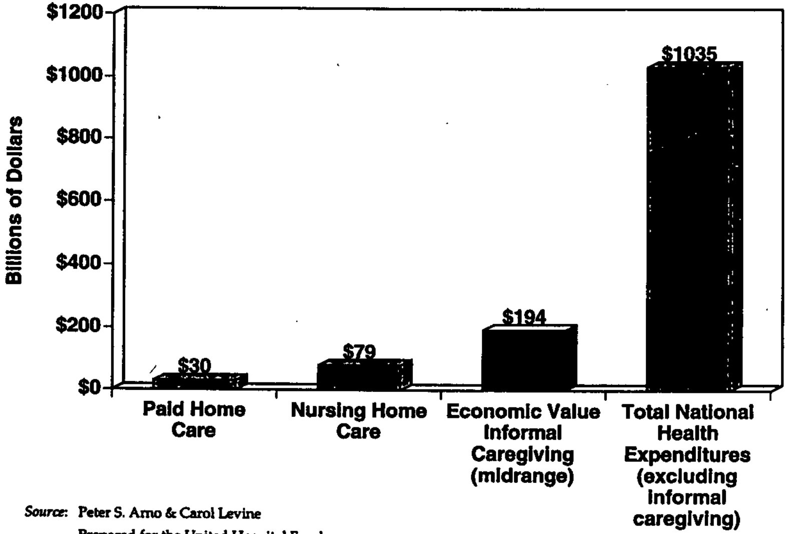
Economic Value of Informal Caregiving, US 1996



Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1998

Figure 6.

Paid Home Care, Nursing Home Care, Informal Caregiving & National Health Expenditures, U.S., 1996
(Billions of Dollars)



Source: Peter S. Arno & Carol Levine
Prepared for the United Hospital Fund
April 1998

The CHAIRMAN. We thank you very much. Obviously, you have done a study in an area that is very much an interest of this committee, as I indicated in my opening comments. On the other hand, I do not want to overemphasize just the economic contribution, because I think there is a great deal to be said about, hopefully, the development of a communitarian spirit within our society where there is some feeling of doing things out of love and concern as opposed to just the economic consequences of those things happening. But on the other hand, there is a very important aspect to understanding the economic impact that it has, because obviously, it helps us to quantify the contribution that this family caregiving does give.

I am going to start with you, Ms. Hunt. It seems that families are scattered around the Nation more than ever, with our mobile society. It strikes me that we need to think ahead about families who will be as likely to live in different cities as they are to live in the same city. It strikes me that these family members face unique challenges in trying to be concerned about elderly family members.

What do we know about long-distance caregiving, and what, if anything, is in place to help these caregivers?

Ms. HUNT. The National Caregiver Survey that we did indicated that about 11 percent of caregivers are 1 hour or more away from the care recipient. There are special issues that they face. In particular, they often have great difficulty setting up support services for the older person, and they take time off work as vacation time or sick leave to go and make arrangements to set these services up, and the services logistics fall apart when they get back home. They also have family issues a lot of times, such as "you are the one who is not here, doing this, so what do you know?" Plus, they have difficulty trying to reach and get information from the family doctor or the home health agency which is taking care of the older person but which does not want to deal with somebody from out-of-town.

So long distance caregivers do face some unique circumstances. Sometimes family members doing long-distance caregiving will turn to geriatric care managers who can be in place in the location where the older person is. That is not a solution for everybody, though. Care managers generally tend to be relatively expensive, so it is really a solution more for people who can afford it, and maybe not on an ongoing basis.

Long-distance caregivers could really use a some system that allows somebody to be there, almost like a proxy, onsite as the caregivers eyes and ears, perhaps not quite as rigorous or structured as a geriatric care manager, but somebody who is able to keep an eye out for the older person. It is a new concept that is being developed but one that would be particularly valuable for long-distance caregivers.

I think Mrs. Carter's idea of having a care manager in each community, so that the long-distance caregiver could come and find out what resources are available, would be really helpful.

The CHAIRMAN. Dr. Arno, if we now know much more about the economic value of family caregivers, and that they are saving our Nation's health care system considerably, what do we know about the cost which it exists on these caregivers? There was a study conducted by MetLife which you are probably familiar with that identified loss in productivity from caregivers, ranging from $11.4 billion to $29 billion each year. Are there data tabulating health care costs for overburdened caregivers?

Mr. ARNO. Actually, I think you should direct that question to Ms. Hunt, since it was their group that commissioned that study.

The CHAIRMAN. I will ask her to comment when you are done, then.

Mr. ARNO. OK. I am actually not aware of any other studies besides this one that look at the indirect—in fact, I do not know of any study that looks at the economic value of caregiving at all, and that is one of the reasons why we conducted this study.

Just one reflection on your comment. Our purpose in estimating the economic value of caregiving was not to say that this value need be paid out of tax dollars necessarily, but rather to demonstrate the magnitude of the caregiving effort that is going on in this country. That was the first and foremost reason and objective of this study.

The CHAIRMAN. I do not want to detract from that; if I said anything implicit, I did not mean to do that.

Mr. ARNO. No, I did not think you did. But just to follow up, any other segment of our health care system that drew the equivalent of 20 percent of our health care system, or $200 billion, would be receiving far more attention in our country than does informal caregiving, and that is the reason we did the study. And yes, some resources should be made available—public resources and private resources—economic resources should be made available to make the system work better, and with growing labor force participation by women and the aging of our population, we are going to place further and further strains on our ability to provide caregiving, and we need to figure out ways to support that effort.

The CHAIRMAN. Do you want to add to that, Ms. Hunt?

Ms. HUNT. Yes. The National Alliance did the study for MetLife, looking at the costs to employers that you just mentioned, and what I can add is that we are just beginning a study to look at the cost to employed caregivers, that is, what it costs employed caregivers in terms of opportunity costs passed up, promotions that were passed up over a career, plus retirement issues—how much money did caregiving cost you that then was not available for you in terms of retirement. MetLife is funding this study, but we are just now getting started on it.

The CHAIRMAN. Well, we certainly know the impact of women who leave the work force for children; they make probably 25 percent less than what a male makes. If a woman is in the work force continuously and never takes time out for family, she makes 97 percent of what a male makes, but for a woman who is in and out of the work force for family reasons I believe would make something like 75 percent.

One last question for Dr. Arno. I guess what I am saying here is that you would have those consequences for women or anybody who takes time out of the work force, then, to care for an elderly relative or family caregiving, in that respect.

We worry here in Congress about the baby boom generation, as I said to Mrs. Carter. What do you see in the future for a generation that will live much longer and who have fewer children? I am really asking you if, in your economic studies, you have made any projections on that.

Mr. ARNO. We have made some projections and I could provide the committee with those at a future time. Clearly, the caregiving burden will grow as the aging of the population grows, but caregiving and the recipients of caregiving are not just the elderly, although it is the majority, and efforts must be made to ensure that that will continue in the future for all segments of the population. But again, now is the time to move on this because with the aging of the population, that will certainly increase the burden, and I think we have time to deal with it, but we must move proactively at this time.

The CHAIRMAN. Senator Reed.

Senator REED. Thank you, Mr. Chairman.

Ms. Hunt, in your testimony, you alluded to the fact that very few people do any planning for their own caregiving; but it also seems that there are not lots of places to go to get help to do that planning. Would you comment on that dilemma?

Ms. HUNT. Yes, it is a dilemma. Actually, one of the issues that we are grappling with is how to begin to get some information out, particularly because our study was of baby boomer women. The second half of the Equitable Foundation project is going to reach women on planning for their own long-term care through women's organizations, for example, as one mechanisms and employer groups.

I actually think, in terms of broader, gender-neutral caregiving, that getting information out through employers would be a really effective way, especially if you tied long-term care information in with retirement information. We know there is a big push with the SAVER Summit and other initiatives to make Americans, particularly baby boomers, understand the need to save for retirement. Well, while they are saving for retirement, they have to remember that that pot of money could be taken away by long-term care needs if they do not do something about it, if they do not plan for that.

As I mentioned in my testimony, I think one good beginning option is the kind of bill that is going to be introduced to provide some tax incentives for people for premiums for long-term care insurance.

I also think we need to start making baby boomers aware of the issue of long-term care—not that they may need it, but they almost certainly will need it, which is something that people my age typically never think about. So you need to make them aware of the fact that they probably will need it, and then give them helpful hints about where to turn for information about long-term care, both the financial side and the services side.

Senator REED. Thank you.

You also pointed out in your testimony that most middle-aged people assume that Medicare and Medicaid, Federal programs or Federal-State programs, will be the source of their long-term care, and I think that that underscores the reliance that Americans place on these two programs particularly. As we debate the future of Medicare and Medicaid, I sense that we have to be much more aware of and explicitly consider the impacts on long-term care, and that is something that I hope all of my colleagues will do.

Would you agree with that notion that we cannot look at Medicare and Medicaid in isolation as just two Federal health care programs, that they have to be looked at in the context of long-term care?

Ms. HUNT. Oh, I think there is no question that that is the case. I think the other thing that the Federal Government could do, though, is let people know that these programs are really not set up to deal with long-term care, that you cannot expect to get extensive home care through Medicare, and that Medicaid will only pay for you if you have spent down. People do not know that. They think, oh, Medicare and Medicaid will take care of me when I turn 65. That cuts across all age groups, all income levels, and gender in this country, that misunderstanding. I think that if people knew that you are not going to be able to stay home and get home care unless you have somehow saved for that or your kids pay for you, I think they would start saving earlier.

So there is no question that they are inextricably entwined: those three things, Medicare, Medicaid and long-term care, and that is not generally recognized.

Senator REED. Dr. Arno.

Mr. ARNO. Just a brief additional comment. I think you raise a larger issue than even informal caregiving, but I think it is a crucial one—that one of the biggest problems in long-term care in the United States is the fragmented nature of our health care system. One of the goals that I think we should move toward is integrating Medicare and Medicaid in terms of long-term care—some services comes under one entitlement, and part under another. There is no real good solution other than integrating financing mechanisms to take care of long-term care.

Senator REED. Thank you. Dr. Arno, perhaps another aspect of that is the private long-term health care insurance. You have probably looked at that or considered it. Might you comment on that for us?

Mr. ARNO. I am not really an expert on that. I would just say that as far as I am aware, the premiums for long-term care insurance are so prohibitive, and there have been a number of congressional reports about this by the GAO and others, that it is not really accessible to the vast majority of people in this country who could use it.

Senator REED. Thank you.

Ms. HUNT. Can I add something to that?

Senator REED. Yes, please, Ms. Hunt.

Ms. HUNT. That may be true when people are older, but if you start buying it when you are a baby boomer say, 45 to 50 years old, the premiums are not nearly so high.

Senator REED. Can I ask one other question, Ms. Hunt. I was fascinated in your report by the different cultural patterns of caregiving, that different groups have different relationships and different ways they approach it. I do not know what other general comments you may want to make, but specifically, are you using this in some way to help reach different cultural groups in different ways, different information—how are you using this? I was fascinated by the fact that the black community has a higher ratio of a certain kind of caregiving, and the different approaches.

Ms. HUNT. I didn't mention this in my testimony, the National Caregiver Survey oversampled the total U.S. population to get a representative sample of black caregivers, Asian American caregivers and Hispanic caregivers in addition to the total population. Those data are available and have been available since last summer when we came out with the study.

The Alliance has not done any analysis focusing on that, but there are people to whom we have given the data who are focusing specifically on how can we do a better job of reaching the Hispanic caregiver, or the implications of the data for Asian caregivers, for example.

In particular, as you highlighted, the black community showed a much higher incidence of caregiving as well as caregiving particularly for people who were non-relatives, and also, even though their income levels were lower in general, a higher percentage of their money went to out-of-pocket spending. So, for example, the $171 a month is an average across the population as a whole. For black caregivers, it was even higher. So a higher percentage of their income is going to help pay for the care recipients' out-of-pocket needs.

Senator REED. To whom have you given this information?

Ms. HUNT. Universities; some universities have asked for it.

Senator REED. I think it would be very useful if we got that kind of analysis, too, so perhaps at the staff level, we could just see who could be doing it; that would be very helpful.

Ms. HUNT. Oh, certainly.

Dr. Arno.

Mr. ARNO. Just quickly, I want to respectfully disagree with my co-panelist. I do not think we should leave here thinking that private, long-term care insurance is going to solve our problems. While it may be true that when you are in your 40's and 50's and in the peak of your wage-earning years, you can afford private insurance, that is fine, but as you get older and your income drops—that is when you are less able to afford the private insurance premiums that become prohibitive. So it is not a good long-term solution.

Senator REED. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much.

I have just one final comment in regard to that. I do not know of Members of Congress who promoted that as a solution to our long-term health care problem, but I think we would encourage people who could save that way through insurance like that, because to the extent to which we could encourage it, it is going to take a burden off of Medicare and Medicaid in future years. So we would only see it as a partial solution and probably not even as a complete solution for the people who might buy it, particularly if they cannot afford the inflation escalators that are present in some policies and not in others, and obviously more expensive.

I am going to dismiss this panel, but remember that you may get some questions in writing.

I am not going to do justice to the introduction of the next panel because of our time constraints, because they are really outstanding people and deserve a long introduction. Please come to the table while I am reading.

Our first witness will be Carol Levine, who is director of the Families and Health Care Project at the United Hospital Fund in New York. She will be releasing a new report today, and we thank her for doing that at this hearing.

We will also hear from Dr. Mary Mittelman, who will discuss her work at the National Institute on Aging Alzheimer's Disease Project, New York University Medical Center.

We will also hear from Carol Weinrod, a registered nurse who works as a complex case manager for Franklin Health, Incorporated. She is also the mother of a child with a congenital disability.

Dr. David Levy is a physician and founder of the Franklin Health Group, a corporate health consulting group with successful case management programs.

Finally, Myrl Weinberg, who currently serves as president of the National Health Council. The Council's membership is a diverse group of over 100 health-related groups.

I would ask you to proceed in the way in which I introduced you, and also, because we might have a vote, I do not think it is going to interfere with your testimony if you stay within the 5 minutes, but I would like to make sure that I am able to hear each of you. I may not be able to ask each of you questions, but I want to be able to actually hear your testimony.

Please begin, Ms. Levine.

STATEMENT OF CAROL LEVINE, DIRECTOR, FAMILIES AND HEALTH CARE PROJECT, UNITED HOSPITAL FUND, NEW YORK, NY

Ms. LEVINE. Thank you, and good morning. My name is Carol Levine, and I am director of the Families and Health Care Project at the United Hospital Fund in New York City. The Fund is a private organization working through philanthropy, research, and program and educational development.

I am delighted to be able to introduce our new report, entitled, "Rough Crossings: Family Caregivers' Odysseys through the Health Care System." The report focuses on transitions— when a patient moves to and from hospitals, nursing homes, rehab units, etc.—and how these transitions affect family caregivers. The main source of information, although not the only one, was a series of six focus groups we held with 56 experienced family caregivers. They were very diverse groups; they included men as well as women and people with many different ethnic and cultural backgrounds, educational levels, family incomes, and ages.

The caregivers ranged in age from 20 to 70, with the majority in their 30's and 40's—a little younger than what we might have expected. Many held jobs, although some had been forced to leave employment to take care of their family member. The care recipients were mostly women between the ages of 60 and 80, and they had multiple serious health conditions. The oldest was 102.

At the beginning of the hearing, you saw three of these caregivers from our focus groups talking about their lack of preparation, their anxiety about taking proper care of their loved one, and the isolation that comes with long-term caregiving.

Here is one more voice which you did not hear. "I had to fight through layers of bureaucracy for 10 days to get a dangerously unstable hospital bed replaced at home. Then, when the bed arrived—without notice, in the evening, when there was no one to help me move him—it turned out to be the wrong bed." This is from a wife who takes care of her 70-year-old husband left quadriplegic and brain-damaged after an automobile accident 8½ years ago.

That voice is mine. Like the caregivers in our focus groups, I am one of the more than 25 million other family caregivers who is struggling with the fragmented, inflexible and increasingly complicated collection of institutions and agencies we call the health care system.

When I joined the United Hospital Fund in October 1996, I had had a long career in health policy and medical ethics, including being awarded a ·MacArthur Fellowship. Nothing in my professional career or my experience as a mother of three children had prepared me to be the caregiver for a severely disabled, brain-injured husband.

Despite the near universality of our experiences, our stories will remain just stories, individual anecdotes, until the health care system begins to change. I believe it is the system that much change, and that is really a potentially revolutionary idea.

Today, the formal health care system expects family caregivers to change, to adapt, to figure out their inflexible and irrational rules, and to deal with the lack of communication and training and follow-up. Even much of the very good self-help literature focuses on coping, figuring out how to help caregivers adapt to an irrational system.

I am all for coping—I do it every day—but it is not the only answer, and I think we really require a change in the health care system, because society is changing, and certainly, financing and delivery are changing.

The United Hospital Fund has taken on my project, which is a very big step for an institution of more than 100 years, which has "Hospital" as its middle name which is now looking at families providing care at home. The fund is aware of the institutions' economic interests as well as humanitarian missions in seeing that family caregivers are supported and can provide the care that their patients needs. As you heard, the Fund commissioned Peter Arno to develop the first systematic estimate of the economic value of informal caregiving. We have prepared a series of guiding principles which are in the report, and we have embarked on an ambitious 3-year, $1.3 million grant initiative to help hospitals in New York change the way they work with family caregivers. Dr. Mary Mittelman, one of my co-panelists, is a recipient of one of those grants.

We cannot meet this challenge alone—no single organization can—so I have some recommendations for our colleagues in health care and for policymakers at all levels.

First—I think this is very well-documented in our report—discharge planning should be a process, not a last-minute, one-time event. It should begin before the patient is ready to go home, and it should have follow-up. Most discharge planning today just focuses on who is paying for what, leaving the caregiver to sort out all the confusing array of medications, machines and instructions.

Second, we have some outlines in our report that we hope will give at least a basis for conversation between the formal caregivers and informal caregivers. But for any aids, any discussion aids or materials to be effective, there must be appropriate services in place and training. For this reason our next recommendation is that a high priority should be given to developing a broader array of programs that support family caregivers.

We think that health care professionals should be assertive advocates for family caregivers and help them negotiate the bureaucracies instead of, as often happens, leaving them on their own. Insurers and their subcontractors should be held to a high standard of performance and accountability. In a hospital, my husband's bed would have been replaced immediately, but because I am an individual customer at home, it took me 10 days. We need a way to make that system work for us as consumers.

Insurers and public program administrators should recognize the communicating with family caregivers is essential to the quality of patient care, and should be reimbursed. Then professionals would at least begin to pay more attention to it.

Finally, at the Federal level, what should policymakers do? I think the most important step is really what you are doing right now, that is, taking real account of the value and importance of family caregivers. As one mechanism, I suggest that a "family impact statement" should accompany major health policy decisions. We expect the same for the environment and for paper reduction. Aren't the people who are the bedrock of the health care system equally important?

The last point. Policymakers at all levels are very ambivalent about family caregivers. Yes, they say, they are very important, and we certainly do not want them to give up because that would add to the public burden; but no, we do not want to give them too much because of what is called the "woodwork effect." The "woodwork effect" suggests that once given some chance for relief, family caregivers would come out of the woodwork asking for more. Well, I do not know what image strikes you when you think of something coming out of the woodwork, but it is certainly not a very pleasant one to me. And speaking for myself personally, I am not part of the woodwork; I am part of the foundation. If the foundation collapses, the entire structure is in danger.

Now, when you ask family caregivers what they want, as Gail said, they really do not know, because nobody has ever asked them before, or they say, as in our focus groups, somebody to talk to, someone to call when I have a question, technical training that recognizes that this is my loved one and not just another patient, a day off, a kind word. These are really modest requests. I think that just beginning to recognize those modest requests will help us build a broader system that would start to humanize what happens with patients and families and professionals.

Thank you.

The CHAIRMAN. Thank you. When I heard you use the phrase "come out of the woodwork," it made me think that you must have spent some time on Capitol Hill. [Laughter.]

Ms. LEVINE. Well, it happens in States, too. But I always hear it, and I always think: Wait a minute. What does that mean? It is not me.

The CHAIRMAN. Thank you.

[The prepared statement of Ms. Levine follows:]

United
Hospital Fund

Shaping New York's Health Care:
Information, Philanthropy, Policy

Empire State Building
350 Fifth Avenue, 23rd Floor
New York, NY 10118-2399
212 494-0700
Fax 212 494-0800

Testimony of Carol Levine

before the U.S. Senate Select Committee on Aging

September 10, 1998

Carol Levine
Director, Families and Health Care Project
United Hospital Fund
350 Fifth Avenue, 23rd Floor
New York, NY 10118
Phone: (212) 494-0755
Fax: (212) 494-0823
e-mail: clevine@uhfnyc.org

Good morning. My name is Carol Levine and I am Director of the Families and Health Care Project at the United Hospital Fund in New York City. Since its founding in 1879, the United Hospital Fund has been devoted to shaping positive change in health care delivery and financing. The Fund works through philanthropy, research, and program and educational development.

Thank you very much for inviting me to testify before you today on the important issues facing family caregivers. In convening this hearing, the U.S. Senate Select Committee on Aging has taken an important step in increasing the awareness of policy makers, health care professionals, and the general public about the critical role of family caregivers in the well-being of our nation's elderly people, and those who are chronically ill or seriously disabled, whatever their age. I am delighted to be able to introduce at this hearing a new special report from the United Hospital Fund called "Rough Crossings: Family Caregivers' Odysseys through the Health Care System." The entire report has been provided to supplement my testimony.

The Importance of Transitions

The report focuses on transitions -- patient moves to and from hospitals, nursing homes, or rehabilitation units -- and how these transitions affect family caregivers. The main source of information was a series of six focus groups held in New York City with 56 experienced family caregivers. The caregivers were a very diverse group, including men as well as women, people with many different ethnic backgrounds, educational levels, family incomes, and ages. The caregivers ranged in age from 20 to 70, with the majority in their 30s and 40s. Many held jobs, although some had been forced to leave employment to take care of their family member. The care recipients were mostly women between the ages of 60 and 80 with multiple serious health conditions.

At the beginning of the hearing you saw and heard on video three of these caregivers talk about their lack of preparation for the task, their anxiety about taking proper care of their loved one, and the isolation that comes with long-term caregiving.

- "The first night she came home from the hospital we went to bed and I found that she was incontinent and that her bandages were oozing. No one had told me what to expect. I didn't know who to be angry at or who to call to help me take care of her."-- A husband whose 71-year-old wife has multiple sclerosis and had extensive surgery for a bone infection

- "I was terrified. My generation doesn't know about computers. They put in a feeding tube and showed me — 1,2,3 -- how to use it. But I was expected to be responsible for it at home." -- A wife whose elderly husband has had several strokes.

Here is another voice, which is not on the video you saw.

- "I had to fight through layers of bureaucracy for ten days to get a dangerously unstable hospital bed replaced at home. Then when the bed arrived -- without notice, in the evening when there was no one to help me move him -- it turned out to be the wrong bed."-- A wife who takes care of her 70-year-old husband left quadriplegic and brain-damaged after an automobile accident 8 ½ years ago.

The last voice is mine. Like the caregivers in our focus groups, I am one of the more than 25 million other family caregivers who are struggling with the fragmented, inflexible, and increasingly complicated collection of institutions and agencies called "the health care system."

I joined the United Hospital Fund in October 1996 to create the Families and Health Care Project after a long career in health policy and medical ethics, which included being awarded a MacArthur Fellowship for my work in AIDS policy. Yet nothing in my professional background, or my experience as a mother of three children, had prepared me to be the caregiver for a severely disabled, brain-injured husband.

Why Systems Must Change

Professionals call us "informal" caregivers to distinguish us from paid workers, implying that there is something casual and nonessential about our care. Because we love the people we take care of, we do not ordinarily see ourselves as anything but spouse, child, sibling, partner, friend. In fact, we take care of the basic health, social, and emotional needs of people who are disabled or chronically or terminally ill, and who are only sporadically hospitalized. Sometimes we have to make our homes into mini-hospitals, crowded with high-tech equipment we operate and monitor. In the past few years the health care system has changed dramatically. Cost-containment has shifted responsibilities to patients and families in unprecedented ways. This hearing is an important step in looking at that impact systemically.

Despite the near-universality of caregivers' experiences, our stories will remain just individual anecdotes that evoke sympathy, shock, or avoidance until the health care system begins to change. And it is the system that must change. This is a potentially revolutionary idea.

Today, the formal health care system expects family caregivers to change, to accept its irrational and often contradictory array of rules and regulations, the pervasive lack of communication and information, and inadequate training and follow-up. Even much of the family caregiving self-help literature focuses on "coping" – learning how to live with an intolerable situation by changing one's own attitude and expectations. Coping skills are important, but there are limits to what even the most successful copers can sustain. Martyrdom--or indeed heroism--is not an ethical or practical standard for public policy or health care practice.

The devastating results of the health care system's lack of attention to family caregivers can be seen every day. Middle-class families who thought they had comprehensive health insurance are being impoverished by caregiving, since much of what they need at home is not deemed "medically necessary" by insurers or falls under the unreimbursable category of "custodial care." There are well-documented mental and physical health risks to caregivers. Employers face productivity loss and absenteeism when valuable workers juggle the competing demands of job and caregiving. Without support and guidance, families can be irreparably torn by dissension. Divorce is not uncommon; suicide not unheard-of. Other family members, children in particular, may be denied the care and attention of the caregiver preoccupied with the ill person.

What can be done to encourage and require the health care system to change? There is no single solution, no law or regulation that will by itself make a difference. In a long-term agenda, high priority should be given to building an understanding of the needs of family caregivers into medical, nursing, and social work education. But several important steps can be taken now.

United Hospital Fund Initiatives

- The United Hospital Fund has already added family caregiving to its philanthropic and research agenda. The very existence of a project like mine in an organization with "hospital" as its middle name is evidence of the growing awareness that it is in institutions'economic interests as well as humanitarian missions to understand and address the needs of family caregivers. Studies show that even modest, targeted attention to family caregivers can prevent or delay costly hospital readmissions or nursing home placement.

- The Fund commissioned Peter Arno to develop the first systematic estimate of the economic value of informal caregiving. He presented the sobering results to you today.

- The Families and Health Care Project prepared a series of guiding principles to promote effective partnerships between health care professionals and family caregivers. These too are included in the special report, "Rough Crossings.".

- The Fund has embarked on an ambitious three-year $1.3 million grant initiative to change the way hospitals work with family caregivers and other health care providers. In its first phase, 16 New York City hospitals were awarded planning grants to gather and analyze information about family caregivers. Dr. Mary Mittelman, my co-panelist, is one of the grantees. In February we will award about six two-year grants of $150,00 to $200,000 each to test model interventions to change hospital practice and procedures.

- In the coming year we will be embarking on other activities that build on our initial work, and we will continue to join in collaborative efforts with the many active consumer and health care groups that are already dedicated to improving services for family caregivers.

Recommendations

Of course we cannot meet this challenge alone. For our colleagues in health care and for policy makers at all levels we offer several suggestions for program review and development. The key elements are family caregiver involvement, information and communication, training and education, and a variety of support services. Specifically,

* *Hospital staff should make discharge planning and transitions between home and hospital a process, not a last-minute, one-time event.* "Rough Crossings" contains not only experiences of caregivers, but also the perspectives of hospital staff as well. Health care professionals confirmed what family caregivers stressed--that discharge planning, as currently practiced, often fails to meet the needs of family caregivers. Most discharge planning focuses on who is paying for what, leaving the family caregiver to sort out an often confusing array of medications, machines, and instructions. Many caregivers felt abandoned at a critical time. If managed care is to fulfill its promise, it must truly be care management, not just cost containment.

Our report contains a series of outlines called "Covering the Basics for Family Caregivers." They are lists of items to discuss when planning for different situations, when the patient is in the hospital, for example, or prior to discharge, or when the patient is terminally ill. We suggest that these outlines can be practical guides for health care providers and family caregivers to start an ongoing discussion.

For these or any other discussion aids to be effective, however, there must be appropriate services and training in place. Thus, our next recommendation:

* *A high priority should be given to developing a broader array of programs that support family caregivers.* There are not enough counseling, support, and respite services for the many different types of caregivers and their special needs. Some excellent programs exist but many caregivers do not know what is available or where to look for help. None of the caregivers in our focus groups reported a professional referral to a community-based agency for further assistance, counseling, or information. Some eventually found such an organization on their own.

* *Health care professionals should be assertive advocates for family caregivers.* As one of our basic principles states, professionals have responsibilities toward family caregivers who provide, monitor, and manage their patients' care at home. Resourceful and willing though they may be, family caregivers need advice, expertise, and especially advocacy from those who know the ins and outs of health care bureaucracies.

* *Insurers and their subcontractors should be held to a high standard of performance and accountability.* In a hospital my husband's unsafe bed would have been replaced immediately, if for no other reason than concerns about liability. Institutions have clout; individual family caregivers have little. Managed care companies and insurers frequently set up barriers to immediate service and limit choices of equipment vendors and other service providers. Family caregivers need a simple, systematic way to report poor service and bureaucratic hassles; and they are entitled to a timely response.

* *Insurers and public program administrators should recognize that communicating with*

family caregivers is essential to quality patient care. Even the most dedicated clinicians cannot spend the necessary time communicating with family caregivers unless they are reimbursed adequately. The simplest intervention -- listening to family caregivers and assisting them to do the hard job they have lovingly taken on -- may be the most critical.

Finally, what can policy makers, especially at the federal level, do?

I believe that the single most important change in federal and state policy is an explicit recognition of the critical role of all family caregivers in the health care system, not just those whose care recipients receive services from Medicaid or Medicare. This implies a recognition of the links between the "public" and "private" sectors. Public policy decisions on programs like Medicare and Medicaid set the basic framework for the private sector in terms of service development and availability, criteria of "medical need," wages in the labor market, and so on. To look at it positively, an emphasis on serving family caregivers in the public sector will have an important carryover into the private sector where managed care companies increasingly determine benefits. Private foundations have an important role as well in supporting innovation, evaluating new programs, and stimulating research.

A Family Impact Statement

Furthermore, health and social service policy decision making should include a family focus. I suggest that a "family impact statement" should accompany major policy decisions. We expect the same for the environment and for paper reduction. Aren't the people who are the bedrock of the health care system equally important?

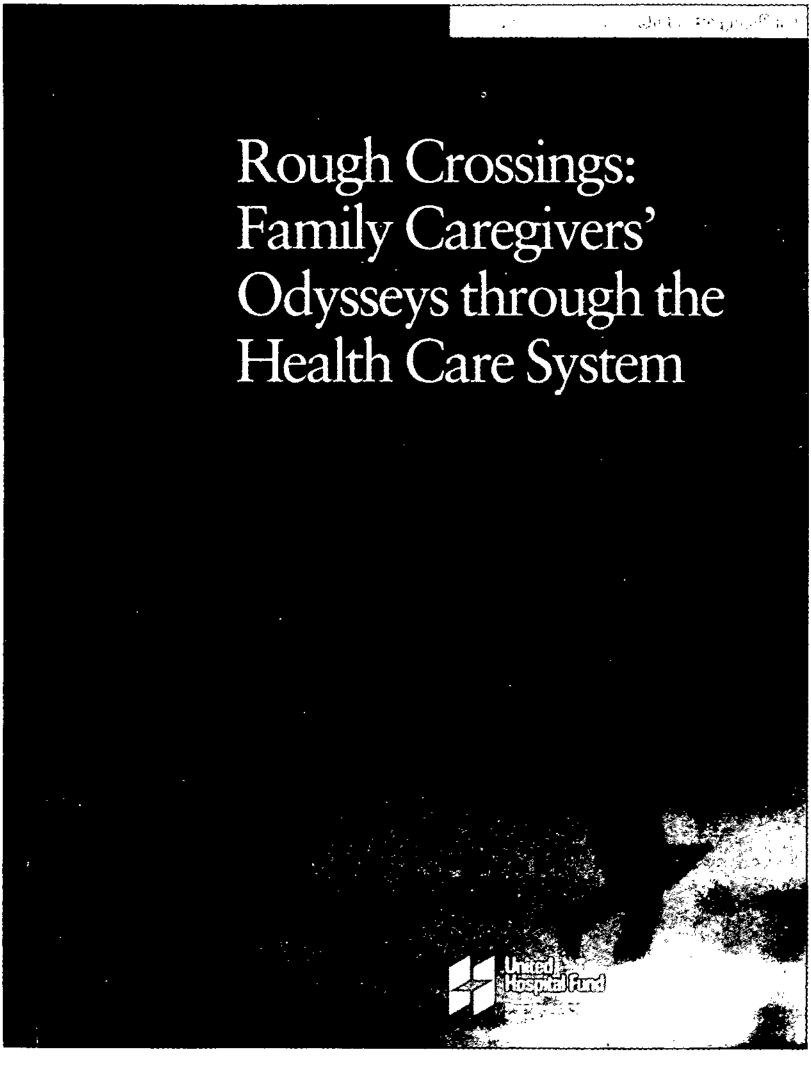
One specific example is the hospice benefit under Medicare. Hospice is one service that is based on the importance of the family unit and offers ongoing support as well as a bereavement and follow-up service. But hospice also relies heavily -- more heavily than most people realize -- on the direct care provided by family members. Efforts to contain hospice costs have had a chilling effect on admission to hospice. This in turn has a serious impact on family members who have been caring for a seriously ill loved one for long periods and who look to hospice for assistance in the final months of intense caregiving. Here is one program where a "family impact" statement would help define the context in which efforts at containing costs and eliminating fraud take place.

Policy makers at all levels have long been ambivalent about family caregivers. Yes, they say, they are important, and we certainly don't want them to give up because that will add to the public burden. But no, they hasten to add, we don't want to do too much for them because of the "woodwork" effect. The "woodwork" effect suggests that once given a chance for some relief, family caregivers would come out of the "woodwork," like so many unwanted insects, with greedy appetites for resources. Speaking for myself, I am not part of the woodwork. I am part of the foundation on which our health care system rests. And if the foundation collapses, the entire structure is endangered.

What do family caregivers themselves say they want? In the twelve hours of caregiver conversations in our focus groups, and in countless other conversations: this is what I have heard again and again: "Someone to talk to who understands what I'm going through." "Someone to call when I have questions." "Technical training that recognizes my emotional involvement with the patient." "A day off." "A kind word from a doctor or nurse or social worker."

These are hardly overwhelming demands. Meeting such modest requests would be a strong beginning to humanizing our health care system for patients, families, and professionals alike.

Thank you again for the opportunity to speak to you today. I will be happy to answer any questions.



Rough Crossings: Family Caregivers' Odysseys through the Health Care System

United Hospital Fund

United Hospital Fund of New York

The United Hospital Fund is a health services research and philanthropic organization addressing critical issues affecting hospitals and health care. The Fund constantly seeks to enhance its traditional role as the nation's oldest federated charity by helping to improve the delivery and shape the financing of patient care in today's changing environment. It does so by organizing and consolidating philanthropic activities; by initiating and conducting research, demonstration projects, educational programs, and health policy development; and by bringing together professionals and volunteers.

A Special Report from United Hospital Fund

Rough Crossings: Family Caregivers' Odysseys through the Health Care System

Carol Levine
Director, Families and Health Care Project

United Hospital Fund of New York

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The Ship Pounding

Each morning I made my way
among gangways, elevators,
and nurses' pods to Jane's room
to interrogate grave helpers
who had tended her all night
like the ship's massive engines
kept its propellers turning.
Week after week, I sat by her bed
with black coffee and the *Globe.*
The passengers on this voyage
wore masks or cannulae
or dangled devices that dripped
chemicals into their wrists,
but I believed that the ship
travelled to a harbor
of breakfast, work, and love.
I wrote: "When the infusions
are infused entirely, bone
marrow restored and lymphoblasts
remitted, I will take my wife,
as bald as Michael Jordan,
home to our dog and day."
Months later these words turn up
among papers on my desk at home,
as I listen to hear Jane call
for help, or speak in delirium,
waiting to make the agitated
drive to Emergency again,
for re-admission to the huge
vessel that heaves water month
after month, without leaving
port, without moving a knot,
without arrival or destination,
its great engines pounding.

—Donald Hall

Executive Summary

Each year more than 60 million Americans are admitted to or discharged from health care facilities. For institutions, these entries and departures are routine processes; for patients and their families, they are often fraught with anxiety and fear. This special report explores these transitions from the unique perspectives of family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are chronically ill or disabled. Its purpose is to contribute to the development of responsible and reasonable ways to respect, understand, and help all families coping with serious illness and the major transitions that mark that journey.

SOURCES OF INFORMATION FOR THE REPORT

- Section I. Academic literature on transitions in illness and family caregiving.
- Section II. Six focus groups of family caregivers which the United Hospital Fund's Families and Health Care Project convened in New York City in September 1997.
- Section III. Planning grant applications submitted by 28 New York City hospitals in April 1998 to the United Hospital Fund's Family Caregiving Grant Initiative, established to help New York City hospitals develop and test programs to respond to caregivers' unmet needs.

SECTION I. ILLNESS, CAREGIVING, AND TRANSITIONS

- Caregiving transitions occur in the context of the progression of a disease. While clinicians treat and classify the stages of disease, patients and families experience the symptoms, suffering, and changes brought about by illness.
- Caregiving can be considered to be a "career," replete with myriad stages, transitions, and stresses, which place caregivers in a state of constant flux.
- Caregiving can be seen in the context of a family's life cycle. A serious illness interrupts common transitions such as births, launching young adults, marriage, and retirement, and requires that families adjust to the anticipation of further disability and untimely death.

- Any transition from one health care setting to another, therefore, adds a complex layer of adjustment to the transitions already underway in a caregiver's family and his or her experience of illness.

SECTION II. CAREGIVERS' VOICES

The focus groups produced remarkably consistent themes, especially in terms of caregivers' feeling unprepared for caregiving tasks. The conversations provide insights into caregivers' individual experiences, and have direct implications for improving the health care system and for creating smoother transitions between care settings.

Family Ties

- Caregivers were usually thrust into their role by necessity, although most wanted to provide care because the ill person was significant in their lives.
- Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone.
- Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but also led to anxiety and fear about the patient's welfare.

Caregivers' Reactions to Changes in Illness and Care Settings

- Transitions can be traumatic because they are often times when caregivers first become aware of changes or deterioration in the patient's condition. Many times they feel a heightened, even overwhelming, sense of personal responsibility for the patient's health and well-being.
- Many caregivers spoke of their sadness and the loss or change in their relationship with the care recipient.

Going Home

- Caregivers experienced discharge from the hospital as an abrupt, upsetting event because hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. Many felt abandoned at a critical time.

Admission to a Hospital or Nursing Home

- Although most of the discussion centered on transitions from institution to home, the reverse—transition from home to hospital or nursing home—also presented problems.

- Many caregivers fear that their loved one will be neglected in hospitals and nursing homes. A transition to an institution means extra vigilance for the caregiver.
- In general, participants reported that hospital staff failed to acknowledge their emotional needs. None of the participants said that health care professionals had referred them to community-based agencies for emotional or other kinds of support.
- Many caregivers believe that older people are not treated sensitively in hospitals.
- Caregivers want compassion and understanding from institutional staff, and they want to be able to communicate with health care professionals about their loved one's condition.

Culture, Family Structure, and Religion

- Caregivers reported that cultural differences created special care needs, and sometimes led to problems with health care professionals whose backgrounds differed from those of the family.
- Some caregivers who are not immediate family members, or who do not fit into the traditional definition of "family," reported having difficulties obtaining information from, and being acknowledged by, hospital staff.
- Although some participants sought a religious explanation for their situation, no one mentioned organized religious institutions or clergy as a source of solace or assistance.

Financial Factors

- In most groups, discussion centered more on the emotional aspects of caregiving transitions, and less on financial concerns.
- When discussion did turn to financial issues, participants criticized the health care system's focus on costs, and spoke of needing more resources to provide care.

Death and Dying

- Bereaved caregivers did not have markedly different caregiving experiences from current caregivers, but they experienced the additional stress of what they felt was inappropriate care at the end of their family member's life.
- Most bereaved caregivers were either unaware of hospice or felt that it was an inappropriate choice for their family member.

SECTION III. HOSPITALS' PERSPECTIVES

The applications submitted by 28 New York City hospitals to the Family Caregiving Grant Initiative demonstrate that hospitals are beginning to recognize the tremendous burdens upon family caregivers. Their comments both confirm and amplify many of the themes articulated in the focus groups.

General Themes

- The health care system fails to adequately support and train caregivers.
- Fragmented communication leaves caregivers confused and uninformed.
- Discharge planning, as currently practiced, often fails to create smooth transitions.
- The health care system does not sufficiently recognize the role of family caregivers.
- Patients from diverse backgrounds have different needs and circumstances.

Barriers to Serving Family Caregivers

- Hospitals lack the time and financial resources necessary to address caregivers' needs.
- In their focus on the patient's clinical condition, health care providers often overlook the caregiver.
- Information systems fail to collect and share facts about the social and emotional aspects of care.
- Language, cultural, and educational differences can create challenges when families and health care professionals come from different backgrounds.
- Families' emotional responses to illness can make it challenging for hospital staff to provide support in a meaningful way.

These applications suggest that, at least at some administrative and clinical levels, professionals want to do better, and recognize the substantial barriers to improvement that they face.

SECTION IV. RECOMMENDATIONS FOR CHANGE

The following recommendations for change are a beginning. They are not so grandiose that they depend on vast changes in the American political or economic system nor so trivial that they accomplish little more than a token bow to family caregivers. These recommendations, in conjunction with the Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System (see Appendix B), can make a difference and should be implemented

Recommendation 1: Health professionals, government agencies, and managed care organizations should recognize explicitly, in policy and practice, that family caregivers who assume significant care responsibilities are a valuable but vulnerable resource.

Recommendation 2: This recognition of the critical role of family caregivers must be built into medical, nursing, and social work training and continuing education.

Recommendation 3: More research is urgently needed to understand the impact on family caregivers of changes in the health care system and on interventions that families need and want.

Recommendation 4: Health care providers must make discharge planning, and transitions from one care setting to another, a process rather than a single event. The outlines entitled "Covering the Basics for Family Caregivers" (Section V) provide a good start toward creating smoother transitions. They are designed for use by both health care professionals and family caregivers, and should be adapted to fit individual circumstances.

Recommendation 5: Hospitals and other health care institutions should develop model programs that offer innovative ways of involving and meeting the needs of family caregivers.

Recommendation 6: Public and private insurance plans and managed care organizations should evaluate benefits and service plans to reflect the importance of training, supporting, and communicating with family caregivers.

Contents

Foreword

This report marks the beginning of an important new dialogue in American health care. For years, while we have examined how the sweeping changes in health care delivery and finance affect institutions and the patients they serve, we have overlooked the needs of those upon whom the health care system greatly depends—the relatives, spouses, partners, friends, and loved ones who provide ongoing care at home to seriously ill and disabled patients.

More than 25 million Americans provide such care, and they face enormous, unprecedented burdens that jeopardize their well-being and threaten their ability to fulfill the duties they willingly take on. Several factors have converged to create these new circumstances: Cost containment and medical advances have trimmed hospital stays and moved daunting and complex care into the home. These advances are saving lives, but as a result, many more people suffer from long-term, chronic illnesses. An aging population requires more care than ever, and women, the traditional caregivers, have moved into the workplace and are less able to provide full-time care.

The United Hospital Fund's Families and Health Care Project has been working since 1996 to advance public understanding of the crucial role of family caregivers, and to stimulate the development of sound practices that support their needs. To capture the issue quantitatively, Carol Levine, the project's director, and Peter Arno, a health care economist and researcher, conducted a study to assess the economic value of family caregiving. Their study found that if these more than 25 million individuals were compensated on the open market for the care they provide, the cost would amount to nearly $200 billion per year, the equivalent of 20 percent of national health care expenditures. This figure dwarfs annual home health and nursing home care expenditures—$30 billion and $79 billion, respectively—making family caregivers the largest provider of long-term care.

The Families and Health Care Project conducted focus groups of family caregivers last year to capture the issue qualitatively as well. The caregivers who participated in the groups spoke about how the health care system often fails to provide them with the technical, practical, and emotional support they need to fulfill their caregiving responsibilities. Not long afterwards, the Fund established a $1.3 million grantmaking initiative to support New York City hospitals in developing and testing programs to respond to caregivers' unmet needs. Independently, the health care professionals who submitted applications to our grant initiative made many of the same observations as the focus group participants.

True to the mission of the Families and Health Care Project, this report highlights what the *family caregivers* had to say. Their stories provide rare insights into the direct and powerful consequences that the vast changes in the health care system are having on this vulnerable population. We also present reports from health care professionals who submitted applications to the grant initiative, and we offer recommendations to encourage the development of supportive, respectful relationships between family caregivers and professionals.

This publication is only a starting point. It introduces a largely unacknowledged but very timely issue into the broader discussion of health care. We hope that it creates understanding of the issues family caregivers face, and inspires health care institutions to more sensitively respond to the needs of those who care for the sickest and most fragile among us.

JAMES R. TALLON, JR.
President
United Hospital Fund of New York

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Finally, this volume would not have been possible without the candid and heartfelt contributions of the focus group members whose experiences make up the core of this report. We are grateful for their willingness to describe their often painful and always meaningful stories.

Introduction

Each year more than 60 million Americans are admitted to or discharged from health care facilities. For institutions, these entries and departures are routine processes; for patients and their families, they are often fraught with anxiety and fear. In many cases these transitions signify not just a medical determination that a patient is sick enough to be hospitalized or well enough to go home, they represent a change in the course of an illness and in the family's caregiving roles and responsibilities.

This special report explores transitions in health care settings from the unique perspective of family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are ill or disabled. Family caregivers, often called "informal caregivers," have complex relationships with "formal" caregivers, who are health care professionals. Formal caregivers include physicians, nurses, and social workers; representatives of hospitals, nursing homes, and rehabilitation centers; employees of managed care organizations, private insurers, and government programs; home care agency staff; equipment and supply vendors; transportation contractors; and other employees or providers in the health care system. The transition process includes a move not just from one place to another but from one care system to another. In the case of a discharged patient receiving home care, it involves encounters with several uncoordinated and fragmented systems.

The report is intended for several audiences:

- **Clinicians:** they rely on family caregivers to provide or manage significant levels of patient care at home and encounter family caregivers in inpatient settings.
- **Administrators:** they establish policies and regulations in institutions that affect family caregivers as well as patients.
- **Legislators and policymakers:** they set a public policy agenda and determine eligibility and reimbursement rates in publicly funded programs for patient and family caregiver services.
- **Insurers and decision makers in managed care organizations:** they determine benefits and services for privately insured patients and caregivers.
- **Representatives of patient/caregiver advocacy and service organizations:** they offer community-based services for caregivers and organize advocacy efforts on behalf of their constituencies.
- **Family caregivers:** they are often so isolated from one another that they fail to realize they are not alone and that others have responsibilities toward them, just as they accept responsibilities toward their loved ones.

GENESIS AND ORGANIZATION OF THE REPORT

This report grew out of several activities of the United Hospital Fund's Families and Health Care Project (FHCP), which was created in October 1996 to analyze the impact of the changing health care financing and delivery system on family caregivers. One important initial goal was to develop principles on which to build constructive partnerships between family caregivers and health care professionals (see "Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System" in Appendix B). As the project developed these principles, through literature reviews, discussions with providers and caregivers, and meetings of the project's national advisory committee, it became very apparent that family caregivers experience particularly serious difficulties when their loved ones move from one care setting to another. Any discussion of how the health care system affects family caregivers, therefore, must include attention to these transitions.

The first section of this report summarizes some of the literature on transitions in illness and family caregiving. It explores the role that underlying family dynamics play in caregivers' experiences, and provides insight into how the illness of a loved one places family caregivers in a constant state of transition. This discussion establishes an important context for understanding how the problems associated with a loved one's *physical* transitions between care settings, explored in Section II, intensify the stress on caregivers.

The second section of the report presents information gathered from a series of six focus groups convened by the project in September 1997 in New York City. The information obtained in these focus groups serves as the primary source for this report. The focus groups engaged 56 individuals who provide, or who have provided, significant levels of care at home to elderly, chronically or terminally ill, or disabled family members and friends, and who have experienced several transitions in care settings. Four of the groups included current caregivers, and two consisted of family members whose loved one had died within the past two years. The groups included individuals of diverse ages, genders, ethnicities, religions, socioeconomic status, and educational backgrounds.

Focus groups are a qualitative research method especially well suited to eliciting detailed and sensitive information. The dynamics of a group interview have two advantages. First, group members stir each other's memories and emotions as they relate their experiences. Second, groups of participants who perceive each other as similar to themselves are generally more open than they would be with an interviewer who is not perceived as having shared their experience. Focus groups are limited in terms of developing quantitative data, but they provide nuances and narratives that are hard to capture in more structured methodologies.

The accompanying vignettes of caregivers' stories, gleaned from the focus groups, offer glimpses of the caregiving experience at critical times in patients' and families' lives. They hint at the intricate web of family relationships that exists apart from, but also as part of, the experience of illness. Little research exists that provides complex, ethnographic descriptions of caregiving. Case histories usually have a pathological focus, and media accounts typically portray only the exceptional circumstances—either the heroic or the abusive family stories. These vignettes suggest that future research should attempt to capture a broader range of caregivers' experiences.

The third section presents a secondary source of information obtained from planning grant applications submitted by New York City hospitals in April 1998 to the Fund's Family Caregiving Grant Initiative. Because the Fund established this major grantmaking initiative a few months after the focus groups were held, but before the results of the focus groups were analyzed, there was an unplanned opportunity to informally compare hospital perspectives with those of family caregivers. Twenty-eight New York City hospitals responded to the Fund's Request for Proposals (RFP) for Phase I of the Family Caregiving Grant Initiative. In May 1998, 16 hospitals were awarded $20,000 each to gather and analyze data about family caregivers' unmet needs and to explore the possibilities of collaboration with community-based partners such as nursing homes, home care agencies, or patient/family advocacy and support groups. The RFP stressed the importance of listening to family caregivers and of developing a multidisciplinary team. Part of the RFP asked applicants to describe the circumstances and environment family caregivers face in their hospital, and to identify barriers to creating services for them. In Phase II of the Initiative, which will begin in February 1999, six hospitals will be awarded two-year grants of $150,000 to $200,000 to implement the most promising program designs.

The two sources are not directly comparable. The focus group information was gathered from extended conversations with a diverse group of nonprofessional caregivers. The hospital applications were written by professionals seeking funding; applicants were not asked specifically to answer questions about transitions. Nevertheless, both the focus group participants and the hospital applicants identified remarkably similar problem areas. That nonprofessional and professional caregivers, who are at times at odds with each other, should independently arrive at the same conclusions, indicates the magnitude of the issue and clearly points to the need for change.

These sources offer, from both the family caregivers' and hospital professionals' perspectives, insights into the day-to-day experience of transitions. The final section of the report offers several recommendations for improvement. Transitions may be problematic, but they are also opportunities for intervention.

I. Illness, Caregiving, and Transitions

> *The chronically ill often are like those trapped at a frontier, wandering, confused in a poorly known border area, waiting desperately to return to their native land....This image should also alert us to the...entrance and exit formalities, the visas, the different languages and etiquettes, the guards and functionaries and hucksters at the border crossing points, and especially the relatives and friends who press their faces against windows to wave a sad goodbye, who carry sometimes the heaviest baggage, who sit in the same waiting rooms, and who even travel through the same land of limbo, experiencing similar worry, hurt, uncertainty, and loss. Social movement for the chronically ill is back and forth through rituals of separation, transition, and reincorporation.*[1]

Illness disrupts expected transitions and creates unplanned ones.

From birth to death, transitions are part of the pattern of an individual's and a family's life. Illness disrupts expected transitions and creates unplanned ones. Sometimes illness-related transitions are dramatic and sharply defined. A stroke or traumatic brain injury brings immediate change to patient and family. Sometimes transitions are apparent only after long periods of subtle accommodations to the changes wrought by Alzheimer's disease. In some cases the period of transition from wellness to death is short and precipitous; in others, there is a dizzying roller coaster of remission and recurrence.

Whatever the disease or injury and its medical course, typically the patient and family at some points encounter the institutionally based health care system through admissions to and discharges from a hospital, rehabilitation center, nursing home, or other facility. In addition to signaling changes in medical condition and prognosis, these are literal transitions—moves from one place where care is provided to another. These transitions involve all the "entrance and exit formalities, visas, and different languages and etiquette" Kleinman invokes in his image of chronic illness as a border area for patient and family. For family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are chronically ill or disabled—often the "heaviest baggage" they carry relates not to the specific tasks, but to the altered relationships and new roles that illness imposes.

Theorists have developed several different ways to view caregiving transitions: as part of the process of disease progression; as a "career" path for the family caregiver; and as part of the family life cycle.

Disease progression. Clinicians diagnose and "stage" diseases; that is, they examine test results, symptoms, and clinical signs to determine what disease category encompasses this set of findings and whether the disease is in an early, middle, or late phase. This analysis helps determine recommendations for curative or palliative treatment, and is an important factor in prognosis. Patients and families, however, experience illness rather than disease. As Kleinman distinguishes the two states, illness is "the innately human experience of symptoms and suffering."[2] The stage of disease, a technical determination, may or may not correspond to the stage of illness, the subjective response of patient and family, and the level of adaptation.[3]

Medalie stresses that "*[E]ach phase* [of the clinical time-cycle] has its *own demands and tasks which require different attitudes and solutions*....Some patients and families adjust well to all the phases, some do not adjust at all, while the majority probably do well most of the time but have difficulties with some phases or parts of phases" [italics in original].[4] His schematic description of the chronic illness cycle begins with the crisis of symptomatic prediagnosis, diagnosis, and initial treatment phases, during which the patient and family experience acute stress. Chronic stress dominates the "long-haul" phase, involving post-treatment adjustment and chronic maintenance, with the possibility of acute stress recurring with repeat crises or emergencies. Acute stress usually occurs when the patient enters a terminal phase of the disease, and when the patient dies. The final period of mourning and adjusting to loss brings another "long haul."

Family caregivers whose loved ones are hospitalized with the same diagnosis or for the same procedure react very differently depending on the stage of the disease and their experience with illness. They may be adjusting to the diagnosis, still hopeful of a cure, or fearing that the end is near. Similarly, the transition from hospital to home differs for those who have been through the experience many times and for those who are new caregivers.

Caregiving as a "career." "Career" may seem an unlikely term to apply to people who are often thrust into the role by circumstances, are not paid and receive no workplace benefits, and have no opportunities for advancement. Nevertheless, the term does suggest that the experience of caregiving is dynamic. Pearlin identifies three transitions in a caregiving career: residential (home) care, institutional placement, and bereavement.[5] Within the context of these transitions, Aneshensel, Pearlin, and colleagues describe career stages: role acquisition, role enactment, and role disengagement.[6] A stage, they note, is not necessarily a period of stability, and within each stage, there is great diversity. Furthermore, the timing and sequencing of transitions vary. These authors emphasize that "the caregiver role is likely to have emerged after other roles have been in place long enough to have been accommodated into the flow of daily life. Caregiving is the new kid on the block. Once it emerges, furthermore, it does not simply take on a stable presence....More typically, the caregiver role keeps expanding in its demands so that even

Alone, Angry, and Worried
Evelyn's story*

I take care of my 79-year-old grandmother who has breast cancer. She was diagnosed last summer and had a mastectomy. After the surgery the doctors told me she was all better, but the cancer eventually spread and she had to go back into the hospital.

My grandmother lives with me, and I do everything for her. I cook and take her back and forth to the hospital for chemotherapy. She has a part-time home attendant, but she doesn't like strangers doing anything for her. She comes from a very clannish background.

For me, personally, I've had a lot of death. My nephew was killed before my eyes. I lost my husband in the hospital. My cousin was robbed and killed, and my mother died. When my grandmother got sick, I was hating God. I said, "What are you doing God?"

I have no one to talk to, either. I tried talking to some of my friends, but you mention the "C" word and they run. The few who keep in touch just tiptoe around the subject. And here I am trying to cheer up my grandmother when she knows she's dying. I feel tremendously angry and resentful. How can I give care to this person when I can't handle it myself, and when there's no one to help me cope? It's terrible.

I was also very angry when my grandmother had to be readmitted to the hospital when her cancer returned. The doctors told me about the recurrence in a very, very cold manner. If one person had sat down and taken my hand, it would have helped. No one did that. They run like you have a disease.

What's most difficult about taking care of my grandmother isn't the physical part, it's the worry. If I turn my back I wonder what's going to happen. I work part-time and I worry about what's going on. It's constant—is she going to get better or get worse?

If I had any say in how things are run, I would have social workers redefine their profession. If they've studied sociology and social work, they should deal better with people, they should be compassionate. But they essentially said to me, "We don't care." They just talked about the bills and discharge. They should give you information about support groups and assistance, like someone to bring food, for instance. Someone should tell them how difficult it is to be a caregiver.

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* Names and identifying characteristics have been changed to preserve the family's privacy.

with adjustments in other areas, it keeps a steady pressure on the boundaries of other roles in the constellation."[7]

Caregivers are more or less in a constant state of transition.

Caregivers, in other words, are in a more or less constant state of transition. Caregiving creates stress by itself but also adds stress to the other areas of the caregiver's life, such as employment, friendships, responsibilities to other family members, financial affairs, and leisure or community activities. While caregiving responsibilities may place stress on a caregiver's job, satisfaction with employment can buffer the negative stress that results from caregiving. One study found that women employed full-time derived more benefit than part-time workers because they spent more time away from caregiving and received greater financial, psychological, and social rewards.[8]

It is very difficult to pinpoint when people start thinking of themselves as "caregivers."

Building on Pearlin's work, Seltzer and Li examine the period during which family members provide direct care. They note that the transition to caregiving usually grows out of existing patterns of support and assistance, unlike transitions such as parenthood or widowhood, which are marked by distinct dates.[9] In cases of acute disease or trauma, of course, the point of transition is easy to identify. And even when the patient's disease develops slowly, caregivers can usually remember when they began to provide substantial assistance. Nevertheless, it is very difficult, as Pearlin and Aneshensel note, to pinpoint when people start thinking of themselves as "caregivers."[10] The transition from "daughter" or "husband" to "caregiver" profoundly affects one's identity, expectations, and actions. Additionally, people might avoid acknowledging themselves as caregivers until a very late stage of disease to preserve or maximize their loved one's identity.[11] Unfortunately, there are no well-defined role definitions or boundaries, and no rituals to accompany this major life transition. The first time a family member may be confronted with this new identity is when the hospital discharge planner presents a care plan that is based on the expectation that the family member will provide whatever "informal" care is needed.

Recognizing the complex and variable nature of caregiving careers, Seltzer and Li suggest that each person's career can be characterized by three indicators: type of disease onset (abrupt or gradual); duration of care (short- or long-term); and stage of caregiving (early, middle, or late). They also point out that the experience of caregiving is conditioned by variations in the kinship relationship (the differences between wives and daughters, for example), and in residential patterns (such as whether the caregiver lives with the care recipient). Caregivers' own perceptions of the stage of caregiving and their response to it may be quite different from an independent observer's evaluation of the situation.[12]

Family life cycle. Illness-created transitions affect families differently depending on their stage of the life cycle. All life cycle models include several key transitions: births, launching young adults, marriage, divorce, retirement, and death.[13] At such moments it is common to think about life and death, separation and loss. Rolland says, "The diagnosis of a serious illness superimposes the illness life cycle onto that of the individual and the family. One of the family's primary developmental tasks then becomes accommodating to the anticipation of further disability and possibly untimely death."

Young parents building careers, homes, and families who face a life-threatening disease experience enormous losses of a sense of future; they may become isolated from peers who are seemingly invulnerable. A teenage boy striving to build an identity separate from his parents may be unable to go away to college because of the financial drain caused by a parent's or sibling's illness. A middle-aged woman looking forward to the end of raising her children may face a new and less rewarding role as caregiver for a debilitated parent.

While certain stages of the family life cycle are typically associated with certain roles, the more fluid family structures seen today may not conform to traditional expectations. A "blended" family with children from previous marriages may function reasonably well until illness disrupts the equilibrium. Adult children from a former marriage may resent their parent's caregiving for a new spouse, or may resent the new spouse who becomes a caregiver and apparently displaces them in their parent's affection or takes over decision making. Illness may bring together—or force further apart—biological and families of choice, such as gay partners.[14]

In brief, a disease is much more than a medical event. For the family caregivers of chronically ill or disabled individuals, it imposes a constant state of stress and flux. Any transition from one health care setting to another, therefore, adds a complex layer of adjustment to the transitions already underway in a caregiver's family and his or her experience of illness.

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2. Ibid., pp. 3-6.

3. Shaul, MP. 1997. Transitions in chronic illness: Rheumatoid arthritis in women. Rehabilitation Nursing 22(4):199-205.

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5. Pearlin, LI. 1992. The careers of caregivers. The Gerontologist 32:647.

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7. Ibid., p. 37.

8. Martire, LM, Parris Stephens, MA, Atienza, AA. 1997. The interplay of work and caregiving: Relationships between role satisfaction, role involvement, and caregivers' well-being. Journal of Gerontology 52B(5): S279-S289.

9. Seltzer, MM, Li, LW. 1996. The transitions of caregiving: Subjective and objective definitions. The Gerontologist 36(5):614-626.

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11. Reynolds, NR, Alonzo, AA. 1998. HIV informal caregiving: Emergent conflict and growth. Research in Nursing and Health 21:251-260.

12. See note 9.

13. Rolland, J. 1994. Families, illness, and disability: An integrative treatment model. New York: Basic Books, p. 187

14. Brown, MA, Powell-Cope, GM. 1991. AIDS family caregiving: Transitions through uncertainty. Nursing Research 40(6):338-345.

II. Caregivers' Voices

The six focus groups held by the United Hospital Fund in September 1997 in New York City produced remarkably consistent reports of caregivers' experiences, especially in terms of their feeling unprepared for caregiving tasks. Often when a participant stated a problem, others throughout the groups followed with nods or other signs of assent. This held true despite the diversity of caregivers who participated. Caregivers represented a wide range of ages, and came from diverse ethnic, religious, socioeconomic, and educational backgrounds. Both women—the traditional providers of care—and men participated. Four groups consisted of current caregivers, and two were made up of bereaved family members. (For information about the focus group methodology employed, and for more details about participant and care recipient demographics, see Appendix C.)

Conversations in the focus groups covered many aspects of caregiving. Some provide insights into caregivers' individual experiences, bringing to life the theoretical discussion of transitions in Section I. Others have direct implications for improving the health care system and the physical transitions from one care setting to another. The themes that emerged from these discussions follow below.

FAMILY TIES

Caregivers were usually thrust into their role by necessity, although most wanted to provide care because the ill person was significant in their lives. By design of the focus groups, the participants were providing or had provided significant physical care and emotional support to patients with serious, debilitating conditions. Caregivers usually found themselves thrust into their role by necessity, although most wanted to provide care because the patient was a loved one. Participants said they hardly discussed the issue of choice in the matter; they simply approached the task, they explained, because "She's my mom," or "He needed me."

In many cases, the patient was a "favorite" relative or one with whom the caregiver had a strong bond. Caregivers were not just children or spouses of the patient, as might be expected, but grandchildren, nieces, and siblings. Only two participants reluctantly assumed caregiving responsibilities; in both cases the recipient was a mother-in-law, and the caregiver a woman. Their husbands, supported by other family members, felt their wives should provide the care but remained largely uninvolved themselves.

One of these women reported that she had gone through early menopause, had developed a thyroid condition, and was in the process of getting divorced as a result of

The Five Most Difficult Things

By Jacqueline, who lost her father-in-law to cancer*

1. The constant tug-of-war with family members over where he should live, even though he obviously chose to come to our home to die.
2. The emotional effects on my children—trying to explain the whole situation to them.
3. My employer not understanding my role as a caregiver and not affording me flexible hours so I could run home or go to the hospital if I had to.
4. The constant friction with my spouse as to whose turn it was to do what.
5. The overwhelming sadness at the loss of a loved one at the end. I couldn't believe that this person I loved had left me.

the stress of taking care of her mother-in-law, who was abusive toward her and required total care. "I couldn't take it any more," she said. "'You slut,' she called me. We finally put her in a nursing home, but it destroyed my husband. She was either going to burn the house down, get lost, I was going to kill myself, or she was going to kill me."

Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone. Major decisions were especially difficult for caregivers providing care without assistance from family, friends, or professionals. From the reports of caregivers in these groups, the variable that seems to be critical is whether or not the caregiver has others sharing the responsibility. Adult only children and caregiving spouses seem to have the most difficult and overwhelming experiences because they are most often alone.

Additionally, very few caregivers felt that their friends and family members acknowledged their stress and frustrations. In fact, one man said he thought that, as a caregiver, he was "invisible" to everybody else. No one asked how he was. He said friends called at night after he had been at work all day and then at the hospital until late in the evening. He said they just asked about his wife and they only wanted to hear good news. He began resenting the calls. One woman, who has several very close friends, was so worn out answering her mother's questions and dealing with doctors and therapists that by the end of the day, she said, "I literally couldn't speak to [those who called] because I had no saliva left in my mouth."

Even those in large families reported that they sometimes found themselves alone in providing care. One woman from a large, Mediterranean family whose father was brain-

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* Names and identifying characteristics have been changed to preserve the family's privacy.

damaged said sadly, "When my father was in a coma, our house was full of friends and family. As soon as he came out of it, and everyone realized he could barely speak, they stopped coming. I don't understand why they can't just stop by to say 'hello.'"

Caregivers who are part of families who cooperate easily and share responsibilities became aware in the focus groups that in spite of their feelings of burden, their situation was actually much easier than that of other participants. They said they did not know how they would provide care alone.

Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but also led to anxiety and fear about the patient's welfare. While the closeness of the relationship provides meaning and emotional reward for the caregiver, it also adds a psychological burden to the physical burden of caregiving. Some caregivers worried that their emotions might make them more prone to errors. One woman said, "When you're a professional and detached, it's one thing. When you're emotionally involved, it's easier to make mistakes with the practical things." Another said of her sister, "The physical care is emotional because of who I'm doing it for."

Several caregivers spoke of their distress at seeing their loved one in constant pain and being helpless to do anything for them. Responsible for the administration of pain medications at home, they felt they had to wait until the designated time to administer the prescribed dose because "that's what the doctor ordered."

CAREGIVERS' REACTIONS TO CHANGES IN ILLNESS AND CARE SETTINGS

Transitions can be traumatic because they are often times when caregivers first become aware of changes or deterioration in the patient's condition. Caregivers often feel surprise and sometimes shock at changes in their loved one. Finding out that a patient returning home from the hospital is incontinent; having to care for a demented patient who is more confused after returning home after major surgery; realizing that a stroke victim will never walk or talk—all these events are traumatic for the caregiver. The less prepared the caregiver is for the patient's condition or the kind of care he or she will have to provide, the more upsetting the transition will be.

One woman talked of her husband's transition from a rehabilitation center to their home after a stroke. She was more technically prepared than many other participants because she had attended all her husband's rehabilitation sessions. "When we went home, I didn't have any help or support," she said. "He couldn't do anything! I felt very isolated and became terribly depressed."

The husband of a woman with multiple sclerosis who underwent surgery for a leg infection said that when she was discharged he expected her to be "well enough to go home" or "as good as she had been before." He did not know that she was incontinent and that her bandages would need changing. During the first night home, he realized the

Fending for Myself, Defending My Partner

Bill's story*

I take care of my boyfriend who has AIDS. He takes up to 45 pills a day, and I make sure he sticks to the right schedule, which is very regimented in terms of taking pills with and without food, and at certain times of the day. I do most of the food shopping and household chores. When his viral load is high it is hard for him to get around, so I help him walk and take a shower.

He's only been in the hospital three times, mostly because he's stubborn and doesn't like being there. When I visit him in the hospital, the staff doesn't even acknowledge me. I usually run into problems seeing him outside of visiting hours, so I arrive within those times and tell them I'm bringing him dinner. When I get to his room I don't leave. I usually stay the night and sleep in a chair. Because I'm not technically a "family member," I'm not supposed to stay. But I *am* his family, and I'm the only family he has in the area.

At first the nurses are brusque and rude and don't help, but after a night, they see I'm not there to cause a scene. I get extra pillows or ice or whatever he needs because it takes them too long. They're not helpful or communicative. When I ask, "When is the spinal tap going to take place?" the nurses won't tell me. Because I'm not his "spouse," maybe they're not legally permitted to communicate with me.

The biggest problem with going to the hospital is that no one acknowledges that I am important to the health care of the patient. I feel as though I'm fending for myself and defending my partner. I sneak around to get what he needs. And with experience, I'm getting better at knowing what to demand right away and what to wait for.

It's ironic because the last time my boyfriend was in the hospital, the doctors depended on me to know what was going on. Every new staff person who came into the room—the neurologist, the internist, the psychiatrist, and the nurses—all asked questions trying to find out what was going on, but never spoke with each other. The transition to the hospital made me extremely anxious. Coordination became *my* job, but I didn't have any authority. And he was only having tests done. I can't imagine what it would have been like had he required immediate care.

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* Names and identifying characteristics have been changed to preserve the family's privacy.

bed was wet and the bandages were oozing. "I didn't know what to do, who to call, or who to get angry at," he recalled. "Nobody said to me, 'This is how your life is going to change.'" One young woman who had difficulty speaking about her predicament to the group explained haltingly, "My grandmother had her legs amputated. I was afraid and didn't know what to expect. Before she went to the hospital she was able to get around. Then when she came home, she had no legs. I was pretty young then and it was hard for me to deal with."

Many caregivers spoke of their sadness and the loss or change in their relationship with the care recipient. Even if the patient is still alive, some caregivers feel they have lost the family member, since the patient is not the person he or she used to be. Caregivers also feel they lose part of their lives in having to provide care, and they suffer when they see their loved one deteriorate to the point where he or she becomes a stranger. One woman taking care of her grandmother who is demented and has cancer said, "It is very sad because she cared for us as children and now she doesn't even remember us." One daughter said, "I think of Mom as dead now because she's not the Mom I knew."

The wife of a stroke patient said, "You see someone you love deteriorating and it breaks your heart." The daughter of a father who suffered brain damage while in the hospital remarked, "It's very hard to see somebody who was so strong end up this way. When I take care of him, there is such sadness in his face." Caregivers also spoke of patients' unexpected moods, such as hostility, and how difficult they are to experience. Participants also shared that they often feel reluctant to express their emotions around their family member. One woman, whose sister died of cancer, said, "It was heartbreaking to see her like that. I tried not to show my emotions around her."

GOING HOME

Caregivers experienced discharge from the hospital as an abrupt, upsetting event because hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. In many cases, participants reported, the patient after discharge required nursing skills or equipment they did not possess and had little time to acquire. Many caregivers felt they were expected to do things for which they were not trained. One daughter, whose mother died of cancer, said she was shocked to learn that her mother would be bedridden and would need a catheter when she came home. She said, "I was afraid. I'm not a nurse. We weren't trained. We didn't even get a piece of paper about how to bathe her or anything."

Another woman, whose husband returned from the hospital after a stroke, had difficulty monitoring a feeding tube, which had confusing computer settings. She had seen it in the hospital but received little training in how to use it at home. "I was terrified of it," she said, "It's broken twice. When we left the hospital they showed me 1,2,3 and that's it.

They said, 'Don't worry, you'll learn it.'" The same woman talked about being unprepared for her husband's moods. She said, "He was full of anger and insults. It was part of the illness but I didn't know it." When another woman commented, "You have to be understanding," the wife retorted, "How can you be understanding when you don't understand?"

Caregivers also find it stressful to be responsible for administering pain medications and often do not feel they have the training they need. One woman said the doctor did not explain to her the medication regimen her critically ill father would require. When she asked, the doctor told her, "Use your instincts."

"When you buy a pet at a pet store, you are given written instructions about how to take care of it, but you get nothing when you take a parent home from the hospital."

Several participants suggested that hospitals provide caregivers with more information to ease the transition. "There should be an 800 number to call up after discharge to find out if something is normal," several stated. As one participant said, "The doctors don't get back to you. They should give you a pamphlet or something." One woman said she calls the pharmacist for medical advice because she can always reach him. One young woman critiqued the lack of information available on how to care for seriously ill patients at home. "When you buy a pet at the pet store, you are given written instructions about how to take care of it, which things to look for, and what to do about them," she said. "There are books about how to take care of babies: when to call the doctor; what is normal; and what is not. But you get nothing when you take a parent home from the hospital. And these are ordinary diseases—things that happen every day."

When a patient leaves the hospital and returns home, the increased burdens of caregiving and the new kinds of care required often frighten and overwhelm the caregiver. A young woman said that when her grandmother, who has dementia and had a mastectomy, returned home from the hospital, "I felt incompetent. They said she might try to take the stitches out. I watched her constantly. I don't think I slept for a week." At the same time, her grandmother lost her ability to walk but was too heavy to lift. Eventually, after this young woman developed back problems, she reluctantly hired an aide to help her lift her grandmother. But the time immediately after discharge was very difficult because she felt she ought to be able manage by herself.

ADMISSION TO A HOSPITAL OR NURSING HOME

Although most of the discussion centered on transitions from institution to home, the reverse—transition from home to hospital or nursing home—also presented problems. Many caregivers gave several reasons why they do not experience the expected relief when their loved one is admitted to a hospital or nursing home. First, because many lack confidence about the quality of care in the institution, they feel responsible for supervising care and protecting the patient. They often feel exhausted from being at the hospital every day, all day, in addition to their other responsibilities. They worry about the condition of their loved one and fear that he or she may never return home. Many caregivers indicated that the unfamiliar surroundings of an institution sometimes make a patient extremely anxious and disoriented. Caregivers also talked about the difficulty of getting information in the hospital. As one man said, "They give you instructions about how to use the telephone and the television, but not how to get medical questions answered."

Many caregivers fear that their loved one will be neglected in hospitals and nursing homes. A transition to an institution means extra vigilance for the caregiver. Caregivers' worries ranged from doubt that the patient was getting enough attention to fear that the patient might actually be harmed. Several caregivers spoke of having to be vigilant so that their family member did not get bedsores. The wife of a stroke victim said she "paid someone to wipe him. They [the patients] get a little more attention if you pay." Others agreed, saying, "You give them a few extra dollars and they get better care." Another person said, "We had to slip an attendant a few dollars to [have my mother be treated] like a human being." Another said he felt the staff considered his father "just another bed."

"I paid an attendant to wipe my husband. Patients get a little more attention if you pay."

Caregivers said they sometimes provided direct care for the patient in the hospital. This was either met with resistance or welcomed by the nursing staff. One woman said her mother "lost her ability to speak so I felt I needed to be there [in the hospital] all the time. I became part of her care team and no one resented me. They showed me where the linen closet was and let me change her bedding." When her mother was moved to a nursing home, which she and her family had chosen after exhaustive research, she began to feel doubtful about the quality of care when she observed the lack of caring on the part of staff toward other residents. "I knew I couldn't turn my back on my mother for one minute," she said. "They tried to get me to go home. When I wouldn't leave, they called a security guard and forced me out." She said her mother had been in the hospital for four months, but the three weeks she was in the nursing home were "the worst weeks of my life." When her mother's condition necessitated readmission to the hospital, she said, "No one from the nursing home called to find out how she was doing. I just got a call about paying her bill."

One man caring for his partner with AIDS said he feels the hospital staff does not acknowledge him as someone close to the patient at all. As a result, he said he feels that he is "fending for myself and defending my partner. I sneak around to get what he needs. And with experience, I'm getting better at knowing what to demand right away and what to wait for." He said no one recognizes that the caregiver is important to what is going on. "No one acknowledges that I am important to the health care of the patient."

The Isolated Caregiver
Sarah's story*

My mother is 79 and lives with me. In the past four years she's had surgery three times, and has difficulty walking. I do the shopping, cooking, and cleaning. I give her medicine and help her take a bath. I have no brothers or sisters, and my mother won't let anyone else near her. My mother is a Holocaust survivor. She thinks her medical problems are caused by spells people in Austria put on her.

The last time my mother had surgery they discharged her into a nursing home for two weeks. It was the hardest time of my life. She was convinced she would not return home, and I had to reassure her every day. When she was in the hospital I could sometimes take a day off from being with her, but when she was in the nursing home I had to be there every day, from seven in the morning until eight at night. When I brought her home she still needed physical therapy, but she didn't want the therapist or the visiting nurses coming in.

Fortunately, I have some exceptionally close friends, but even they became a burden. When my mother came home from the hospital, over and over I had to talk to the therapist, the pharmacist, and the doctor. When my friends called at the end of the day I literally couldn't speak to them because I had no saliva left in my mouth. I started resenting their calls, and finally told them there is no point in reiterating what she does every day because it doesn't change. I became angry. I was angry with God, too. I took care of my father through three strokes, wasn't that enough? Why did we have to be Holocaust survivors?

During that period I could have used some help so I could have had some time to myself. But she doesn't trust other people. She has no friends, not since her entire family was killed. She believes there is no God. When I light Sabbath candles, she looks at me like I'm an idiot, as if I haven't found out yet that there is no God.

Looking back, it would have helped if the doctors had talked to me about what it was going to be like for me as a caregiver. They could have also started preparing my mother about her condition before she left the hospital. I think it comes better from a professional.

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* Names and identifying characteristics have been changed to preserve the family's privacy.

He also talked about the lack of coordination between health care professionals at the hospital. "Every new staff person who came into the room—the neurologist, the internist, the psychiatrist, and the nurses," he explained, "all asked questions trying to find out what was going on, but never spoke with each other. The transition to the hospital made me extremely anxious. Coordination became *my* job, but I didn't have any authority."

There were only a few reports of consistently good care. The good experiences seemed to reflect institutional, rather than individual provider, attitudes and behavior. Most of the time caregivers reported having had positive institutional experiences when their loved one had been in a specialized facility or unit.

In general, participants reported that hospital staff failed to acknowledge their emotional needs. None of the participants said that health care professionals had referred them to community-based agencies for emotional or other kinds of support. One woman said she spoke with her husband's doctor about her depression, and the doctor said, "You don't need medication. Just make up your mind that this is how it's going to be."

A granddaughter of a woman who had breast cancer said she thought the cancer was "all better" but was told the cancer had returned and her grandmother would have to go back in the hospital. The granddaughter felt angry, she said, because the doctor told her in a very "cold" manner. "How can I give care to this person when I can't handle it myself?" she asked. "If one person had sat down and taken my hand, it would have helped." She also stressed that the physical part of providing care isn't that bad, "it's the worry."

While participants reported that they had not received any referrals for emotional or other kinds of support, it is possible that hospital staff may have made such referrals at times when caregivers were too overwhelmed to absorb or act on the information.

Many caregivers believe that older people are not treated sensitively in hospitals. One woman said that hospital staff members "don't take the time with older people." Another woman described her experience when she took her mother to a nursing home for an interview. She said the social worker did not explain the purpose of her questions and began the interview by asking her mother very loudly, "Do you know where you are?" Her mother, who had no cognitive impairments, replied, "Yes, don't you?" When it became obvious that her mother was not cognitively impaired, the social worker nevertheless continued, "Do you know who the President is?" The mother snapped back, "You mean you don't know that either?" That ended the interview.

Another participant echoed this same sentiment. "Hospital personnel don't care about the elderly," she said. "My father had a colostomy and they didn't want to help. I had to change it. I had to be there all the time and it was embarrassing for him." Another woman complained that nurses shouted at her father. The daughter said they had placed a sign over his hospital bed with his age written in large numerals. She said when the nurses saw "80" on the sign, they assumed he was deaf.

Caregivers want compassion and understanding from institutional staff. Family caregivers and professionals seem to develop better relationships when professionals acknowledge that caregivers are important to the patient's well-being, and that they are also going through a difficult time themselves. As one woman said, "Professional staff should recognize that families are upset and acknowledge that it's a difficult time and that the hospital team is there to help."

In several cases, individual nurses were perceived as compassionate. As one woman said, though, "They're either great or they're rotten." When nurses are good at communicating compassion, caregivers are very grateful. One woman said that she kissed the nurse when her mother went home, because the nurse had been so good to the family. Others said that hospital staff needed courses in being sensitive and sympathetic. One participant went so far as to say, "Sometimes the cleaning people are nicer [than the professional staff]." One woman said that there is a line between being professionally distant and overly involved, and that most professionals are on the wrong side of it.

When nurses are good at communicating compassion, caregivers are very grateful.

Participants criticized social workers the most. Typically the social worker's only interaction with the family focused on discharge plans and paying the hospital bills. No one reported that a social worker had spoken with them about caregiving needs after discharge. One woman said, "Social workers need to redefine their profession. If they've studied sociology and social work, they should deal better with people." Social workers were reported as being helpful in two cases, however. One woman's grandmother is 102 years old and lives with her 70-year-old daughter who is legally blind. A social worker visits once a week and arranged for the grandmother to go to hospice for respite care for a short period every other month.

No one reported that a social worker had spoken with them about caregiving needs after discharge.

Another woman's aunt, who lived with her, underwent surgery for a colostomy. Nursing staff assumed the niece would change the colostomy bag, and on the day of discharge tried to show her how to do it. The niece almost fainted when she realized it involved direct contact with an open intestinal lesion and approached the hospital social worker in tears. The social worker arranged for the aunt to go to a nursing home until the colostomy was reversed as planned. This nursing home option, which was available under Medicare, was not presented to the niece until she became upset and refused to take her aunt home. This was the only instance in the focus groups in which a participant reported refusing to provide a particular kind of care.

CULTURE, FAMILY STRUCTURE, AND RELIGION

Caregivers reported that cultural differences created special care needs, and sometimes led to problems with health care professionals whose backgrounds differed from those of the family. Several caregivers attributed their parents' reluctance to receiving home care from strangers to their cultural backgrounds, even though these care recipients' racial and ethnic backgrounds differed from each other. One African-American woman explained that her mother is "clannish" and does not like strangers coming to her home. Three other women from varying cultural backgrounds who were in the same group also said their parents were suspicious of strangers and want their daughters to "do everything for them." One caregiver stated, "If I'm not in the plan, she won't have anything to do with it." A daughter reported that her foreign-born mother, who does not speak any English, will not let any physical therapists or other professionals in the house.

Another caregiver recounted her family history, which included surviving the Holocaust. Her mother now thinks her medical problems are caused by "spells people in Austria put on her." The result is that she is afraid to be left alone in the hospital and will not have strangers in the house.

Cultural differences emerged as being important in other ways. A woman from a large Hispanic family said that when her mother was dying many family members came to the hospital. "There were too many doctors doing too many things. They gave us all different stories. My sister doesn't speak English but she was the one authorized to sign the papers because she is the oldest." She said that because there were so many family members, the staff got tired of them. When they had to make a decision about ending care, the doctor told them, "There is no hope. You don't want her to be a vegetable. Let her go." She said, "We had no choice. We could have used more help in understanding this decision."

Some caregivers who are not immediate family members, or who do not fit into the traditional definition of "family," reported having difficulties obtaining information from, and being acknowledged by, hospital staff. Some participants reported feeling unacknowledged or encountered difficulty in obtaining information in the hospital because they fall outside traditional family roles. This was especially true of the man who is the caregiver for his partner with AIDS and the only person emotionally close to him in the area. He says he is ignored in the hospital, does not get information, and has a hard time seeing his partner outside visiting hours. The niece who cares for her aunt says she does not get information because "they only want to talk to the next-of-kin." One young woman caring for her grandmother said, "The nurses patronize me because I'm so young. But I'm willing to learn."

Although some participants sought a religious explanation for their situation, no one mentioned organized religious institutions or clergy as a source of solace or assistance. A middle-aged woman who cares for her grandmother said caregiving was particularly hard because she had already experienced so many deaths. Her cousin and nephew had been killed, and her husband had recently died. When her grandmother became ill with cancer, this woman said, "I was hating God. I said, 'What are you doing, God?' I didn't have anyone to talk to. I tried to talk to some of my friends, but you mention the 'C' word and they run." The woman whose family survived the Holocaust said, "I was angry with God. I had taken care of my father through three strokes, wasn't that enough? Why did they both have to be in this condition? Why did we have to be Holocaust survivors?" Despite her anger, she continues to observe religious rituals, which her mother disparages. "My mother believes that there is no God. I light Sabbath candles and she looks at me like I'm an idiot—as if I haven't found out yet that there is no God." Another woman who cares for her rapidly deteriorating father said, "God will decide when it's his time to go, but I have to take care of him every day, and I need more help."

None of these or other individuals reported obtaining guidance or assistance from a religious leader, church or temple, or other religious organization. When specifically asked about hospital chaplains, one woman, whose mother had died in a hospital, said that a chaplain had spoken to her family and that it was "helpful."

FINANCIAL FACTORS

In most groups, discussion centered more on the emotional aspects of caregiving transitions, and less on financial concerns. While the ability to pay for help at home and to maintain other important family goals is certainly a factor in a family's capacity to provide ongoing care, the caregivers in these focus groups did not emphasize the financial aspects of care. They were much more concerned with describing the emotional and physical drain of caregiving. The only direct conversation about money and costs pertained to paying extra for better care in the hospital or nursing home. There was no discussion of the cost of medical care or about the illness being a financial burden on the family. However, several women said that they had quit their jobs to provide care. Many others were juggling jobs and caregiving, and reported that even when hospitals did provide some support groups to caregivers, they were held during the day when caregivers were at work.

When discussion did turn to financial issues, participants criticized the health care system's focus on costs, and spoke of needing more resources to provide care. Many caregivers expressed the opinion that hospitals are "only interested in the money," and that care decisions are made on an economic basis. Several participants critiqued managed care organizations for discharging their family members from hospitals before they were

Unprepared for the Task

Arthur's story*

My wife is 71 years old. She has multiple sclerosis and is wheelchair-bound. She can't feed herself, lacks motor control, and is incontinent. She goes in and out of dementia as well. Sometimes she's passive and pleasant, other times she is very irritable, angry, and acts out. You never know which person you're going to be talking to.

Earlier this year I took her to a local hospital where she received physical therapy twice a week. But Medicare stopped paying for it because they said it was only maintaining her health, not improving it, even though it helped her.

Not long ago, she was hospitalized for 40 days after developing a life-threatening infection, which required aggressive surgery. All that time I would go to work, drive 25 miles to the hospital after work, stay with her, talk to the nurses, have supper in the cafeteria, visit with her some more, and go home to return 40 phone calls. I was exhausted by the time I got home, and I began to resent the calls. People were well-intentioned, but it was very tough on me personally.

When she came home from the hospital she seemed fine. I put her to bed, and went to bed myself. During the middle of the night I woke up to find the bed wet and her bandage oozing. My first thought was, "Why did they discharge her? She's not ready, she's not perfectly well." No one told me she was incontinent, and that her bandages would need changing. They just said to come back in three days to see the doctor. At that moment I asked myself, "How am I going to wait three days to see the doctor?" I didn't know what to do, who to call, or who to get angry at. Nobody said to me, "This is how your life is going to change." I had to discover that myself.

It would have helped if I could have spoken to a counselor in the hospital—and I don't mean the social worker. All she talked about was discharge. I also wish someone had informed me about support groups for caregivers of people with multiple sclerosis. I eventually learned about one, and it has been a great comfort. My friends and family members ask how my wife is, but they don't really want to know. They only want to hear me say she's okay. But when I talk to someone else whose husband or wife has MS, they really understand.

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* Names and identifying characteristics have been changed to preserve the family's privacy.

ready to come home, or for limiting the time spent in a rehabilitation center. One woman said her father was denied further rehabilitation because, "They said it would be a waste, since he'll never get better." Some caregivers cited the need for more home care assistance than their insurance would pay for. A few participants said they had looked into hiring private duty nurses from the hospital where their loved one had received care, but could not afford the rates. None of them considered pursuing any lesser level of care, such as a home health aide, however.

DEATH AND DYING

Bereaved caregivers did not have markedly different caregiving experiences from current caregivers, but they experienced the additional stress of what they felt was inappropriate care at the end of their family member's life. Since several participants were both current and bereaved caregivers, there was overlap in the groups. One participant currently caring for her cousin had taken care of both of her parents, who died in hospitals. She expressed regret for having brought her parents to the hospital because she believed their treatment was inappropriate and painful. Her mother received cardiopulmonary resuscitation, even though she did not want it. Her father was operated on even though he was near death. She said, "It was traumatic because no one told me what was going on. It would have helped if someone could have assisted me in making decisions since I am an only child—someone who could give real facts and probabilities. I read a book about a good death, but I didn't know how to do it—how to keep them home. I just went along with sending them to the hospital."

"It would have helped if someone could have assisted me in making end-of-life decisions since I am an only child."

Most bereaved caregivers were either unaware of hospice or felt that it was an inappropriate choice for their family member. Only one or two of the participants reported that they had used hospice. A few said they had heard about it but had not explored it any further. Those who were familiar with hospice said it was not appropriate in their situations because the care recipient was not close to death. One woman, who had already experienced one death, asked, "When do I call them, the week before?" A daughter who does not like the hospice philosophy said, "We didn't want to buy into the idea that this meant [my mother] 'had six months to live.'" One man whose father died in a hospice unit said he had received helpful information about his father's impending death, but complained about the facility's dreary appearance. "The atmosphere was awful and scary," he said. "It would have been nice for him to have been in a beautiful room or at home."

SUMMARY OF THEMES FROM THE FOCUS GROUPS

Caregivers want recognition that they are a part of what is happening to the patient, both the distress and the care. They want information and training to prepare them for what is going to happen and to allow them to feel confident in their own ability to provide care. They want access to professional advice during transitions and they want support from other caregivers who are having similar experiences. When the patient is in a hospital or nursing home, caregivers want to be able to communicate with health care professionals about their loved one's condition, and they want to be able to trust that the patient will be given good care and treated compassionately.

Transitions are difficult for the caregiver because they are times of discontinuity and uncertainty. During transitions, caregivers often feel a heightened, even overwhelming, sense of personal responsibility for the patient's health and well-being. The more fluid family structures that exist today mean that these caregivers might not be immediate family members or the next-of-kin. Focus group participants stressed the need for professionals to identify the primary caregiver, and to recognize that some are alone and without support. Finally, a greater sensitivity on the part of hospital staff to the needs and perspectives of caregivers will lessen caregivers' anxiety and may promote cooperation with health care professionals.

In brief, caregivers felt unprepared, both technically and emotionally, for the responsibilities they willingly undertook. Many felt abandoned at a critical time.

III. Hospitals' Perspectives

The previous section describes, from individual perspectives, the pressures that family caregivers face on many fronts. Their circumstances are by no means isolated incidents, however. They demonstrate the impact of broad changes that are occurring in health care delivery and financing systems. As hospital stays become shorter, patients are discharged with more complex medical needs. At the same time, pressures on staff to discharge patients quickly mean they have less time to prepare family caregivers, both technically and emotionally. As nonprofessionals, family caregivers often find the increasingly complex medical technology moving into the home to be intimidating. As a result, they feel overwhelmed and frightened by their new responsibilities. Their loving attachment to the patient complicates the learning process because they fear they will make mistakes.

The applications submitted by 28 New York City hospitals to the United Hospital Fund's Family Caregiving Grant Initiative demonstrate that hospitals are beginning to recognize this impact on family caregivers. As professionals, of course, hospital staff approach these problems from a different perspective. Some applications address the general hospital population, while others focus on specific patient populations, such as those with Alzheimer's disease, traumatic brain injury, AIDS, and chronic pain. While hospital staff wrote these applications with a different purpose (to obtain funding), and addressed somewhat different issues, their comments both confirm and amplify many of the themes articulated in the focus groups. (See Appendix F for excerpts from the Family Caregiving Grant Initiative planning grant application.)

GENERAL THEMES

The following themes sum up the observations of the health care professionals who submitted grant applications about the circumstances family caregivers face.

The health care system fails to adequately support and train caregivers. All the applications describe hospitals' concern about family caregivers and outline activities they currently provide to serve them, including some very active programs. Nevertheless, the applications in general acknowledge that whatever efforts do exist are largely unsystematic and inadequate to meet the enormous need. One application states candidly: "[T]here are few hospital resources that have been devoted to family caregivers. Caregivers are an invisible and unrecognized resource, except as a means to reduce direct costs of care. Professionals give little, if any, thought to the havoc that results when a family member

Living with an Accident's Aftermath

A Case Study from Jamaica Hospital Medical Center, Brady Institute for Traumatic Brain Injury*

Robert and Theresa Smith heard a knock on the door one warm summer evening, alerting them to their worst nightmare: their 18-year-old daughter Jill, who had been crossing a neighborhood street, had been struck by a speeding delivery van. Running to the scene, they arrived just before the ambulance doors closed, and accompanied their bleeding, unconscious daughter to the hospital. She remained in a coma for two weeks.

Jill's prognosis was not promising, but her parents held out hope. They befriended the staff hoping to glean bits of information about her condition. They waited at the cognitive therapy rooms to speak with the neuropsychologist in the traumatic brain injury unit. With more than 20 patients at a time, he could sometimes offer only a few sympathetic words.

During the third week Jill opened her eyes, but could not speak or control her limbs, bladder, or bowels. She needed to be fed a thick liquid so she wouldn't choke. Her diapers required frequent changing. She was strapped into bed so she wouldn't try to get up and injure herself.

When the insurance for inpatient care ran out after two months, Robert and Theresa had to decide whether to place Jill in a long-term care facility or care for her at home. After much agonizing, they brought her home and began a grueling schedule of seemingly endless caregiving.

Thus also began a continual campaign for services—in-home physical, occupational, and speech therapy, nursing care, and equipment. The Smiths advocated for home health aides to care for Jill so they could both return to work. They developed a workable, but tense, strategy: Mrs. Smith cut her job to part-time so she could spend the balance of the day taking care of Jill's affairs—interviewing home attendants, few of whom lasted more than a week, contacting health providers, and negotiating and scheduling services.

Robert received little attention from his wife. During evening meals, which were usually take-out, she would engage him in decisions about Jill's care, and conflicts often erupted. After a long day at the office he didn't want to think about or second-guess his wife's preferences. Tension grew between them until they seldom spoke. They stopped going out alone together. Their intimate life ended.

This was only the first chapter in the Smith's ongoing struggle. After two years of caring for Jill at home, they faced the arduous task of getting her on Medicaid. And for the rest of her life, Jill will remain seriously disabled and will require ongoing, intensive rehabilitation.

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* Names and identifying characteristics have been changed to preserve the family's privacy.

"Caregivers are an unrecognized resource, except as a means to reduce direct costs of care. Professionals give little, if any, thought to the havoc that results when a family member assumes caregiving duties."

assumes caregiving duties." One hospital describes the problem this way: "While family care can be emotionally supportive, it is also inherently unstable....[F]amily members are not always trained to provide the care that is needed. While well-meaning, they may not understand the medications, treatment regimens, or physical care that is needed to properly care for the patient."

One application focusing on patients with difficult pain management problems reports, "Caregivers play a key role in pain management. This role may involve administering the analgesic medication prescribed by the physician; using non-drug pain relief methods; obtaining, filling, and refilling prescriptions; assessing pain; making decisions about dosages; communicating with the health care team; reminding or encouraging the patient to take medications; keeping records; and controlling technical aspects of patient controlled analgesic pumps. Sleep deprivation and exhaustion from dealing with pharmacies and insurance companies have also been reported over the course of a long-term illness." Despite the crucial role family caregivers play, and their vulnerability due to exhaustion, the hospital offers them little training and support.

A hospital that provides substantial services to its family caregivers who care for patients with disabling head injuries nevertheless feels that, "Our impression is that these services only begin to address the substantial needs of this population. [Family members] frequently complain about the enormous impact and extent of their burden, and the dearth of services in the community. They desperately but unsuccessfully seek day programs and...unable to find them, complain of *their own* increasing imprisonment in the home."

Fragmented communication leaves caregivers confused and uninformed. Echoing the focus group participants' complaints about poor communication, one application notes that, "Communication with health care providers is often fragmented, leaving caregivers uninformed or confused. Ongoing communication with the caregiver is essential to effective planning and outcomes and remains a significant challenge. For example, frequently neither caregivers nor patients have the opportunity to discuss issues such as advance directives prior to a critical event." This application states that because many caregivers are employed full-time, it is extremely difficult for them to be available during daytime hours, which hinders effective communication between professionals and family caregivers and can compromise quality of care.

Discharge planning, as currently practiced, often fails to create smooth transitions. One hospital explains, "Theoretically, discharge planning should make the hospital-to-home transition a smooth one. Significantly, the voice of the caregiver is not heard nor is it solicited; patients are asked to sign off on plans already made, disempowering the patient and more importantly the family caregiver." Compounding difficulties in discharge planning, another hospital states, "is our lack of educational and training materials to educate clinicians and caregivers about the challenges that confront family caregivers....There has been relatively little in-depth training of clinicians in negotiating and understanding the acute care-community interface. Furthermore, tools that are currently used by clinicians to assess how well 'caregivers' understand their emotional and technical responsibilities do not distinguish individuals who provide short-term assistance following a loved one's acute illness or injury from those who provide ongoing care and decision making for their loved one's chronic or terminal condition."

"Compounding difficulties around discharge planning, our hospital lacks educational and training materials to educate clinicians and caregivers about the challenges that confront family caregivers."

The health care system does not sufficiently recognize the role of family caregivers. One application says: "In mainstream American medical care, the family has never been truly integrated into the system of caregiving in the hospital, a situation that presents extraordinary difficulties for families of dementia patients. Unfortunately, [these families] often actually feel unwelcome and unsupported in their efforts to ensure the best care for the patient....Family caregivers who feel that hospital staff do not properly attend to the special needs of the patient with dementia may become angry and lose trust in the institution's ability to provide care without their constant vigilance." The expertise that these families develop regarding the patient's unique needs and personality often remains unutilized and unacknowledged by health care professionals.

"In mainstream American medical care, the family has never been truly integrated into the system of caregiving in the hospital."

Patients from diverse backgrounds have different needs and circumstances. Several applications mention the ethnic and cultural backgrounds of their family caregivers. In describing African-American family caregivers, one application states: "In addition to the burden placed on female black adult children, many times the prime caregiver is a sibling, elderly himself/herself. Often doubling up and living together, the well elderly sibling is asked to assume caregiving responsibilities beyond his/her capability. The desire to keep the loved one at home and out of a nursing home prompts these elderly siblings to take on these caregiving responsibilities." Another hospital, with a predominantly Hispanic population, says, "Due to the extended family structure, Hispanic and other minority families are frequently opposed to long-term placement of loved ones. The impact of managed care regulations, shortened length of stay, and reduction of formalized home care assistance, are imposing stronger demands [which notably affect these] families....Most [of these] family caregivers have no outlet for respite to maintain their health and well-being."

BARRIERS TO SERVING FAMILY CAREGIVERS

The RFP asked applicants to describe the most significant barriers to involving family caregivers and meeting their needs. Applicants identified the following:

- **Lack of time and financial resources.** This was by far the most common response. One application sums up the problem: "The major barrier within our hospital and extended care facilities to improving services to family caregivers currently comes down to a lack of funds to address these important and newly recognized needs. In the current Medicare and Medicaid environment, we are anticipating further cuts rather than additional funds to address these issues." One hospital places economic constraints as the primary barrier, but also notes a second barrier: "The limited time that social work staff can devote to counseling and developing an in-depth understanding of family needs."

- **Overlooking the caregiver.** One application notes that health care providers—both clinicians and staff—generally focus on the patient's clinical condition and, in doing so, often overlook the needs of the caregiver. "This may be due to a variety of causes," it states, "including: the power health care providers have over others; personal values; an unwillingness to admit that they do not have all the answers; concerns about patient confidentiality; and a reluctance to deviate from procedures to accommodate the varied situations of families."

- **Inadequate information systems.** "Information systems focus on sharing clinical information," an application notes, "while no infrastructure exists to collect and share the social and emotional aspects of care."

- **Language, cultural, and educational differences.** Problems can arise, one hospital states, when families and health care professionals come from different cultural backgrounds, and when they speak different languages. Educational differences can also create barriers to communication and understanding between families and the medical establishment.

- **Families' emotional responses to illness.** A loved one's illness can prompt a range of emotional reactions for caregivers, including guilt, fear, and anxiety. "It is especially challenging for strangers [i.e., hospital staff]," one application says, "to [provide] emotional [support] in a meaningful way....There are no clear prescriptions for help."

These frank and thoughtful applications suggest that, at least at some administrative and clinical levels, professionals are aware of the increasing burden on family caregivers.

They want to do better, and recognize the substantial barriers they face. This is the beginning of what will inevitably be a long process. The failure to recognize and support family caregivers did not begin with managed care; it has been intrinsic to the American health care system. The changes in health care delivery and financing in the past several years, and the advances of technology, have brought the issues to a new level of concern. No single action or program will be a solution. Building long-term partnerships of mutual trust and respect takes time. The following recommendations outline some key steps.

IV. Recommendations for Change

The following recommendations for change are a beginning. They are not so grandiose that they depend on vast changes in the American political or economic system nor so trivial that they accomplish little more than a token bow to family caregivers. These recommendations, in conjunction with the Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System (see Appendix B), can make a difference and should be implemented. The first three recommendations are general in nature; the last three address transitions specifically.

GENERAL RECOMMENDATIONS

Recommendation 1: Health professionals, government agencies, and managed care organizations should recognize explicitly, in policy and practice, that family caregivers who assume significant care responsibilities are a valuable but vulnerable resource. Recognizing that family caregivers can no longer be taken for granted is the first step in meeting their needs. Family caregiving is sometimes conveniently seen as only the simple and ordinary assistance provided to elderly people. Yet, at the most intensive end of the caregiving spectrum, family caregiving is often total care and management of seriously ill or cognitively impaired family members, and often lasts for many years. While all family caregivers can benefit from assistance and support, those with the most demanding or long-term responsibilities are particularly vulnerable to physical and emotional problems. A new awareness of the potentially devastating impact of increased responsibilities on family caregivers, and on family functioning and stability, must shape program and policy development.

Recommendation 2: This recognition of the critical role of family caregivers must be built into medical, nursing, and social work training and continuing education. New efforts are underway to bring training in home care, including working with family caregivers, into the medical school curriculum. These efforts should be supported and expanded. All health care providers whose patients are cared for at home should learn and experience the challenges of providing quality care in an environment designed for family intimacy. A home is not a hospital.

Recommendation 3: More research is urgently needed to understand the impact on family caregivers of changes in the health care system and on interventions that families need and want. Although there is a vast literature on family caregivers, most of it focuses on a health care system that no longer exists, on the needs of the frail elderly, and on conventional family structures. Much more research is needed. Some examples are: the establishment of a common research definition for caregiving and disability so that studies can be more easily compared; the elements of successful respite programs; and cross-cultural studies of family caregivers in the new health care environment.

SPECIFIC RECOMMENDATIONS ABOUT TRANSITIONS

Recommendation 4: Health care providers must make discharge planning, and transitions from one care setting to another, a process rather than a single event. Health care organizations must identify better and earlier ways to organize transitions so that family caregivers are given targeted and ongoing training, support, and follow-up. Links to community-based sources of support—religious organizations, patient/family advocacy and support organizations, civic organizations, and others—should be developed and maintained for appropriate referrals. The outlines in Section V, entitled "Covering the Basics for Family Caregivers," provide a good start toward creating smoother transitions. They are designed for use by both health care professionals and family caregivers, and should be adapted to fit individual circumstances.

Recommendation 5: Hospitals and other health care institutions should develop model programs that offer innovative ways of involving and meeting the needs of family caregivers. While most family caregiving is provided at home, hospitals and other health care institutions (home care agencies, rehabilitation centers, community-based agencies, nursing homes) play an important part in the patient's and family's life. Because they are often leverage points in arranging services in the community, they can be leaders in involving family caregivers in creatively developing model programs, for example, in meeting the needs of culturally diverse populations, or for caregivers with family members with a specific medical condition.

Recommendation 6: Public and private insurance plans and managed care organizations should evaluate benefits and service plans to reflect the importance of training, supporting, and communicating with family caregivers. As more responsibilities and direct costs are shifted to patients and family caregivers, there is a potential for adding new costs to the health care system: re-hospitalizations or additional treatments for complications caused by the family's inability to cope or understand how to provide adequate care; the added health care costs when a caregiver develops illnesses from the physical, emotional, and social strain of caregiving; and the subsequent need to substitute for that caregiver.

Additional, modest paid help for training or respite at critical points in the course of the patient's care may reduce these undesirable consequences. Family advisory councils should be created or given enhanced roles in managed care organizations and public and private insurance plans to provide feedback on benefits and service plans, proposed policies, and other issues.

The implementation of these recommendations must involve the people who provide most of the nation's health care (family caregivers) and focus on the setting in which most care is actually provided (the home). These recommendations go beyond helping families cope with common ailments, the miseries of the flu, the inconvenience of a broken wrist, or the emergency of an appendectomy. They are designed to help those who are often the lifelines for the cognitively impaired elderly, the seriously ill, the severely handicapped, and those who need continuous intervention to survive and flourish. While it is understandable that heroic families are praised, public policy should not be based on an expectation of martyrdom.

This report and its recommendations are intended to contribute to the development of responsible and reasonable ways to respect, understand, and help all families coping with serious illness and the major transitions that mark that journey.

V. Covering the Basics for Family Caregivers Outlines

- **THE INPATIENT STAY**
- **DISCHARGE TO HOME**
- **WORKING WITH HOME CARE AGENCIES AND VENDORS**
- **WHEN THE PATIENT HAS A TERMINAL ILLNESS**

The following outlines are intended to suggest some concrete ways to create smoother transitions, as mentioned in Recommendation 4. Because a change in a patient's health status and/or a move to a different care setting provide opportunities to review and reevaluate the family caregiver's situation, the outlines are organized around these common transition points. They can be used by health care professionals and family caregivers in these instances, and others as well, such as when changes in a family caregiver's health, responsibilities, or financial circumstances occur. They should be adapted or expanded to meet specific family needs.

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COVERING THE BASICS FOR FAMILY CAREGIVERS

The Inpatient Stay

For patients admitted to hospitals, nursing homes, rehabilitation centers, and other health care facilities.

FIRST STEPS

Identify the primary family caregiver(s).
Name(s) ____________________
Relationship to the patient ____________________

Identify the one or two health care team members (physician, nurse, social worker, physician assistant, etc.) who are responsible for communicating information about the patient to the primary family caregiver(s):
Name(s) ____________________
____
Phone number(s) ____________________

DISCUSSION DURING THE PATIENT'S STAY

With consent of the patient, health care professionals, family caregivers, and patients should discuss the following:

Patient Status/Continuing Care

1. The patient's condition in clear, lay-language terms.
2. Treatment options in terms of risks, benefits, financial coverage, and likely outcome.
3. Estimated date of discharge.
4. Any likely changes in the patient's condition after discharge.
5. The family's caregiving capacity and needs.
6. If this is a readmission, a reassessment of the family's caregiving capacity and needs.
7. Options for placement after discharge.
8. The institution's policies and expectations of family participation in care.
9. Advance directives, designation of health care proxy.

Support Services

Health care professionals and family caregivers should discuss how to access the following services:

1. Emotional and decision making support.
2. Individual counseling, on site or in the community.
3. Support groups, on site or in the community.

Other Needs as Appropriate

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COVERING THE BASICS FOR FAMILY CAREGIVERS

Discharge to Home

For patients discharged home from hospitals, nursing homes, rehabilitation centers, or other health care facilities.

DISCUSSION

Health care professionals, family caregivers, and the patient (if appropriate) should discuss the following before discharge:

1. The patient's condition, and any changes that may have occurred as a result of treatment at the facility.
2. Any likely symptoms, problems, or changes that may occur when the patient is at home.
3. The patient's care plan, the caregiver's needs, and any adjustments that must be made to meet these needs.
4. The potential impact of caregiving on the caregiver; warning signs of stress; techniques for reducing stress.

PLANNING

With consent of the patient, health care professionals and family caregivers should make the following plans/arrangements before discharge:

1. Readying the home by arranging for equipment rentals, home modifications, hiring of aides, etc.
2. 24-hour phone number a caregiver can call to speak with a health care professional.
3. Transportation home for the patient.
4. Follow-up appointment.

TRAINING

Health care professionals should provide family caregivers with applicable training before discharge:

1. Specific instructions on medication regimen, along with a written medication list with information about possible side effects and duration of regimen.
2. Adequate training in techniques, procedures, equipment, medications, recognition of symptoms, and other elements of patient care.

REFERRALS

Health care professionals, caregivers, and patients should explore available support services before discharge:

1. Community sources of social support for caregivers and patients.
2. Community-based agencies that provide services such as transportation, equipment maintenance, respite care, home care, volunteer services.
3. Information resources such as books, pamphlets, videos, web sites, etc.

OTHER NEEDS AS APPROPRIATE

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COVERING THE BASICS FOR FAMILY CAREGIVERS

Working with Home Care Agencies and Vendors

For patients discharged home who require home care and equipment.

INFORMATION

Hospital staff and home care agencies should work together to ensure that the patient and family caregiver know the following:

1. How the home care plan is developed, and how the patient and family can participate in creating it.
2. The level of training home care staff have completed (RN, home health aide, etc.).
3. The number of hours per day and days per week the aide and/or nurse will visit.
4. The types of services the aide and/or nurse will perform.
5. The types of services the aide and/or nurse is not expected to perform.
6. Whether the same aide and/or nurse will be consistently available.
7. The availability of backup support.
8. Fee structure.
9. If the service is paid for by insurance or a government program, the approximate length of time the service will be available.
10. Others who will be involved in home care (therapists, nutritionist, etc.).
11. The process for resolving problems and complaints among patient, caregiver, and aide or nurse.

CONSIDERATION

Home care agencies should serve patients and family caregivers while considering:

1. Patient preferences about daily routines, likes, and dislikes.
2. Special family traditions around religious rituals, food, visits, etc.

SERVICE

Home health care vendors who supply equipment, supplies, or transportation should provide patients and family caregivers with:

1. Prompt, courteous, respectful delivery and/or service.
2. Training on equipment in use at home, which may differ from that used in hospital.
3. Service or consultation on an emergency basis.
4. Prompt attention to repairs and replacements.
5. Information on how to register complaints.

OTHER NEEDS AS APPROPRIATE

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COVERING THE BASICS FOR FAMILY CAREGIVERS

When the Patient Has a Terminal Illness

For terminally ill patients in hospitals or nursing homes.

INFORMATION

With consent from the patient, if competent, a designated member or members of the health care team should provide family caregivers with information about:

1. The patient's condition in clear, lay-language terms.
2. Treatment options in terms of risks, benefits, financial coverage, and likely outcome.
3. The importance of health care proxy designation, if not already in place.
4. Options of palliative care or hospice, at home or as an inpatient.

DISCUSSION

The patient, if competent, the family caregiver, and a designated member of the health care team should discuss:

1. Preferences for how to make decisions about end-of-life care.
2. Decisions for sustaining or withdrawing treatment, DNR orders, palliative care, etc.
3. These wishes should be put into a written statement and included in the patient's medical chart, if he or she remains hospitalized.

SUPPORT

Health care professionals should provide family caregivers and patients with:

1. Spiritual support for patients and family members from staff clergy or members of the patient's own faith community.
2. Bereavement counseling before and after patient's death.
3. Follow-up contact after death.

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Appendix A
Families and Health Care Project National Advisory Committee 1997-1998

EMILY ABEL, PH.D.
Professor of Public Health
and Women's Studies
University of California
Los Angeles, California

BARBARA BERKMAN, D.S.W.
Professor of Social Work
Columbia University School of Social Work
New York City

HARRISON BLOOM, M.D.
Vice Chairman for Clinical Affairs
Department of Geriatrics
Mt. Sinai-NYU Medical Center and
Health System
New York City

HENRY CHUNG, M.D.
Medical Director
Chinatown Health Clinic
New York City

KENNETH COVINSKY, M.D., M.P.H.
Assistant Professor of Medicine
Division of General Internal Medicine
Case Western Reserve University
School of Medicine
Cleveland, Ohio

NESSA COYLE, R.N., M.S.
Director, Supportive Care Program
Department of Neurology Pain Service
Memorial Sloan-Kettering Cancer Center
New York City

PAMELA DOTY, PH.D.
Senior Policy Analyst
Office of the Assistant Secretary for
Planning and Evaluation
U.S. Department of Health and Human
Services
Washington, D.C.

NANCY DUBLER, L.L.B.
Director, Division of Legal and Ethical
Issues in Health Care, Epidemiology, and
Social Medicine
Montefiore Medical Center
Bronx, New York

MINDY FULLILOVE, M.D.
Associate Professor of Psychiatry
New York State Psychiatric Institute
New York City

RUBY GREENE, M.P.A.
Director, Patient Relations
The Long Island College Hospital
Brooklyn, New York

JIMMIE HOLLAND, M.D.
Chief, Department of Psychiatry
Memorial Sloan-Kettering Cancer Center
New York City

GAIL GIBSON HUNT
Executive Director
National Alliance for Caregiving
Bethesda, Maryland

ROSALIE KANE, D.S.W.
Director, Long-Term Care Resource Center
University of Minnesota
Minneapolis, Minnesota

LEN MCNALLY
Program Director
New York Community Trust
New York City

LIDIA POUSADA, M.D.
Chief, Division of Geriatrics and Gerontology
Geriatric Institute of Westchester
Sound Shore Medical Center
New Rochelle, New York

CAROL RAPHAEL
President and Chief Executive Officer
Visiting Nurse Service of New York
New York City

GARY ROSENBERG, PH.D.
Senior Vice President
Mt. Sinai-NYU Medical Center and Health System
New York City

WILLIAM RUDDICK, PH.D.
Professor of Philosophy
New York University
New York City

ANDREA SANKAR, PH.D.
Professor of Medical Anthropology
Wayne State University
Detroit, Michigan

R. KNIGHT STEEL, M.D.
Director
The Homecare Institute
Hackensack, New Jersey

PATRICIA STILL
Support Group Leader
Well Spouse Foundation
New York City

RICK SURPIN
President
Cooperative Home Care Associates
Bronx, New York

RABBI GERALD WOLPE
Har Zion Temple
Penn Valley, Pennsylvania

Appendix B

Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System*

The U.S. health care system is changing. As a result of fewer hospitalizations and shorter stays, and a market-based approach to health care financing, family caregivers confront increasing responsibilities, burdens, and challenges.

While family members have always been important providers of direct care and emotional support for their ill loved ones, their role is now even more critical. Some reasons are:

- Chronic illnesses, rather than acute illness, are the most prevalent forms of disease.
- High-technology care has moved from hospitals to homes.
- More women, the traditional caregivers, are in the labor force and less available to provide full-time care.
- An aging population requires more care, especially with progressive neurological diseases.
- Successes in acute-care medicine have saved lives but have left many people with long-term care needs.

Most families feel an obligation to help an ill loved one, and those who assume the demanding role of family caregiver typically do so because of their close attachment to the person or because of a combination of practical, emotional, and social reasons. The impulse to provide care cannot thrive without support from many sources. The Families and Health Care Project of the United Hospital Fund offers these principles as a basic framework to guide the relationships among patients, families, and professionals. The goal is a partnership based on mutual trust, respect, and cooperation.

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Principle 1: FAMILY CAREGIVERS ARE AN ESSENTIAL PART OF THE HEALTH CARE SYSTEM

Family caregivers have been largely invisible in the current system. They have been "silent partners," whose contribution has been taken for granted. A new approach is urgently needed to make family caregivers valued partners in care. Family members who take on caregiving responsibilities must be well prepared, provided with ongoing training and support, and given information about a full range of options for themselves and their loved ones.

Principle 2: HEALTH CARE PROFESSIONALS, INSTITUTIONS, AND INSURERS HAVE RESPONSIBILITIES TOWARD FAMILY CAREGIVERS

The primary responsibility for initiating and continuing the discussions and negotiations that flow from these principles lies with the health care professional or team leader who provides medical care to the ill family member. This may be a physician, physician assistant, nurse, social worker, or other professional. Institutions have responsibilities to train professionals to fulfill this responsibility and to develop programs that improve the process. Managed care organizations, private insurers, and public programs have responsibilities to set realistic and achievable limits on the type and amount of care family caregivers are expected to provide. Family caregivers may also initiate and direct the process, but they should not be assumed to know all the aspects that are and will become important to them.

Principle 3: EACH FAMILY HAS DIFFERENT STRENGTHS, LIMITATIONS, RESOURCES, AND CAPACITIES FOR CAREGIVING

"Family" should be broadly defined. Legal definitions of "family" do not reflect the diversity of relationships that often make up an individual's support network. Family caregivers include people related by blood, marriage, or adoption as well as individuals who have longstanding emotional ties to the care recipient.

All families should not be expected to provide the same level of care that some families are able to provide. Family caregivers come from many different cultures, religions, ethnicities, and socioeconomic groups; even within these broad groups, individual family caregivers have different personal goals, priorities, and values. In developing and evaluating care plans, health care professionals should assess each family situation and avoid

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stereotyping family caregivers on the basis of their gender, relationship to the care recipient, age, income, educational status, or other characteristics. Some family members are not appropriate caregivers, either because of their own health needs, other family responsibilities, substance abuse, mental illness, or hostility toward the care recipient.

Principle 4: FAMILY CAREGIVERS SHOULD BE INCLUDED IN DECISION MAKING

Family caregivers' decisions to provide care should be based on an informed negotiation with health care providers. Just as patients' treatment decisions are guided by their informed consent or refusal, similar discussions of potential risks or harms, benefits, and available sources of support and alternatives should precede family caregivers' agreements to provide significant levels of care, especially at home and for long periods.

In decisions about patient care that significantly affect the interests and well-being of family caregivers, an ethic of accommodation is more appropriate than patient autonomy alone. Both the care recipient's autonomy and preferences and the interests and well-being of the family caregiver are important considerations in decisions, for example, to discharge a seriously ill or disabled person to home care. Turning a home into a quasi-hospital involves considerable sacrifice of privacy, sanctuary, and other important values. The care recipient may be reluctant to accept caregiving from anyone but the primary family caregiver, but this preference should be balanced by the caregiver's own needs and other responsibilities.

Principle 5: FAMILY CAREGIVERS NEED INFORMATION, EDUCATION, AND SUPPORT

Family caregivers should be given consistent, accurate, and up-to-date information about the care recipient's condition and current and foreseeable caregiving needs. Physicians should discuss with patients and family caregivers the boundaries of patient confidentiality and whenever possible should obtain consent for discussing the patient's condition and care with family caregivers. When there are many members of a health care team—either in an institution or at home—it is especially important that the team leader introduce each member and define his or her role and responsibility. Team members should be consistent with each other in their communications with family caregivers.

Family caregivers should be provided initial and ongoing education and training. Family caregivers need an orientation process that may take many sessions. This training should

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include, at a minimum, practice in the skills they are expected to master, whether they involve medical procedures or therapies, behavioral management, or other aspects of providing personal care. One-time-only training, when the family caregiver is anxious and in an unfamiliar environment like a hospital, is insufficient.

Family caregivers should be given emotional support and counseling. Typically family caregivers experience anxiety, stress, fatigue, isolation, and sadness. They also frequently gain satisfaction from their role. They need support from other members of the family, friends, clergy, and health care professionals in adjusting to their frequently ambivalent reactions.

Family caregivers should be offered appropriate services or referrals to community-based agencies and other sources for assistance with home care, financial management, support groups, and other services. These offers should be repeated frequently, since family caregivers often do not recognize their own needs until they are overwhelmed by their tasks. Family caregivers need respite both on a short-term basis and for vacations.

Principle 6: FAMILY CAREGIVERS NEED OPPORTUNITIES TO REEVALUATE THEIR RESPONSIBILITIES AND, IF NECESSARY, TO REASSIGN THE TASKS

Family caregivers should be given regular opportunities to reevaluate their situation and to make changes in the care plan. Family caregiving is a dynamic role. Transitions in the care recipient's condition, care setting, family structure or financial status, or the primary family caregiver's health may all be occasions to reevaluate the care plan. At some point the primary caregiver may no longer be able to provide care; this should not be seen as a failure. An appropriate transition should be arranged.

Family caregivers, care recipients, and professionals should have access to a sensitive process to mediate conflicts. Conflicts may arise over confidentiality, informing the patient of prognosis, cultural traditions, end-of-life decisions, and many other issues. These conflicts should be avoided if possible or resolved in a respectful, fair, and balanced way through a process that allows full consideration of all viewpoints. Conflicts between different agencies, institutions, or professionals should be resolved without jeopardizing patient care or the family's stability.

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Principle 7: FAMILY CAREGIVERS NEED GUIDANCE FOR END-OF-LIFE CARE AND DECISIONS

Patients and family caregivers should be encouraged to talk about end-of-life decisions, as well as to identify persons to act as health care proxies and, if desired, to prepare advance directives. Health care professionals should begin this dialogue at an early stage, and in ongoing discussions should explain all the options for care, including palliative care and hospice, as well as continued aggressive cure-oriented treatment. Respect for cultural values and traditions should inform these decisions. Trained clergy can play a crucial role in addressing the spiritual dimensions of end-of-life care.

Physicians and administrators should honor advance directives and the decisions of health care proxies. Honoring patients' wishes at the end of life is well established in law and ethics, but less so in clinical practice. The principles outlined here are intended to support a joint decision making process that will result in consensus about the goals of care and the most compassionate way to achieve them.

Principle 8: AS PARTNERS IN CARE, FAMILY CAREGIVERS ASSUME OBLIGATIONS

Family members who assume the role of caregiver have an obligation to perform their role to the best of their abilities, to work toward developing constructive relationships with professional caregivers, and to seek help when they encounter problems that jeopardize quality of care or their own health or well-being. In a well-functioning system that implements these principles, family caregivers will be better prepared to perform their tasks and more readily recognize their strengths and limitations. By knowing what they can do and being better prepared and assisted to do it—and by knowing what responsibilities they cannot sustain—family caregivers will work more closely with professionals in a mutually advantageous way.

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Appendix C
Focus Group Methodology

The United Hospital Fund's Families and Health Care Project conducted six focus groups of family caregivers in September 1997 in New York City. The following details the methodology that was employed.

Recruitment. A professional focus group firm in New York City was retained to recruit the participants, provide space for the sessions, and handle the arrangements. The focus group firm recruited family caregivers from its database, advertisements in local newspapers, and other outreach activities. In addition, the Well Spouse Foundation sent information about the focus groups to its support group leaders. A professional focus group facilitator worked with Families and Health Care Project staff to develop a questionnaire (a "screener") provided to the firm. The screener asked questions about demographics, level of caregiving provided, number and types of transitions, patient disease, when the care was provided, and whether the patient had since died (see Appendix E). Participants who had ever been in a focus group about health or in any focus group in the past year were excluded. Recruitment was reviewed with project staff on a weekly basis.

While focus group organizers frequently report that many people who agree to participate fail to show up, the focus group firm's intensive and persistent contact with participants resulted in excellent participation rates in all the groups. Participants were paid an honorarium for their time, transportation, and any costs involved in hiring substitute caregivers. For each group, approximately 13 participants were recruited, because it was expected that some would not attend. When more than ten participants arrived for a group, which occurred in four groups, ten were selected based on information in the screener. Participants who were dismissed at the time of the session were paid.

Focus group format. Groups were audiotaped, videotaped, and observed by Fund staff, all with permission of the participants. Participants were assured confidentiality, that their last names would not be used, that there was no connection with the medical care their family member was receiving, and that the tapes would be available only to the study team. Following the groups, Fund staff contacted participants to ask further written permission to use parts of the videotape for presentations related to the project. A 15-minute video was created for educational purposes. Fund staff also requested written permission to print the vignettes that appear in Sections I and II of this report.

The Moderator's Guide consisted of three sections (see Appendix D). First, participants were asked to describe the condition of the person they care for and about the kinds of care they provide. Next, they were asked to think of a significant transition and any difficulties they may have had providing care during this transition. Finally, they were asked to think of what would have helped to make the transition easier.

Groups lasted from one-and-a-half to two hours each. All six groups proceeded smoothly with enough opportunity for each group member to participate. At many times during the groups, there was lively conversation, expressions of mutual support, and emotional statements. Several participants spoke openly about their depression. One participant in the bereaved group was so overcome at the beginning of the session that he could barely say his name but later participated fully. Another man in the same session was reluctant to leave at the end of the session and engaged the moderator in extended conversation. It was apparent that many participants had not had any prior opportunity to discuss their experiences. In several groups a participant spontaneously said that what was needed was "more support groups like this one."

Participant demographics. Characteristics of the caregivers are presented in Table 1. A total of 56 people participated. The participants ranged in age from 20 to 70. Women—the traditional caregivers—and men participated. There was significant ethnic diversity, including African-American, Caribbean black, Greek, Hispanic, Irish, Italian, Jewish, and Native American caregivers. About half of all participants had gone to college but more than half had family incomes of less than $25,000 per year. Participants in the focus groups came from the New York metropolitan region, and from both urban and suburban locations.

Table 1

Demographics of 56 Focus Group Participants

Gender/Age	No.	Race/Ethnicity	No.	Education/Income	No.
Women	45	White	35	No College	30
Men	11	Black	17	College	26
		Hispanic	3		
		Native American	1		
Age				**Annual Family Income**	
20–29	8			Low (less than $24,999)	32
30–39	16			Moderate ($25,000 to $49,999)	15
40–49	18			High ($50,000 and up)	9
50–59	6				
60–70	8				

Care recipient demographics. Most of the care recipients were women, older than 60, and had one or more chronic diseases. An unexpected variety of relationships was also represented. For instance, many of the participants were patients' grandchildren. The care recipients had also been patients in a variety of types of institutions: community hospitals, large academic medical centers, rehabilitation units or centers, and nursing homes.

Table 2
Demographics of 56 Care Recipients

Age	No.	Relationship to Caregiver*	No.	Primary Diseases*	No.
80 or older	21	Mother	15	Cancer	15
60–79	25	Grandmother	12	Heart Condition	7
40–59	5	Aunt	6	Alzheimer's Disease	5
39 or younger	5	Father	4	Stroke	5
		Neighbor/Friend	4	Arthritis	5
		Husband/Partner	3	AIDS	5
		Mother-in-Law	3	Diabetes	2
		Sister	2	Other (including: Emphysema, Cirrhosis, Old Age, Multiple Sclerosis, Lupus)	12
		Cousin	2		
		Wife	1		
		Father-in-Law	1		
		Sister-in-Law	1		
		Brother	1		
		Uncle	1		

*These are the primary care recipients. Many focus group participants had cared for more than one person.

*Many care recipients have multiple conditions.

Appendix D
Focus Group Moderator's Guide*

1. **Welcome participants:** Thank you for coming. We appreciate your help.

2. **Tell very briefly about the project:**
This group is sponsored by a philanthropy called the United Hospital Fund. The purpose of the project is to help professionals understand the concerns and needs of caregivers. Eventually the goal is to help health care professionals and family caregivers form more effective partnerships.

   We will be talking today about the experiences you've had as family caregivers and especially about the times when the patient moved from one place to another, such as home from the hospital or from the hospital to a nursing home. We will ask you to discuss how the move affected you as a caregiver.

3. **We have some ground rules for the group today:**
   - No right or wrong answers.
   - We need to hear from everyone.
   - Just give your own opinions (don't try to convince or get people to agree).
   - We have several topics to cover so we will not want to talk about every aspect of your experience. Most everyone's experience could take two or more hours to discuss in detail.
   - We want to give everyone an opportunity to talk about each topic, so each person needs to be somewhat brief.
   - I may sometimes need to stop you so we can get back on focus and get through all of our topics.
   - Discussion is being taped (audio and video) (easier, don't have to take notes).
   - Since we are taping, we all need to speak up, one person at a time.
   - The discussion in this group is anonymous. This group is not connected with any health care facility, provider, or funder. That means we won't be connecting your name with what you say and your information will not be available to anyone outside the study team without your permission.

---

*The focus group guide that appears here was used for groups of current caregivers. The same guide, with minor changes to the text, was used for groups of bereaved caregivers.

- Location of bathroom (we'll take a break halfway through the group).
- Refreshments.
- Usually people enjoy these groups as an opportunity to talk with others. Please relax and be as open as possible.

4. **Introductions:** first, I'd like to go around the room and ask each of you to give your first name and tell us about the illness of your family member.

Probe for:

- **relationship**
- **age of patient**
- **condition of the patient**
- **history of care and transitions**

Elapsed time = 30 minutes

Most of the time, the focus of questions is on the patient. For the purposes of this group, though, we will ask you to focus on your experiences as a caregiver. In other words, tell us how it was for you (how you felt and how you were treated), not what happened to the patient.

Thinking back to the last move the patient made (specify for each participant) write the one word that best describes the biggest problem you faced as a caregiver.

PAUSE

Under it write the next biggest problem you faced as a caregiver.

PAUSE

Then the next. What did you write? Please explain.

Encourage interaction

Probe for:

- **Feelings:** how did you feel when this happened?
- **Specific needs:** What responsibilities did you have? Did you have all the information you needed? Were you able to get everything you needed?
- **Interactions and communication:** Were you included in decisions? How were you treated by doctors, nurses, social workers, or other staff members? Were staff members helpful or not? Concerned about you? Annoyed or angry with you? Did you know what was going on?

Elapsed Time = 60 minutes
Break = 10 minutes

Thinking back, again, to the time the patient moved from one place to another, how could it have gone more smoothly? What was needed? Please describe the ideal situation in detail.

Probe for:

- **all issues mentioned earlier**
- **specify everything needed**
- **anything else**

Elapsed Time = 100 minutes

Thank you for coming. Your participation may help other families who are caregivers. I hope everything goes well for you and your family in the future.

Appendix E

Focus Group Recruitment Screener for Current and Bereaved Caregivers

Form A

1. Hello, my name is _______________ with _______________ organization. We are conducting a survey for the United Hospital Fund. I am calling to talk with people who have some experience taking care of someone who is ill or disabled. May I ask you a few questions?

2. Are you now taking care of someone for at least a year who is ill or disabled or did you take care of someone in the last three years who has since died?
   ☐ Yes—Patient died (Skip to Form B)
   ☐ Yes—Current
   ☐ No—Terminate

3. How old is the person you care for?
   Age_____ If less than 18, terminate.

4. What is the condition of the patient and how long has he or she been in this condition?
   ____
   ____
   ____

   Disabled means needing regular care from another person for walking, eating, or going to the bathroom or having memory or speech problems requiring regular care—for at least a year.
   If not disabled, terminate.

5. What does your caregiving entail? In other words, what do you have to do for the patient?
   ____
   ____

   Significant level of care includes regular ongoing help with walking, eating, bathing, or going to the bathroom (or managing someone else doing this care). It also means doing tasks for someone with memory, thinking, or speech problems.
   If not significant level of care, terminate.

6. Has the patient been in a hospital, nursing home, or another care setting (other than home) for any time while you've been taking care of him or her?
   ☐ Yes—Continue
   ☐ No—Terminate

7. Please tell me the times s/he has moved from home to another setting (such as a hospital or nursing home or rehab center) or from the other setting to home (or gone from having a paid caregiver to having no paid caregiver at home).
   1.____
   2.____
   3.____
   If less than three moves or changes, review with project staff.

8. What is your age? ______Years

9. Have you ever been in a focus group?
   ☐ Yes—What was the topic? **See below**[*]
   ☐ No—Continue

10. How would you describe your race?
    ☐ White
    ☐ Black—Record below
    ☐ Asian—Record below
    ☐ Hispanic—Record below
    ☐ Other—Record below

11. Do you have a college degree?
    ☐ Yes
    ☐ No—Record below

12. Are you employed for pay?
    ☐ Yes
    ☐ No

---

[*] Group should not include participants who know each other or are related in any way. None may have been in a health-related group ever or any group in the last year. All groups should have **at least** three non-whites and **be either** all female or an even mix of males and females. Groups 3 and 4 should have all members with family income less than $25,000 and no college degree. Patient disease, age of patient, age of caregiver, relationship of caregiver, and employment status of caregiver should be mixed.

Check recruitment table to see if respondent is needed.
If no, terminate.
If yes, say:
We would like you to participate in a group discussion to be conducted at our facility on__________ at ___:___. The discussion will last approximately two hours and you will be paid $75.00 for your time and any expenses you incur. Will you be able to attend?

Form B

1. Did you take care of a family member or friend for at least a year before he or she died?
   ☐ Yes—Continue
   What was the person's relationship to you?________________
   ☐ No—Terminate

2. How old was the person you cared for?
   Age_____ If less than 18, terminate.

3. What was the condition of the patient and how long was he or she in this condition?

   Disabled means needing regular care from another person for walking, eating, or going to the bathroom or having memory or speech problems requiring regular care—for at least a year.
   If not disabled, terminate.

4. What did your caregiving entail? In other words, what did you have to do for the patient?

   Significant level of care includes regular ongoing help with walking, eating, bathing, or going to the bathroom (or managing someone else doing this care). It also means doing tasks for someone with memory, thinking, or speech problems.
   If not significant level of care, terminate.

5. Was the patient in a hospital, nursing home, hospice, or another care setting (other than home) for any time while you were taking care of them?
   ☐ Yes—Continue
   ☐ No—Terminate

6. Please tell me the times s/he moved from home to another setting (such as a hospital or nursing home or rehab center) or from the other setting to home (or gone from having a paid caregiver [or outpatient hospice] to having no paid caretaker at home).
   1.________________________________
   2.________________________________
   3.________________________________
   If less than three moves or changes, review with project staff.

7. What is your age? ______Years

8. Have you ever been in a focus group?
   ☐ Yes—What was the topic? **See below**[*]
   ☐ No—Continue

9. How would you describe your race?
   ☐ White
   ☐ Black—Record below
   ☐ Asian—Record below
   ☐ Hispanic—Record below
   ☐ Other— Record below

10. Do you have a college degree?
    ☐ Yes
    ☐ No—Record below

11. Are you employed for pay?
    ☐ Yes
    ☐ No

Check recruitment table to see if respondent is needed.
If no, terminate.
If yes, say:
We would like you to participate in a group discussion to be conducted at our facility on __________ at ___:___. The discussion will last approximately two hours and you will be paid $75.00 for your time and any expenses you incur. Will you be able to attend?

---

[*] Group should not include participants who know each other or are related in any way. None may have been in a health-related group ever or any group in the last year. All groups should have **at least** three non-whites and **be either** all female or have an even mix of males and females. Group 5 should have four or more members with family income less than $25,000 and no college degree. Patient disease, age of patient, age of caregiver, relationship of caregiver, and employment status of caregiver should be mixed.

Appendix F
Excerpts from the United Hospital Fund Family Caregiving Grant Initiative Planning Grant Application

OVERVIEW

The Family Caregiving Grant Initiative will support the development and testing of programmatic responses to the unmet needs of family caregivers providing care for seriously ill or disabled adults, where hospitalization and admission to and from other care settings is common. The Initiative will address family caregivers' needs through a two-phase, multi-year process, beginning with planning grants averaging $20,000 to approximately 15 hospitals. These grant awards will be made in May 1998 with the goal of developing program proposals by December 1998. The Initiative will award five to seven implementation grants in February 1999.

PLEASE BE SURE TO ADDRESS THE FOLLOWING:

1. **Project Summary (1/2 page)**
   Summarize the goals of your project and the analytic and planning activities you propose to undertake. Please be sure to describe:
   - Your target population of family caregivers and the general characteristics of the patients for whom they provide care.
   - The methods you will use to involve family caregivers in the planning process.
   - Your plans for exploring possible partnerships with community-based organizations or other health care providers.

2. **Background (3-4 pages)**
   In the current health care delivery and financing environment, there are many reasons to develop innovative family-centered care and support programs. These reasons include an increase in the number of patients with chronic illnesses requiring ongoing care at home with intermittent hospitalizations; shorter and fewer inpatient stays with discharge plans that increasingly depend on family caregivers; building integrated care networks; enhancing consumer satisfaction and loyalty; improving quality of patient care; avoiding staff conflicts with families; and others.

A. *Describe the current situation in your hospital. You may use case examples to illustrate your response. Include the following and any other relevant information:*
  - Your hospital's reasons for participating in this grant initiative.
  - Specific adult patient groups for whom unpaid, "informal" family caregivers provide significant levels of care over time at home.
  - Current educational and training initiatives in your hospital to educate clinicians about family caregivers' roles in patient care and decision making and the problems family caregivers face in fulfilling these roles.
  - Current educational and training initiatives in your hospital to educate family caregivers about their roles in patient care and decision making and how to meet the challenges they face.
  - Any non-medical services or programs in your hospital that address the psychosocial, emotional, or spiritual care needs of family caregivers dealing with chronic or terminal illness.
  - Current programs that link family caregivers to services in the community, either while their loved one is hospitalized or after discharge.

B. *Describe what you consider the most significant and challenging barriers within your hospital to the effective involvement of family caregivers in patient care and decision making and in providing services that are directed at family caregivers themselves.*

3. **Project Description: Planning Phase** (4-5 pages)
Describe your planning strategy, relating it to the goals, conditions, and obstacles described above:
  - Describe in detail the methods you plan to use with family caregivers, patients, and staff—e.g., surveys, focus groups, interviews—to assess the unmet needs of family caregivers and to identify areas for improvement and opportunities for demonstration projects.
  - Describe any tools or materials you will need to help conduct your planning strategy.
  - Describe how the proposed planning strategy engages the commitment of hospital leadership.
  - Describe how you plan to ensure the multidisciplinary participation of staff (physicians, nurses, social workers, chaplains, physical or occupational therapists, or others) in the planning phase.
  - Describe how you plan to ensure active family caregiver involvement in the planning process.

- Describe how you plan to explore forming relationships with one or more community partners (community-based organizations or health care providers). If you already have chosen a partner, describe the relationship and include a letter of agreement.
- If you anticipate engaging consultants for any aspect of project planning, please describe the anticipated use; and, if possible, identify the consultants and provide appropriate background material.

ANSWERS TO FREQUENTLY ASKED QUESTIONS

Q: What do you mean by "family caregivers"?

A: Family caregivers, sometimes called "informal" caregivers, are unpaid individuals who provide significant levels of care and management for a patient with a chronic, serious, or terminal illness or a severe disability. The care may include obtaining and supervising medications, changing bandages, monitoring symptoms or home care equipment like oxygen, supervising activities, feeding, shopping, cleaning, assisting with bathing and toileting, arranging transportation, accompanying the patient on medical visits, or many other activities that the patient cannot manage independently. Family caregivers are distinguished by the ongoing nature of their responsibilities (as opposed to helping a patient for a few days after coming home from the hospital) and by the level of their responsibilities, which extend far beyond providing emotional support or intermittent companionship, which many other people may also provide.

Q: Do family caregivers have to be related legally?

A: No. Family caregivers include many people in non-traditional relationships. They may be friends, neighbors, or partners who undertake significant levels of care.

Q: Are family members who provide care to ill or disabled children a target population under this grant initiative?

A: No. Although we recognize the significant challenges facing parents and caregivers of children, this initiative is limited to family caregivers of adult patients.

Q: Why is a "community partner" an important component of the initiative?

A: A continuum of care requires coordination of many different services and agencies. Community-based providers and service organizations are important elements in comprehensive patient care. Community partners can provide significant assistance when patients and family caregivers make transitions from hospital to home or nursing home or other facilities.

Q: **What kinds of groups are eligible to be "community partners"?**

A: Community partners may be home care agencies, nursing homes, or rehabilitation facilities; patient/family advocacy and support groups, usually focused on a specific disease or condition; general social service or mental health community-based agencies that assist patients and families in coping with the financial, emotional, and social impact of illness; community-based health care providers such as ambulatory clinics; fraternal, civic, or religious organizations.

Q: **What will be the selection criteria for awarding planning grants?**

A: Selection criteria will include: a demonstration of top-level administrative and clinical commitment to the project; an interdisciplinary approach; a thorough review of current practices involving family caregivers in some key area of service delivery; level of involvement of family caregivers and patients in information gathering and planning; and plans for exploring partnerships with community-based organizations or other health care providers.

Appendix G
Hospitals Awarded First-Phase Planning Grants under the Family Caregiving Grant Initiative

Sixteen hospital grants totaling $320,000 at $20,000 each were awarded to the following New York City hospitals in May 1998:

Beth Israel Medical Center
The Brooklyn Hospital Center
Cabrini Medical Center
Calvary Hospital
Harlem Hospital Center
Jamaica Hospital Medical Center
Lincoln Medical and Mental Health Center
The Long Island College Hospital
Maimonides Medical Center
Montefiore Medical Center
The Mount Sinai Medical Center
The New York and Presbyterian Hospital
New York University Medical Center
Peninsula Hospital Center
Saint Vincents Hospital and Medical Center
Sisters of Charity Health Care System

Current Publications

Better Jobs, Better Care: Building the Home Care Work Force ***Paper Series***

This paper presents specific strategies to meet home care workers' needs for more defined career opportunities, improved supervision and support, and better training.

#7038 56 pages 1994 $10.00

Beyond the Clinic: Redefining Hospital Ambulatory Care ***Paper Series***

Based on the Fund's Ambulatory Care Services Initiative, this report distills case histories from 12 New York City hospitals' programs to increase and improve outpatient services. Sections on reengineering the outpatient department, developing and implementing networked information systems, and training primary care providers and other staff are supplemented by examples of new tools and job descriptions.

#7348 64 pages 1997 $12.00

The Challenge of Caring for Patients near the End of Life: Findings from the Hospital Palliative Care Initiative ***Paper Series***

This report describes findings from the first phase of the Fund's Hospital Palliative Care Initiative, in which 12 New York City hospitals gathered information about deaths in their hospitals. The report identifies areas for improvement in current hospital practice and necessary institutional commitments to change, and concludes with recommendations for developing new models to promote palliative care.

#7372 64 pages 1998 $15.00

Health Care Annual: Data on Hospitals in New York City, Long Island, and the Northern Metropolitan Area, 1998 Update

This annual data publication presents updated information about the capacity and utilization of hospital inpatient and ambulatory care services in southern New York, and includes information on physical medicine and rehabilitation, psychiatry, and substance abuse care. Ten-year trend data are included, along with a directory of hospitals and maps showing hospital locations.

#7429 80 pages 1998 $20.00

Health Care for Children: What's Right, What's Wrong, What's Next

With 17 chapters by pediatric and health policy experts, this book examines the health status of U.S. children and describes how they currently get health care, including, increasingly, through managed care arrangements. The book outlines needed improvements in children's health services, and assesses the prospects for reform in today's political climate. It concludes with a broad-ranging agenda for change.

#7313 416 pages 1997 $40.00

Hospital Watch: A Quarterly Report on Hospital Finance and Utilization

This report examines key indicators of the current trends in the utilization, operations, and financial performance of hospitals in New York City. The most recent issue is available upon request.

No charge*

How to Choose a Nursing Home: A Guide to Long-Term Care in New York City, 1998 Guide

This pocket-sized publication helps consumers, families, and friends obtain the information needed to choose a nursing home. The guide offers step-by-step instructions, and lists 179 New York City nursing homes, providing information on their locations and ability to accommodate special care needs.

First copy, no charge (each additional copy $1)

Mediating Bioethical Disputes ***A Practical Guide***

This publication provides an overview of the use of alternative dispute resolution strategies, particularly mediation, to resolve bioethical disputes. A step-by-step process is described for mediating such disputes. Case studies, glossary, and bibliography are included.

#7194 104 pages 1994 $20.00

Medicaid Home Care Services in New York City: Service Utilization and Family Involvement

This data book documents the health status, needs, and makeup of New York City's Medicaid home care population, including their health conditions and impairment levels, demographic profiles, and the availability of family support.

#7402 28 pages 1998 No charge*

Medicaid Managed Care Currents

This quarterly newsletter discusses developments in New York's Medicaid managed care program. It is based on research and analytic work of the New York Consortium for Health Services Research. The most recent issue is available upon request.

No charge*

Meeting Patients' Needs: Quality Care in a Changing Environment ***Paper Series***

Based on a Fund conference, this paper summarizes and evaluates methods to define, measure, and demonstrate the quality of hospital care and reorganize the delivery of hospital services, with a special focus on two current trends: reengineering and patient-centered care.

#7275 36 pages 1995 $12.00

*These publications are also available at the Fund's web site: http://www.uhfnyc.org

Monitoring Medicaid Managed Care: Developing an Assessment and Evaluation Program ***A Special Report***
Based on an invitational conference, this report discusses the information, reporting, and analytic systems that would support meaningful evaluation of Medicaid managed care in New York City. The report focuses on three key dimensions: enrollment, quality, and cost.
#7259 52 pages 1995 $25.00

New York City Community Health Atlas, 1994
Designed for use by health care planners and analysts, the *Atlas* integrates demographic, economic, health services, and health status data to provide a picture of health needs and service patterns in 41 New York City communities. Borough and neighborhood data profiles describe demographic and health service patterns, which are also graphically illustrated by detailed maps and charts.
#7003 192 pages 1994 $50.00

New York City Medicaid Managed Care Enrollment Atlas
This data resource presents citywide and zip code-level information on Medicaid managed care eligibility and enrollment in New York City as of June 1997. City and borough maps show the geographic distribution of each plan's enrollees and the percentage of Medicaid beneficiaries enrolled in managed care, and tables provide program eligibility and plan enrollment statistics by aid category, as well as total enrollment, for 175 zip codes, each borough, and citywide.
#7380 104 pages 1998 $40.00

Reshaping Inpatient Care: Efficiency and Quality in New York City Hospitals ***Paper Series***
This report on Fund initiatives in length of stay and patient-centered care describes targeted efforts among two groups of hospitals in New York City to identify and change practices that unnecessarily prolong inpatient stays and to deliver care that is highly responsive to the personal needs and preferences of patients and their families.
#7291 44 pages 1996 $12.00

Rough Crossings: Family Caregivers' Odysseys through the Health Care System ***A Special Report***
Based on focus groups conducted by the Fund's Families and Health Care Project, this publication chronicles the troubling experiences that caregivers of chronically ill or disabled family members face when encountering the health care system. Drawing from applications to the Fund's Family Caregiving Grant Initiative, it also provides perspectives on the subject from hospital staff. The report concludes by offering recommendations for systemic improvement.
#7437 88 pages 1998 $15

The State of New York City's Municipal Hospital System, Fiscal Year 1997
Based on the findings of the Fund's City Hospital Visiting Committee, a 125-year-old citizens' group, this annual publication reports on conditions affecting patient care in New York City's public hospitals.
#7364 48 pages 1997 $10.00

State Strategies for Financing Graduate Medical Education ***A Special Report***
This special report describes various options for funding graduate medical education and examines how different states are using GME funding to address public policy goals.
#7356 56 pages 1997 $25.00

Taking Steps, Losing Ground: The Challenge of New Yorkers without Health Insurance ***A Special Report***
This publication presents a thorough and revealing analysis as to why the numbers of uninsured in the country, and in New York State in particular, have risen dramatically in the last several years. It offers various feasible, concrete strategies for expanding coverage to the uninsured in the state.
#7410 72 pages 1998 $25.00

An Unfinished Revolution: Women and Health Care in America
This 16-chapter book describes women's special contributions to health care in the United States and takes a hard look at the challenges that remain, providing perspectives on women's roles as consumers of health services, health care professionals, research subjects, informal caregivers, and health care leaders.
#7178 304 pages 1994 $20.00

Zip Code Area Profiles, 1994
This companion volume to the *New York City Community Health Atlas* integrates demographic, economic, health services, and health status data to provide a picture of health needs and service patterns in 165 zip code areas.
#7208 358 pages 1994 $100.00 (book)
$250 (Disk—*please specify Lotus or SPSS.* Includes hard copies of *New York City Community Health Atlas* and *Zip Code Area Profiles.*)

To order, please write to the United Hospital Fund, Publications Program, Empire State Building, 350 Fifth Avenue, 23rd Floor, New York, NY 10118. Checks should be made payable to the United Hospital Fund and include postage and handling (see chart). For information about bulk orders or for a complete list of publications, please call 212-494-0700 or visit the Fund's web site at http://www.uhfnyc.org.

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Raymond L. Rigoglioso, *Editor*
Lipman Hearne, *Cover Design*
Liza Buffaloe, *Production*

The CHAIRMAN. Ms. Mittelman, please proceed.

STATEMENT OF MARY S. MITTELMAN, ALZHEIMER'S DISEASE CENTER, NEW YORK UNIVERSITY MEDICAL SCHOOL, NEW YORK, NY

Ms. MITTELMAN. Thank you, Mr. Chairman.

Everyone in this room either is or knows someone who is caring for a relative suffering from Alzheimer's disease. Alzheimer's disease has devastating effects on both patients and the families who care for them. Drugs produce only modest improvements, and the possibility of curing or preventing Alzheimer's disease remains far in the future. In the meantime, as the population continues to age, the financial and emotional cost to patients and families, as well as the cost to the Federal health care budget continues to grow.

Many caregivers become overwhelmed and find it necessary, much against their sense of what is right, to place their relatives in nursing homes. The problem is that no matter how good a nursing home is, it cannot provide patients with love. Only their families and the people who are close to them can provide true love and caring—not manufactured, and not per diem. You cannot buy that.

It costs the taxpayer between $30,000 and $70,000 a year to keep a person in a nursing home, but for a lot less, we can keep our elderly relatives at home, and we can keep our families together. So what we need is a way to help families keep their loved ones at home.

At NYU, we have shown, with a scientifically rigorous trial, what common sense might suggest is the way. We have proved that counseling and support of caregivers and their families is an extremely effective treatment. Our study focused on spouse caregivers of Alzheimer's patients, most of whom are elderly themselves. More than 400 husbands and wives of patients with Alzheimer's disease have enrolled in the NYU Spouse-Caregiver Intervention Study since it began in 1987. Using the kind of design usually reserved for trials of new drugs, we randomly assigned subjects to either a treatment or a control group.

The treatment has two goals: first, to make it possible for the spouse-caregivers to do what almost all of them say they want to do to postpone or avoid placing their husbands and wives in nursing homes, and second, to reduce the negative impact of caregiving on the caregiver.

Because every caregiver has different needs, the treatment includes individual, custom-tailored counseling. Because most caregivers would benefit from more understanding and help from their families, the treatment includes family counseling. Because Alzheimer's disease can last for many years, and its effects change over time, the treatment is not time-limited.

In the first 4 months after enrolling in the study, caregivers in the treatment group had two counseling sessions along with a counselor and four counseling sessions with selected family members. A vital component of the treatment is that counselors continue to provide support for caregivers and their families for the duration of the disease. Counselors are available to help caregivers and their families deal with crises and with the changing nature of the patients' symptoms, to provide information and referrals for additional help, and to help them understand and manage the patients' behavior. The treatment also required caregivers to agree to join support groups that met weekly.

Caregivers in the control group received the support that had been routinely offered to caregivers at our center, which included resource information and help when they requested it, but no formal counseling.

What were the results? We found that caregivers in the treatment group were able to postpone placing patients in nursing homes for about a year longer than caregivers in the control group. The median difference was 329 days. The treatment was most effective for caregivers of mildly to moderately demented patients for whom nursing home placement is least appropriate.

The well-being of the caregivers also improved. Many caregivers suffer from symptoms of depression. While caregivers in the control group became increasingly depressed after they entered the study, caregivers in the treatment group did not. In addition, caregivers in the treatment group grew closer to their families and expressed increasing satisfaction with the emotional support they received. This was not true of caregivers in the control group. Moreover, caregivers in the treatment group were significantly better able to tolerate and manage the behavior of the patients, which undoubtedly resulted in their providing them with a better quality of care.

The study at NYU showed, without a doubt, that counseling and support helps families keep Alzheimer's disease patients at home. It is clear that the availability of generous, humane, long-term, competent emotional support and referral to high-quality community resources can make a huge difference.

What does it say about us as a society if we are not prepared to support the family so that it can care for its members as they age? The ability of an elderly spouse to care for his or her ill partner is often enhanced by the contribution of their adult children. These adults, often in mid-life, are torn by the conflicting needs of parents, children, their own spouses and their own personal aspirations. Thus, the impact of the disease trickles down to all members of the family. It is not likely that any family will be exempt from the role of caregiving. We need to find ways to provide the kind of help that was found to be so effective in the NYU Spouse-Caregiver Intervention Study to all the family caregivers who need it. We need to find a mechanism for paying for care at home that does not drain the family resources. The challenge is to convince those who provide and pay for health care of the value of counseling and support for family caregivers.

The National Institute of Aging has recently provided us with added funding for a Caregiver Core, a major research resource that will also provide counseling and support to all caregivers who are responsible for patients at the NYU Alzheimer's Disease Center. We are convinced that the well-being of caregivers is essential to the well-being of patients. I believe that the model that was so successful in helping Alzheimer's disease caregivers at NYU can also be an effective part of the treatment of any chronic illness that creates a need for long-term care.

I would like to thank Senators Grassley and Breaux for inviting me to describe our work at NYU to you today.

The **CHAIRMAN**. And that reminds me—Senator Breaux is always so loyal in being here, but he is also chairman of the Commission on Medicare, and that is taking up a great deal of his time, and he could not be here today—I did not announce that ahead of time, and you reminded me about that.

[The prepared statement of Ms. Mittelman follows:]

TESTIMONY OF

Mary Mittelman, Dr. P.H.
Aging and Dementia Research Center
Department of Psychiatry
New York University Medical Center

BEFORE THE

Special Committee on Aging

September 10, 1998

Everyone in this room either is, or knows someone who is, caring for a relative suffering from Alzheimer's disease. Alzheimer's disease has devastating effects on both patients and on the families who care for them. Drugs produce only modest improvement and the possibility of curing or preventing Alzheimer's disease remains far in the future. In the meantime, as the population continues to age, the financial and emotional cost to patients and families as well as the cost of the federal health care budget, continues to grow.

Many caregivers become overwhelmed and find it necessary, much against their sense of what is right, to place their relatives in nursing homes. The problem is that no matter how good a nursing home is, it cannot provide patients with love. Only their families and the people who are close to them can provide true love and caring, not manufactured and not per diem. You cannot buy that. Now, it costs the taxpayer between $30 and $70 thousand a year to keep a person in a nursing home. But - for a lot less, we can keep our elderly relatives at home and we can keep our families together. So what we need is a way to help families to keep their loved ones at home.

At NYU, we have shown, with a scientifically rigorous trial, what common sense might suggest is the way. We proved that counseling and support of caregivers and their families is an extremely effective treatment. More than 400 husbands and wives of patients with Alzheimer's disease have enrolled in the NYU Spouse-Caregiver Intervention Study since it began in 1987. Using the kind of design usually reserved for trials of new drugs, we randomly assigned subjects to either a treatment or a control group.

The treatment has two goals: first, to make it possible for spouse-caregivers to do what almost all of them say they want to do - to postpone or avoid placing their husbands and wives in nursing homes; and second, to reduce the negative impact of caregiving on the caregiver.

Because every family has different needs, the treatment includes individual custom-tailored counseling. Because most caregivers would benefit from more understanding and help from their families, the treatment includes family counseling. Because Alzheimer's disease can last for many years and its effects change over time, the treatment is not time-limited.

In the first four months after enrolling in the study, caregivers in the treatment group had two counseling sessions alone with a counselor and four counseling sessions with selected family members. A vital component of the treatment is that counselors continue to provide support for caregivers and their families for the duration of the disease. Counselors are available to help caregivers and their families deal with crises and with the changing nature of the patient's symptoms, to provide information and referrals for additional help, and help them understand and manage the patient's behavior. The treatment also required caregivers to agree to join support groups that met weekly.

Caregivers in the control group received the support that had been routinely offered to caregivers at our center which included resource information and help when they requested it, but no formal counseling.

What were the results? We found that caregivers in the treatment group were able to postpone placing patients in nursing homes for about a year longer than caregivers in the control group - the median difference was 329 days! The treatment was most effective for caregivers of mildly to moderately demented patients, for whom nursing home placements is least appropriate.

The well-being of the caregivers also improved. Many caregivers suffer from symptoms of depression. While caregivers in the control group became increasingly depressed after they entered the study, caregivers in the treatment group did not. In addition, caregivers in the treatment group grew closer to their families and expressed increasing satisfaction with the emotional support they received. This was not true of those in the control group. Moreover, caregivers in the treatment group were significantly better able to tolerate and manage the behavior of the patients, which undoubtedly resulted in their providing them with a better quality of care.

The study at NYU showed, without a doubt, that counseling and support helps families keep Alzheimer's patients at home. It is clear that the availability of generous, humane long term competent emotional support and referral to high quality community resources can make a huge difference.

What does it say about us as a society if we are not prepared to support the family so that it can care for its members as they age? The ability of a spouse to care for his or her ill partner is often enhanced by the contribution of their adult children. These adults often in mid-life, were torn by the conflicting needs of parents, children, their own spouses and their own personal aspirations. Thus the impact of the disease trickles down to all members of the family. It is not likely that any family will be exempt from the role of caregiving. We need to find ways to provide the kind of help that was found to be so effective in the NYU Spouse-Caregiver Intervention Study to all the family caregivers who need it. We need to find a mechanism for paying for care at home that doesn't drain the family resources. The challenge is to convince those who provide and pay for health care of the value of counseling and support for family caregivers.

The National Institute of Aging has recently provided us with added funding for a Caregiver Core, a major research resource that will also provide support and counseling to all caregivers who are responsible for patients at the NYU-Alzheimer Disease Center. WE are convinced that the well-being of caregivers is essential to the well-being of patients. I believe that the model that was so successful in helping Alzheimer's disease caregivers at NYU can also be an effective part of the treatment of any chronic illness that creates a need for long-term care.

The Importance of Caregiver Research at NIA-Supported Alzheimer's Disease Centers

Mary Mittelman, Dr.P.H.
Alzheimer's Disease Center, NYU Medical Center

The concept of conducting caregiver research within the context of an Alzheimer's Disease Center (ADC) is justified both by its immediate intuitive appeal and by the pragmatic advantages that would accrue to each entity. Caregiver research substantially enhances the ability of an ADC to achieve its scientific and service goals. The presence of the caregiver research can *enhance the public image of the ADC* and improve its ability to recruit and retain patients as clinical subjects of the *Clinical Core,* clinical trials and other research studies. Similarly, the ADC provides those conducting caregiver research with increased access to potential subjects, the opportunity to interface with researchers knowledgeable about other facets of Alzheimer's disease (genetics, new and innovative treatment strategies for patients, etc.). In addition, the services provided to caregivers can be of direct benefit in improving the quality of life of patients and caregivers. We have recently received funding from the National Institutes of Aging to establish a *Caregiver Core* at the NYU-Alzheimer's Disease Center. This will make it possible to provide the types of supportive interventions that have been proven effective in the NYU Spouse-Caregiver Intervention study as a service to all caregivers of patients at the Center.

- Liaison between families of patients with AD and ADCs improves the ability of ADCs to recruit and retain subjects. The caregiver of an AD patient is the decision maker — establishing a relationship with the caregiver will improve patient tracking and overcome resistance to participating in research studies.
    - The ADC staff participating in caregiver research generally is trained in professions such as social work and clinical psychology and provides emotional support to family members of patients with Alzheimer's disease as a natural accompaniment to their research. The interactions and services provided by the caregiver research staff to family members of Alzheimer's disease patients can establish relationships that facilitate research subject recruitment, maintain family contacts and enhance subject retention as well as autopsy program enrollment and tracking. In addition, the staff conducting caregiver research can serve as the liaison between the families of center patients and the ADC clinicians and investigators, thereby enhancing recruitment into clinical trials and other important research programs. Finally, caregivers recruited for caregiver research can also participate directly in the ADC *Clinical Cores* and research as cognitively normal subjects.
    - The presence of caregiver research in an ADC can create a strong alliance between family members of patients and staff of the ADC. This alliance enables the ADC to meet the caregiver's needs for emotional and concrete resources and to educate the caregiver about the ADC. The pro-active approach of educator and counselor enables the caregiver research staff to bring delicate issues, such as permission to perform an autopsy to the attention of the caregiver in a way that both complements the role of the medical personnel and does so in the context of an ongoing supportive relationship. Similarly, issues regarding the genetic transmission of AD, whether to become involved in genetic testing and be informed of the findings, especially in the absence of viable treatment, can be addressed by caregiver research staff sensitive to the clinical implications of pursuing such information.
    - The *caregiver research* staff can function both independently and in collaboration with other researchers at the ADC. By building positive relationships with family members of

Alzheimer's disease patients, the social workers and psychologists conducting caregiver research can bridge the various ADC *Core* agendas and value bases, guide caregivers through the sometimes complicated evaluation process and advocate for them as they experience the dual role of client and research subject. If occasional conflict should arise among the different professional disciplines (physicians, psychologists, researchers) and the client in terms of retention in a study or compliance with the protocol, for example, the social worker's mediation skills and training in liaison activities may facilitate resolution.

  - The staff participating in caregiver research can obtain accurate information to convey to family caregivers because they are working at an ADC rather than in an independent social agency. ADC physicians can ask the social workers to provide support, reassurance or resource information to family members; they thus can serve as the friendly liaison between the families and the medical/research environment.
  - Because they maintain contact with caregivers and other family members, the social service staff who participate in caregiver research can obtain information about changes in the patients' functional level, cognitive capacity and behavioral problems.

- Enhancing the activities of the *Education and Information Transfer Core*
  - A primary goal of the *Education and Information Transfer Core* of an ADC is to disseminate information about Alzheimer's disease (AD) which is available at research institutions to the general public, particularly to Alzheimer's disease patients and their families, and to the health care professionals who care for them. It also helps to coordinate research training and education within the ADC. The staff members participating in caregiver research frequently are also the best qualified members of an ADC to provide linkages to community organizations and educational activities for family and professional caregivers.
  - The *Education Core* can leverage its generally limited financial resources to achieve its aims by using the skills of staff conducting caregiver research.
  - One of the aims of the *Education Cores* is to educate health care and service providers in the community about Alzheimer's disease and its effects on patients and families. Members of the professional staff conducting caregiver research at the ADC can provide lectures, consultation and in-service training to social service providers such as the Alzheimer's Association and other community organizations.
- Enhancing interventions for patients
  - *Testing new interventions that combine treatment for patients with treatment for caregivers.* It has become clear that to adequately provide treatment for Alzheimer's disease patients, it is essential to understand and take into account the needs of the caregiver. Caregiver research can investigate the efficacy of new interventions using a combination of treatment for both patients and caregivers in comparison to treatment for patients alone. Recruitment of subjects for these studies would be facilitated by the research being conducted at an ADC.
  - *Enhancing recruitment into clinical trials of new pharmacologic treatments.* Age and burden make some caregivers reluctant to allow patients to participate in drug treatment trials. Social workers and psychologists participating in caregiver research can also provide information and support both to encourage enrollment and maintain participation.

- Facilitating caregiver research
  - An Alzheimer's Disease Center provides the optimal setting to recruit caregivers from diverse backgrounds. Recruiting caregivers of patients participating in an Alzheimer's Disease Center makes it possible to have information not only on those who agree to participate but also on those who do not, increasing the reliability and validity of the research results.
  - Caregivers who accompany patients to be evaluated at an Alzheimer's Disease Center are more likely to remain in longitudinal research on caregiving than those recruited from the community, because they will continue to return to the Center with the patients.
  - The multidisciplinary nature of the staff of Alzheimer's Disease Centers broadens the perspective of caregiver research, adding the expertise of medical specialties such as neurology and psychiatry. In addition, detailed information about the patients is readily accessible to integrate with information about the caregivers.

The Caregiver Core of the NYU-Alzheimer's Disease Center

Overview

- This new core resource will:
    - Comprehensively assess all primary caregivers of all AD patients
        - follow them longitudinally
        - provide them with counseling services
        - maintain a centralized caregiver database linked to the patient database
    - Develop a database of community services
    - Interact with and enhance other cores and research programs of the ADC
        - The *Clinical Core*
            - Participate in research subject recruitment
            - Maintain family contacts
            - Enhance subject retention
            - Arrange longitudinal follow-ups
        - The *Neuropathology Core*
            - Participate in autopsy program enrollment and tracking
            - Ensure close communication with family members during the months prior to death.
        - The *Education Core*
            - Provide community outreach programs
            - Provide educational activities for family and professional caregivers
        - The ADC's research programs
            - serve as the liaison between the families of our patients and the ADC clinicians and investigators

Detailed Description

- **Aims of the Caregiver Core**
    - **To administer a Caregiver Assessment Battery to all primary family caregivers of AD patients of the ADC at intake and follow-up,** concurrently with the *Clinical Core* evaluations of the patients. Telephone contacts will be made every six months and full caregiver evaluations will be conducted every two years.
    - **To provide a comprehensive program of support, education and resource information for all family caregivers** of AD patients from their first contact with the ADC through all stages of the patient's illness, whether the patient lives at home or in a nursing home.
    - **To establish a formal program evaluation of the effectiveness of the support, education and resource information** provided by counselors to caregivers. This will include regular monitoring, using a structured questionnaire, of the recommendations made by counselors to evaluate their use and effectiveness.
    - To use selected questions or scales from the Caregiver Assessment Battery with all **cognitively normal subjects** of the *Clinical Core* who are not caregivers. All scales that do not pertain specifically to caregiving will be included every time they complete the *Clinical Core* evaluation (every two years). Comparison of these subjects with age-matched caregivers will make it possible to increase the understanding of the effects of caregiving.
- **Interface between *Caregiver Core* and *Clinical Core***
    - **The *Clinical Core* protocol.** Patients are evaluated at the ADC by the *Clinical Core* every two years. A *Caregiver Core* counselor, assigned either at intake or at the previous *Clinical Core* follow-up evaluation will telephone the caregiver to schedule this evaluation visit and meet with the caregiver and other family members to provide psychosocial support and resource information after the evaluation has been completed. This program will benefit not only the patient and the family, but research studies at the ADC as well. The caregiver of every AD patient receives a follow-up telephone call every 6 months to maintain a relationship between the ADC and participating subjects. Their *Caregiver Core* counselor will now make these follow-up telephone calls to obtain a brief assessment of current status. This assessment will serve to maintain the relationship between the caregiver and the clinic and make us aware of any major changes in the patient or caregiver.
    - **Telephone follow-up for caregivers of homebound and nursing home patients.** The counselors at the ADC have been conducting 6-month telephone contacts of *Clinical Core* subjects currently involved in studies. However, the *Clinical Core* protocol does not include regular telephone follow-ups to determine the status of homebound or nursing home patients. Although the schedule of follow-ups only requires that such patients be visited every four years, the counselors in the *Caregiver Core* will telephone *all* caregivers every six months. This will enable the ADC to be more up-to-date on the status of such patients and will increase the likelihood of obtaining autopsies at the time of death. It will also make it possible to offer counseling and support to their caregivers and thereby minimize the attrition of patients from clinic follow-ups and other research.

- **Outline of the Structure of the *Caregiver Core***
    - We will incorporate routine procedures for intake, needs assessment and planning for family members of patients with AD into the procedures of the ADC. We will build upon and expand current formal and informal procedures to provide a *formal* system of psychosocial assessment and treatment for family caregivers of all *Clinical Core* patients with AD. The assessments will be done concurrently with the Clinic assessment of the patients.
    - Whenever information is obtained about an AD patient in the *Clinical Core*, information will also be obtained about the well-being of the primary caregiver of that patient. We will obtain concurrent data about the primary caregiver at the time of each patient evaluation.
    - Family counseling and ad hoc counseling, critical elements of our proven spouse-caregiver intervention, will be incorporated into *Caregiver Core* procedures within the already established evaluation schedule of the *Clinical Core*. In particular, we will use the opportunity of the *Clinical Core* post-diagnostic conference to involve family members in the support of the primary caregiver. Informal ad hoc counseling as needed by the caregiver is, in essence, an ongoing supportive intervention. The regular formal evaluation is, in itself, a therapeutic intervention.
- **Subjects of the *Caregiver Core***

The subjects of the *Caregiver Core* will be the primary caregivers of newly diagnosed AD patients and those who are currently subjects of the *Clinical Core* at the NYU-ADC and the Bellevue SDTC. Nondemented subjects of the *Clinical Core* who are not caregivers will serve as a comparison group for research into the specific problems of caregivers.

All these subjects will be tracked longitudinally, and information about them will be maintained in a central database and linked to *Clinical Core* information about the patients through a common identifying number. In addition, all families of new patients who are evaluated for a possible diagnosis of AD and all new cognitively normal subjects who are not AD caregivers will become part of the *Caregiver Core.*

- **Eligibility criteria for all caregivers.** Caregivers who satisfy the following criteria will be eligible: (1) The caregiver must be over the age of 21 and a family member (spouse, daughter, son or daughter-in-law, sibling, grandchild) of an ADC patient; (2) The caregiver must be self-defined as the *primary* caregiver and (3) The patient must have a diagnosis of possible or probable AD, consistent with the NINCDS-ADRDA criteria.
- **Identifying the primary caregiver.** If patients are not accompanied by the person who identifies himself as the primary caregiver an attempt will be made to identify and contact the primary caregiver and to enlist his or her participation as a subject in the *Caregiver Core.* In the rare case when a patient has is no available primary family caregiver (e.g., if the patient is always accompanied to the ADC by paid help and no relative lives in the New York metropolitan area) that fact will be noted in the *Caregiver Core* database but there will be no subject in the *Caregiver Core* to correspond to that patient.
- **Caregivers of patients of the NYU-ADC.** Caregivers who accompany dementia patients to the NYU-ADC for evaluation fill out the *Caregiver Questionnaire* as part of the routine assessment. All primary caregivers who satisfy the eligibility criteria listed above will be

invited to participate in the *Caregiver Core.*

- ○ **Caregivers of patients of the Bellevue Satellite.** Caregivers also complete the *Caregiver Questionnaire* at the Bellevue SDTC. The *Caregiver Questionnaire* will be administered to Hispanic caregivers by a bilingual counselor. A Spanish version of this instrument, and all other instruments administered by the *Caregiver Core* are currently available or will be created during the first year after the formal inception of the *Caregiver Core.*

- ○ **Cognitively normal subjects of the ADC.** All nondemented subjects of both sites will be included in the *Caregiver Core* as they apply for or return for evaluation.

- ○ **Caregivers of dementia subjects with non-AD diagnoses.** Caregivers of all patients who are accepted by the *Clinical Core* for diagnostic evaluation and are subsequently determined to have a dementia diagnosis other than AD will be treated in the same way as caregivers of AD patients during the diagnostic process, and the data resulting from these procedures will become part of the *Caregiver Core* database. However, the ADC does not currently follow such patients and the caregivers will therefore not receive follow-up evaluations.

- **Procedure for Enrollment, Evaluation and Counseling of Caregivers in the *Caregiver Core***

  The schedule of evaluations for the *Caregiver Core* coincides exactly with the protocol for the *Clinical Core.* The counseling intervention includes all the elements of the NYU Spouse-Caregiver Intervention, including family and informal ad hoc counseling and the use of the data from the evaluation to inform the counseling process. However, the *Caregiver Core* intervention will be more efficient and less intensive, since the magnitude of the assessment battery is reduced and the formal family counseling is included in the post-diagnostic conference.

  - ○ **Intake into the *Caregiver Core***

    - **Caregivers of new clinic patients.** After the initial clinic telephone screening assessment, if dementia is suspected and the subject is eligible for the full evaluation, the family caregiver will be eligible for the *Caregiver Core.* The caregiver will be assigned to a family counselor who will be available during subsequent patient clinic visits to engage the caregiver and conduct the evaluation. While the patient is being evaluated, a family counselor will conduct a formal assessment of the primary caregiver's well-being, sources of formal and informal support and perception of the patient's illness, using a structured assessment battery (see below for details). Since clinic procedures take three to four visits, the evaluation will be spread out over that time. In order to prepare for the post-diagnostic family conference the caregiver will be asked to identify family members who may potentially provide support for the caregiver and the patient.

    - **Caregivers of current clinic patients.** The first time subjects with a diagnosis of AD return to the ADC for a clinic evaluation, their caregivers, who accompany them, will be asked to complete the Caregiver Assessment Battery. This will constitute their enrollment in the *Caregiver Core.*

  - ○ **Post-diagnostic family conference.** After the post-diagnostic conference with the *Clinical Core* physician, the primary caregiver, and other interested family members will meet with the family counselor. The counselor will explore the meaning and understanding of the diagnosis to the family and answer their questions. The specific focus of this meeting will be based on the individual situation and most pressing problem the family has in response to the diagnosis. In our experience, commonly expressed concerns include worry over finances, nursing home placement or that their relative will die. The counselor will address the identified problem with education, emotional and concrete support, resources and referral. One of the objectives of the post-diagnostic conference is to make the caregiver aware of potential informal resources. Caregivers will be encouraged to join support groups at the ADC or in their communities. The counselor will also recommend formal services, as appropriate, such as legal advice, day care centers, paid help at home, etc. If we learn that the caregiver does not have such support, this is a problem that must be addressed. It may be that in such cases extra formal services will be needed.

The counselor will fill out a structured questionnaire detailing the questions asked and the concerns expressed by the family as well as the recommendations made. While this information will become part of the *Caregiver Core* database, the counselor will also write down the recommendations in a chart format for the family. This chart will also have the counselor's name and telephone number. The counselor will advise the family that she is available at their request for informal counseling, further resource information or help in a crisis. Subsequently the counselor will document the number of times and reasons for calls from each family. Knowing ongoing support is available has a major psychological effect and helps establish an alliance with the family.

In the post-diagnostic family conferences that occur at the two-year clinic patient follow-up evaluations, the counselor will reassess the current appropriateness of previous recommendations for use of services and care of the patient. New recommendations will be made based on changes in the patient's or family's circumstances. All such recommendations will be documented in writing.

It should be noted that people who exhibit pathology of such a dimension that it interferes with their ability to improve their coping skills (e.g., those who appear clinically depressed, anxious, psychotic or who engage in substance abuse) will be referred elsewhere for therapy or further diagnosis and treatment as appropriate.

- **Informal counseling.** Counselors will be available for telephone consultation at the initiation of the caregiver, the patient or any participating family member. Some of the more common reasons for informal consultation in the ongoing spouse-caregiver intervention study have included changes in symptoms of dementia in the patient, the onset or worsening of patient behavior problems, physical problems of the patient and/or the caregiver, requests for and complaints about doctors, attorneys, aides, social services and nursing homes, miscellaneous family problems including problems of spouses and children and caregiver stress, requests for additional resource information and changes in family composition. Counselors will maintain a continuously updated log of contacts, problems mentioned by caregivers and family members, their own recommendations and the extent to which these recommendations were followed. This log will be part of the *Caregiver Core* database and be an important research resource.

Because the counselors will be available to caregivers for consultation, not only will they be able to make referrals for pharmacologic management of behavioral symptoms, but they also will have the opportunity to provide them with information about alternatives to drugs to alleviate behavioral problems. For example, if caregivers complain that patients don't sleep at night, they can advise them to make sure the patients get physical exercise and don't sleep during the day, as a possible alternative to medications to make them sleep.

- There will be a **general emergency number** for caregivers to call on evenings and weekends which will be monitored by a counselor.

- **Six-month telephone follow-up.** The counselor who was assigned to the family at intake into the *Caregiver Core* will contact the caregiver every six months by telephone. This contact will encompass the current *Clinical Core* follow-up procedure for patients. The records of the last complete clinic evaluation and any interim telephone follow-ups will be available to the counselor. Current problems and contemplated changes in life style will be documented. In addition, caregivers will be given an opportunity to talk about their problems and receive advice or information if they request it. The counselors will reinforce the idea that they are available for further consultation if there are any new problems. Relevant information will be provided to the *Clinical Core* to be included in patient records. It should be noted that, although it is not currently part of the *Clinical Core* protocol, families of nursing home and homebound patients will also be called every six months. An abbreviated version of the intake evaluation to assess the short term changes in patient status (*FAST*), caregiver burden (Caregiving Appraisal Scales) and service utilization (*Formal Service Utilization Inventory*) will be administered to all caregivers. These instruments are described in Section 5, below.

- **Two-year clinic follow-up.** Every two years, the full evaluation battery will be administered to the primary caregiver. The timing of this assessment coincides with the two-year patient reevaluation required by *Clinical Core* protocol. If the primary caregiver has changed, the reasons for that change (for example the death or illness of the former primary caregiver) will be documented. All cognitively normal subjects return to the ADC for reevaluation every two years and will also complete appropriate instruments in the Caregiver Assessment Battery.

- ***Caregiver Core* Assessment Instruments**

Counselors will administer the entire structured battery listed below to all primary family caregivers and cognitively normal noncaregivers at intake and every two years thereafter. The intermediate 6-month telephone follow-ups will include an abbreviated battery to assess the short-term changes in patient status (FAST), caregiver burden (*Caregiving Appraisal Scales)* and service utilization (Formal Service Utilization Inventory). These instruments are described below.

- **General information.** The *Caregiver Questionnaire* was developed at the NYU-ADC to provide comprehensive and detailed information about the caregiver: basic demographic information, the changes in the caregiver's life and new responsibilities resulting from the patient's condition; role conflicts, living arrangements, the use of resources, the financial status of patient and caregiver, including financial difficulties due to the patient's illness, the quantity, quality and cost of home care, and whether the caregiver has considered nursing home placement of the patient.

- **Caregiver Psychological Status.**
  - *Beck Depression Inventory* (*BDI;* $\alpha = .86$; Beck et al., 1987) is a 21-item self-rating

inventory used widely in detecting possible depression in normal populations. The Beck Depression Inventory is more sensitive to mild to moderate severity of depression than more biologically weighted scales (Hammen, 1981).

- *Beck Anxiety Inventory* (*BAI*; Beck, Epstein, Brown et al., 1988) is a 21-item self-rating scale that shows high internal consistency (.92) and test-retest reliability (.75). Evaluations of the psychological cost of caregiving (e.g., Anthony-Bergstone, Zarit & Gatz, 1988; Parks & Pilisuk, 1991) suggest that anxiety is a consequence of caregiving, particularly for women.

o **Caregiver physical health.** We will use items from The *Caregiver Physical Health Form*, which was adapted from the *OARS* battery of questionnaires for use in the spouse-caregiver study (ICC = 0.83; Duke Center for the Study of Aging and Human Development, 1978). We will include questions about number of visits to a physician, days sick and days hospitalized and three subjective ratings of the caregiver's current physical health, each on a four-point scale (from excellent to poor). These are the items that have proved most important in our analyses of the data from our spouse-caregiver study.

o **Social support and family conflict.** Our research has suggested that social support and family conflicts are major mediators between the primary stress of caregiving and caregiver well-being. We will conduct an assessment of both constructs.

- *Social support assessment. The Stokes Social Network List* (α = .92; Stokes, 1983) measures how satisfied subjects are with their support networks in three areas (emotional and tangible assistance and general support, each rated on a six-point scale) and whether they would like it to change. Subjects are also asked to name the people in their social networks and for each, whether they are relatives and whether they feel close to them.

- The *Family Conflicts Scales* (α=.80 to .86; Semple, 1992) include twelve items, each measured on a four-point scale to assess three distinct dimensions of family conflict: conflict around definitions of the illness and strategies for care (α=.80); conflict around family members' attitudes and actions toward the patient (α=.86); and conflict around family members' actions and attitudes toward the caregiver (α=.84).

o **Caregiver appraisal and mastery.** In our current research we have hypothesized that the caregiver's sense of mastery and appraisal of caregiving mediates between the primary stress of caregiving and caregiver well-being. We therefore will include a general mastery scale. In addition, we will include the *Revised Memory and Behavior Checklist* to assess the caregiver's reaction to the patient's behavior. We will also include the *Caregiver Appraisal Scales* that measure both positive and negative aspects of caregiving and include a caregiving mastery scale.

- *Mastery* (α=.75; Aneshensel et al., 1993) is a scale with seven items assessing a general sense of sense of self-efficacy (first reported by Pearlin & Schooler, 1978) postulated to mediate the impact of stress.

- *Revised Memory and Behavior Problems Checklist* (α = .84 for behavior and .90 for reaction; Teri, Truax, Logsden et al., 1992) consists of 24 questions regarding problem behaviors of the patient that are likely to be upsetting for the caregiver. The frequency of the behavior and the severity of the caregiver's reactions are each rated on a five-point scale, ranging from "not at all" to "extremely."

- *Caregiving Appraisal Scales* (Lawton, Kleban, Moss et al., 1989) consist of 34 items, each measured on a five-point scale: Subjective burden (α=.85), caregiver satisfaction, (α=.67), caregiving impact (α=.70), caregiver mastery and caregiving ideology.

○ **Caregiver time expenditure.** A questionnaire, *Caregiver Time Expenditure*, used in the UCSD study of the cost of caregiving (Rice, Fox, Max et al., 1993) was adapted for the spouse-caregiver intervention study. It includes questions about whether caregivers had to leave their jobs because of caregiving, whether they changed their living arrangements to care for their parents, and how much time they spend in specific areas of caregiving. The questionnaire also itemizes the time spent by the primary caregiver, other unpaid caregivers and paid caregivers in 17 activities such as housekeeping, meal preparation, respite services, AD day care and other services.

○ **Quality of life.** The global quality of life (QOL) question from the *Euroqol Questionnaire* (The Euroqol Group, 1990; test-retest reliability = .90; van Act, Essink-Bot, Krabbe et al., 1994). The global QOL measure is necessary for quality of life estimation methodology.

○ **Additional special instruments to assess the utilization of the services of the *Caregiver Core* by family caregivers.** Our experience with the spouse-caregiver intervention suggests that part of the explanation of its success is that, to a large extent, subjects themselves determine how much support they will receive from the counseling staff and support groups. We will use several methods to monitor how much help is used by each family and the extent of compliance with advice.

- Family conference. Attendance of family members at the family conference that will occur after each *Clinical Core* evaluation will be recorded. The concerns expressed by the family and counselor recommendations will be recorded. At the telephone follow-up six months later, whether the subjects followed with this advice will be recorded.

- Ad hoc counseling. We will record the number and length of ad hoc requests for counseling by caregivers, family members and patients and the purpose, in general categories, of each request.

- *Formal Service Utilization Inventory*. At each assessment caregivers will be asked by the counselor whether and how frequently they have gone to support groups or used any other formal services. The form will include questions about the extent to which original recommendations were followed and the caregiver's perception of the helpfulness of the services used. This will enable us to learn whether a relationship exists between the amount and kind of services used, the characteristics of the caregiver or patient, and the well-being of the caregiver. We will also be able to describe the determinants of service use and compliance.

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Original Contributions

A Family Intervention to Delay Nursing Home Placement of Patients With Alzheimer Disease

A Randomized Controlled Trial

Mary S. Mittelman, DrPH; Steven H. Ferris, PhD; Emma Shulman, CSW; Gertrude Steinberg, MS; Bruce Levin, PhD

Objective.—To determine the long-term effectiveness of comprehensive support and counseling for spouse-caregivers and families in postponing or preventing nursing home placement of patients with Alzheimer disease (AD).

Design.—Randomized controlled intervention study.

Setting.—Outpatient research clinic in the New York City metropolitan area.

Participants.—Referred, volunteer sample of 206 spouse-caregivers of AD patients who enrolled in the study during a 3½-year period. All patients were living at home at baseline and had at least 1 relative living in the area.

Intervention.—Caregivers in the treatment group were provided with 6 sessions of individual and family counseling within 4 months of enrollment in the study and were required to join support groups. In addition, counselors were available for further counseling at any time.

Main Outcome Measure.—Time from enrollment of caregivers in the study to placement of the AD patients in a nursing home.

Results.—Using Kaplan-Meier survival analysis, we estimated that the median time (weighted average of estimates for male and female caregivers) from baseline to nursing home placement of AD patients was 329 days longer in the treatment group than in the control group ($z=2.29$; $P=.02$). The relative risk (RR) from a Cox proportional hazard model of nursing home placement (intent-to-treat estimate) after adjusting for caregiver sex, patient age, and patient income was 0.65 (95% confidence interval [CI], 0.45 to 0.94; $P=.02$), indicating that caregivers were approximately two thirds as likely to place their spouses in nursing homes at any point in time if they were in the treatment group than if they were in the control group. Treatment had the greatest effect on risk of placement for patients who were mildly demented (RR, 0.18; 95% CI, 0.04 to 0.77) or moderately demented (RR, 0.38; 95% CI, 0.17 to 0.82).

Conclusions.—A program of counseling and support can substantially increase the time spouse-caregivers are able to care for AD patients at home, particularly during the early to middle stages of dementia when nursing home placement is generally least appropriate.

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ALZHEIMER DISEASE (AD) is long-lasting and ultimately severely debilitating. Although deterioration is inevitable, the rate of progression of the disease for individuals is quite variable.[1] The uncertainty about how long a particular stage will have to be endured makes caring for a patient with AD uniquely difficult and emotionally distressing for family members.

Family caregivers generally prefer to avoid placing their elderly relatives in nursing homes, and spouse-caregivers are more reluctant than other relatives to do so. However, spouse-caregivers require considerable support and assistance to keep patients at home.

For editorial comment see p 1756.

Our clinical experience, corroborated by the outcomes of research evaluating the needs of family caregivers, suggested that a treatment strategy for caregivers should be based on 4 principles: (1) each family has unique problems; (2) most caregivers would benefit from more understanding and support from their families; (3) all caregivers run the risk of isolation; and (4) it is necessary to continue to provide support for caregivers throughout the duration of the disease rather than for only a short period of time.[2]

The results of several intervention studies conducted in the past few years suggest that a psychosocial intervention could prevent or postpone nursing home placement.[3-4] We previously demonstrated the short-term effectiveness

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From the Aging and Dementia Research Center, New York University Medical Center (Drs Mittelman and Ferris, and Mss Shulman and Steinberg), and the Division of Biostatistics, Columbia University School of Public Health, The G. Sergievsky Center, and the New York State Psychiatric Institute (Dr Levin), New York, NY.

Reprints: Mary S. Mittelman, DrPH, Aging and Dementia Research Center, New York University Medical Center, 550 First Ave, THN 312C, New York, NY 10016.

of such an intervention in helping spouse-caregivers to postpone or avoid placement of AD patients in nursing homes[7] and alleviating symptoms of depression in their caregivers.[8] We now present the long-term effect of the intervention in postponing nursing home placement of AD patients.

METHODS

All subjects were the spouses of patients with clinically diagnosed AD living at home at baseline and had the primary responsibility for their care. The patient or the caregiver also had to have at least 1 relative living in the New York City metropolitan area to permit participation of family members. Caregivers could not be participating in another caregiver counseling program or support group at baseline and could not have a serious medical condition. Those who satisfied these eligibility criteria were invited to participate in a study of caregivers of AD patients. Subjects were recruited over a 3½-year period from among caregivers of patients at the New York University–Aging and Dementia Research Center (NYU-ADRC), from the local Alzheimer's Association, and through media announcements and referrals from physicians, social workers, lawyers, and AD day-care centers. Among the 141 spouse-caregivers of AD patients of the NYU-ADRC during that time period, 99 (70.2%) were eligible. Among those who were eligible, only 2 declined to enroll.

Study subjects were randomized by lottery to a treatment or a control group. All caregivers were interviewed at regular intervals following entry into the study, every 4 months during the first year and every 6 months thereafter, with up to 8 years of follow-up. At baseline and at each scheduled follow-up interview, a comprehensive battery of structured questionnaires was administered. The specific assessment measures have been previously described.[8]

Treatment Group

The treatment consisted of 3 components. The first component, 2 individual and 4 family counseling sessions, occurred in the first 4 months after the caregiver enrolled in the study. The counseling sessions were task oriented, promoting communication among family members, teaching techniques for problem solving and management of troublesome patient behavior, and improving both emotional and instrumental support for the primary caregiver. These sessions also provided education about AD and resource information. Each family in the treatment group participated in the same number of sessions with the same general format; the content of these sessions was determined by the needs of each caregiver as documented by the assessment battery of questionnaires filled out on entry into the study. Counseling sessions ranged in length from 1 to 3 hours, depending on the needs of the caregiver and family, but typically lasted about 1½ hours.

At the end of the initial 4-month period, the second component of the intervention required caregivers to join support groups that met weekly and continued indefinitely. These groups provided a venue for continuous emotional support and education and an extended social network in a nonjudgmental atmosphere.

The third component of the treatment consisted of the continuous availability of counselors to caregivers and families to help them deal with crises and with the changing nature and severity of the patient's symptoms. Based on a 1-month survey, the most frequent reasons for requests for help by caregivers and family members were for emotional support (38%), advice about services such as home health agencies (21%), problems with patient behaviors (18%), crises (11%), and assistance with nursing home placement (8%).

Control Group

Control subjects were offered the services normally provided to families of patients at the NYU-ADRC. They did not receive the structured individual and family counseling provided to treatment subjects, and their family members had no contact with the study counselors. They were not required to join support groups and received counseling and advice on specific issues and resource information only when they requested it.

Treatment and control subjects received 2 different levels of support. For example, if control subjects asked about obtaining paid help at home, they were given the names of service providers, whereas treatment subjects were given as much help as they needed to find and appropriately use such services. Counselors interacted with family members of subjects in the treatment group, giving them advice about how to support the spouse-caregiver.

Predictors of Institutionalization

We reviewed the existing literature to select appropriate predictors of institutionalization. However, the literature is inconclusive regarding most factors.

Because prior research suggests several possible factors, we used a multistage method of building a model of predictors of nursing home placement, beginning with an exploratory stage in which each of the potential predictors mentioned above was tested for inclusion in the final model.

Measures Used in the Analysis

Caregiver sex, patient and caregiver age, and patient income, which affects eligibility for Medicaid payment for both home care and nursing home care, were treated as potential confounding variables. The global severity of dementia of the patient was determined by the Global Deterioration Scale (GDS),[9] a semistructured rating of patient functioning by the counselor (GDS, $\alpha = 0.83$), based on the interview of the caregiver at baseline and at each follow-up interview. Patients with dementia have scores ranging from 4 to 7 on this scale. Each subject was coded (0,1) for a set of 3 dichotomous variables representing moderate dementia (GDS 5), severe dementia (GDS 6), and very severe dementia (GDS 7). Thus, the coefficients associated with each of these variables represented the effect on nursing home placement of that stage of dementia compared with being at a mild stage of dementia (GDS 4), which is used as the reference group. The stage of dementia was coded as a set of dichotomous variables rather than as a continuous variable because exploratory analyses suggested that risk of placement did not increase linearly with level of dementia. However, for the variable representing the interaction between stage of dementia and treatment group membership, stage was coded linearly for the purpose of parsimony and in view of a good fit.

The caregiver's assessment of both his or her own and the patient's physical health were each estimated by the sum of 3 subjective questions from the physical health portion of the Older Americans Resources and Services questionnaire[10] (overall health, health compared with health 5 years ago, and how much health gets in the way of doing what the person wants to do). Possible scores ranged from 1 (healthiest) to 10 (least healthy).

How satisfying the caregiver found the support provided by the social network was measured by averaging 3 questions from the social network questionnaire[11] (general satisfaction, satisfaction with assistance, satisfaction with emotional support), each ranging from 1 (very satisfied) to 6 (very dissatisfied). Help from family and friends was indicated by the sum of the responses to 4 questions (the number of days in a month of patient sitting, taking the patient out, housekeeping, and shopping). Paid help was coded in 4 categories (none to 24 hours). These summary measures were developed as a result of factor analyses described in a previous report.[7]

Table 1.—Characteristics of Caregivers and Patients at Baseline*

Characteristic	Treatment (n=103)	Control (n=103)	Total (n=206)	Statistic (*P* Value)
Caregivers, No. (% female)	52 (50.5)	68 (66.0)	120 (58.3)	χ^2=5.1 (.02)
Age of female caregivers,† % <60 y/60-69/70-79/80-89	11.5/32.7/48.1/7.7	17.7/27.9/38.2/16.2	15.0/30.0/42.5/12.5	*t*=0.09 (.93)
Age of male caregivers,† % <60 y/60-69/70-79/80-89	11.8/33.3/41.2/13.7	8.6/14.3/51.4/25.7	10.5/25.6/45.3/18.6	*t*=1.9 (.06)
Age of male patients with female caregivers,† % <60 y/60-69/70-79/80-89	5.8/17.3/51.9/25.0	1.5/19.1/50/29.4	3.3/18.3/50.8/27.5	*t*=0.79 (.43)
Age of female patients with male caregivers,† % <60 y/60-69/70-79/80-89	17.0/29.4/41.2/11.8	11.4/25.7/54.3/8.6	15.2/27.9/46.5/10.5	*t*=0.75 (.46)
Patient income, female caregivers, in thousands of $, % <10/10-14.9/15-24.9/≥25	48.1/17.3/13.5/21.2	33.8/20.6/30.9/14.7	40.0/19.2/23.3/17.5	*t*=−0.17 (.86)
Patient income, male caregivers, in thousands of $, % <10/10-14.9/15-24.9/≥25	74.5/13.7/7.8/3.9	74.3/11.4/8.6/5.7	74.4/12.8/8.1/4.7	*t*=0.25 (.81)
Severity of dementia of AD patient with female caregivers, % mild/moderate/severe	42.3/38.5/19.2	25.0/42.6/32.4	32.5/40.8/26.7	χ^2=4.75 (.09)
Severity of dementia of AD patient with male caregivers, % mild/moderate/severe	27.5/45.1/27.5	34.3/31.4/34.3	30.2/39.5/30.2	χ^2=1.62 (.44)

*Despite random assignment of caregivers, there was a statistically significant difference between the treatment and control groups in the distribution of caregivers by sex. We therefore present data on age of caregiver and patient and patient income separately for male and female caregivers. AD indicates Alzheimer disease.

†Age and income are presented in 4 categories for presentation purposes only. The *t* tests were based on original continuous age and income data.

Caregiver depression was measured with the Geriatric Depression Scale (α=0.94), a 30-item questionnaire in a yes-no format that was specially developed for use with the elderly.[12] The caregiver's reactions to troublesome patient behaviors were assessed with a summary score derived from the Memory and Behavior Problems Checklist (α=0.80)[13] by multiplying the frequency of each of 30 behaviors by the caregiver's reaction to that behavior and summing the results.

Statistical Methods

To estimate the effectiveness of the intervention in increasing the time to nursing home placement, we first conducted a single unadjusted intent-to-treat analysis, retaining all subjects in the analysis in the group assigned at randomization. Despite random assignment, 52 (50.5%) caregivers in the treatment group were female, compared with 68 (66.0%) in the control group (Table 1). To ensure that our results were not artifacts of this chance inequality, we included sex of caregiver as a covariate in all subsequent statistical analyses.

We estimated the survival function for time in days from entry into the study until nursing home placement for both the treatment and control groups stratified by sex of caregiver using the Kaplan-Meier method. Significance of the difference between time-to-placement curves for patients in the 2 groups was assessed using the sex-stratified Breslow test,[14] which is particularly sensitive to differences between distributions at the beginning of the follow-up period when the intervention was expected to have its greatest impact. The Cox proportional hazards regression model[15] was used to compare the hazard rate (or risk) of nursing home placement of patients associated with caregivers in the 2 groups, adjusting for other variables. Significance of individual regression coefficients was assessed with Wald tests, and subsets of coefficients were tested by log-likelihood ratio statistics.

The potential predictors of institutionalization that do not change over time such as sex of the caregiver or those that change predictably over time were entered into the analyses only at baseline. However, most of the potential predictors vary unpredictably over time. For example, a caregiver's physical or mental health may decline and the severity of dementia of the patient increase, while the patient's physical health declines. These types of variables were entered as time-dependent covariates and were updated from baseline at each follow-up interview. We also included the interaction between intervention group membership and severity of dementia. Models including multiple time-dependent covariates were estimated using specially written software for fitting discrete time Cox models with an arbitrary number of tied observations at event times (models and strategy available from authors).[16,17]

In most cases, complete data about the patient and caregiver were available for all scheduled follow-up periods. Occasionally, when caregivers died or dropped out of active participation in the study, we were unable to obtain regular follow-up information about patients, although with 1 exception we were able to ascertain the primary outcome (nursing home placement, death, or home residence). In these instances, we used the last observed values of predictor variables and carried them forward until the time of a definite outcome or the censoring date. (Patients who had neither been placed in a nursing home nor died by December 15, 1995, were treated as censored observations.) A few interviews (0.9%) were unavoidably so late that they actually were closer in time to the due date for the subsequent period than to the intended period and were recoded to belong to that next period. In these cases, data points for the missing interviews were calculated as the mean of the value from the prior and next interviews (except in the case of severity of dementia [GDS], where fractional categories were rounded down).

RESULTS

A total of 206 subjects enrolled in the study over a 3½-year period beginning in 1987. After adjusting for sex, the treatment and control groups did not differ (Table 1).

The outcome of the patient is unknown in only 1 case (0.5%). This patient is included in the analysis as a censored observation as of December 15, 1995. At that point, 121 caregivers (58.7%) had placed patients in nursing homes. An additional 54 patients (26.2%) died before being placed in nursing homes, and 30 patients (14.6%) were still living at home. Only 15 caregivers (7.3%) stopped participating in the regular follow-up assessments while the patients were still living at home, of whom 8 (2.8%) had died (5 treatment and 3 control), 4 (1.9%) were too ill to continue (2 treatment and 2 control), and 3 (1.5%) refused to continue (all treatment caregivers). Attrition does not affect sample composition because of the intent-to-treat analysis, which retains all subjects in the group to which they were originally randomized. Nonparticipation did require the imputation of covariate values but the small proportion of subjects did not materially affect our results.

Support group participation was required of caregivers in the treatment group but not denied caregivers in the control group. Not all caregivers in the treatment group complied with this requirement (72% joined support groups). Among those in the control group, 40.8% ultimately joined support groups on their own. Thus, this part of the intervention is not unique to treatment group caregivers.

Nursing Home Placement

Only 1 patient in the study entered a nursing home while in the mildest stage of AD (GDS 4). Among the 35 patients who reached the moderate stage of dementia (GDS 5) at home, 20 (57.1%) entered the nursing home while still at that stage. Among the 125 patients who reached the severe stage of dementia (GDS 6) at home, 86 (68.8%) entered a nursing home at that stage. Among the 41 patients who survived and remained at home until they reached the most severe stage of dementia (GDS 7), 14 (34.8%) were subsequently placed in nursing homes.

Patients in the treatment group remained at home significantly longer than those in the control group (Breslow[22] test for equality of survival distributions, stratified by caregiver sex, χ^2_1=5.16; *P*=.02). The median length of stay at home for patients in the treatment group, adjusted for caregiver sex, was 329 days longer than for those in the control group (Table 2). The unadjusted relative risk (RR) for nursing home placement estimated from the Cox proportional hazards model comparing treatment vs control was 0.67 (95% confidence interval, 0.47 to 0.96; *P*=.03).

The potential explanatory variables are shown in Table 3. In univariate analysis, at any point in time, female caregivers were at a higher risk of placing their spouses in nursing homes than male caregivers. Caregiver age was not significant, but for every 10 years of patient age the RR of placement increased by 32%. Patients with higher income were less likely to be placed in nursing homes than those with lower incomes. The estimates indicate that the risk of placement of patients with incomes of $100 000 was 62% of the risk of those with an income of $10 000. All subsequent models included caregiver sex, patient age, and patient income as covariates.

The severity of dementia of the patient was a major predictor of placement. The risk of placement of patients at GDS 5 was almost 6 times the risk, and at GDS 6 was more than 25 times the risk of those at GDS 4. Those who remained at home until they were in the very severe stage of dementia (GDS 7) had approximately the same high risk as those who were at GDS 6.

The effect of the number of caregiver symptoms of depression and caregiver reaction to the patient's troublesome behavior, when considered one at a time, were both statistically significant over and above caregiver sex, patient age, and patient income. We therefore examined 2 models consecutively in which we included these 2 explanatory variables, one at a time, along with severity of dementia, treatment, and the treatment-severity interaction. Finally, we examined a model with both these explanatory variables at once. Variables that did not have a significant effect on nursing home placement in the preliminary analyses (Table 3) were not included in subsequent hazard models.

Table 2.—Median Time Before Nursing Home Placement (Kaplan-Meier Survival Estimates)*

	Treatment Group		Control Group		Difference	
Caregiver Sex	Median Time ±SE, d	95% CI	Median Time ±SE, d	95% CI	Median Time ±SE, d	95% CI
Total (unadjusted for sex)	1356±288	791 to 1921	905±178	555 to 1255	451±339	−213 to 1115
Female	1021±113	799 to 1243	777±126	530 to 1024	244±169	−88 to 576
Male	1680±247	1195 to 2165	1129±118	897 to 1361	551±274	14 to 1088
Total (adjusted for sex)†	1203±107	944 to 1412	874±97	684 to 1064	329±144	47 to 611

*CI indicates confidence interval.

†This row represents a weighted average of sex-specific medians or differences in medians. The weights are 0.723 for female and 0.277 for male caregivers. These weights are inversely proportional to the estimated variance of the sex-specific difference between medians in the final column.

Table 3.—Preliminary Models: Estimated Values of Coefficients of Explanatory Variables From Proportional Hazard Models of Nursing Home Placement (Each Line Represents a Separately Fitted Model)

Variables in Model	Log Relative Hazard (β)*	Relative Hazard (e^β)	95% Confidence Interval (e^β)	*P*
Sex of caregiver†	0.39	1.48	1.03 to 2.14	.04
Patient age, mean age in decades‡	0.28	1.33	1.05 to 1.68	.02
Caregiver age, mean age in decades‡	0.07	1.07	0.88 to 1.31	.48
Log_{10}([1+ patient income]/1000)§	−0.47	0.62	0.45 to 0.87	.006
Severity of patient dementia (Global Deterioration Scale [GDS])‖				
Moderate (GDS 5)	1.78	5.94	0.79 to 44.8	.08
Severe (GDS 6)	3.24	25.6	3.53 to 185	.001
Very severe (GDS 7)	3.34	28.1	3.60 to 220	.001
Decline in patient physical health‖	0.08	1.09	0.97 to 1.19	.07
Decline in caregiver physical health‖	0.06	1.06	0.98 to 1.21	.14
Caregiver member of a support group‖	−0.21	0.81	0.54 to 1.21	.31
Increase in amount of help from family and friends‖	−0.01	0.99	0.97 to 1.00	.14
Increase in caregiver use of antidepressants, anxiolytics, or sedatives‖	0.33	1.39	0.94 to 2.02	.09
Increase in amount of paid help‖	0.13	1.14	0.96 to 1.35	.14
Increase in caregiver dissatisfaction with social network‖	0.11	1.11	0.98 to 1.26	.09
Increase in symptoms of depression in caregiver‖	0.04	1.05	1.02 to 1.07	.001
Increase in caregiver negative reaction to frequency of troublesome patient behavior‖¶	0.10	1.11	1.08 to 1.14	<.001

*Each line represents a separately fitted model. The sign of the estimated β coefficients indicates directionally how the presence of a characteristic affects the hazard rate and thus the time before nursing home placement. A positive coefficient indicates that higher values of the variable are associated with increased hazard and therefore shorter time. When dichotomous variables such as treatment group membership or sex are coded as indicator variables (0, 1), the β coefficients associated with such factors represent the logarithm of the ratio of the estimated hazard of the outcome for a subject with the characteristic to the hazard for a subject without the characteristic and e^β is the estimated relative risk associated with the variable. For continuous variables, the value of β indicates the approximate percentage change in the hazard rate per unit change in the covariate.

†Sex of caregiver was coded as a dichotomous variable (female caregivers =1; male caregivers =0) as was support group participation (yes =1; no =0).

‡Age of patient and caregiver were coded in 10-year increments and expressed as deviations from the mean for all subjects in order to reveal significant digits in the table.

§Information on patient income, which was obtained in 7 categories and coded at the midpoint of each category interval, was transformed by taking $\log_{10}$ ([1+ income]/1000), to linearize its relationship to treatment and reduce the effects of extreme values.

‖After controlling for sex of caregiver, patient age, and patient income. Reference is mild (GDS 4).

¶The scores on the instrument to measure the caregiver's reaction to the patient's behavior were divided by 10 in order to reveal significant digits in the table.

Table 4.—Estimated Effects of Treatment and Other Explanatory Variables From Proportional Hazard Models of Nursing Home Placement

Variables in Model	Log Relative Hazard (β)	Relative Hazard ($e^β$)	95% Confidence Interval ($e^β$)	*P*
Model 1				
Treatment after controlling for female caregiver, patient age, and patient income	−0.43	0.65	0.45 to 0.94	.02
Model 2*				
Female caregiver	0.76	2.14	1.40 to 3.26	.004
Increasing patient age	0.15	1.17	0.93 to 1.46	.18
Increasing patient income	−0.79	0.45	0.30 to 0.68	.001
Moderate dementia (GDS 5)	1.61	4.99	0.66 to 37.7	.12
Severe dementia (GDS 6)	2.71	14.99	2.02 to 111	.008
Very severe dementia (GDS 7)	2.35	10.43	1.14 to 95.8	.04
Treatment by linear GDS interaction	0.73	2.06	1.02 to 4.23	.04
Treatment effect				
At GDS 4	−1.71	0.18	0.04 to 0.77	.02
At GDS 5†	−0.98	0.38	0.17 to 0.82	.01
At GDS 6†	−0.25	0.78	0.53 to 1.15	.21
At GDS 7†	0.49	1.62	0.70 to 3.76	.26
Model 3 (in addition to model 2)				
Greater number of symptoms of depression in caregiver	0.035	1.04	1.01 to 1.07	.02
Model 4 (in addition to model 2)				
Greater caregiver negative reaction to frequency of patient troublesome behavior	0.078	1.08	1.05 to 1.12	<.001
Model 5‡§				
Increase in symptoms of depression in caregiver	0.005	1.01	0.97 to 1.04	.75
Increase in caregiver negative reaction to patient troublesome behavior	0.075	1.08	1.04 to 1.12	<.001
Treatment by linear GDS interaction	0.82	2.28	1.11 to 4.66	.02
Treatment effect‡				
At GDS 4	−1.66	0.19	0.05 to 0.82	.03
At GDS 5§	−0.83	0.43	0.20 to 0.96	.04
At GDS 6§	−0.01	0.99	0.67 to 1.48	.97
At GDS 7§	0.81	2.26	0.97 to 5.27	.06

*Model 2 is a joint test of significance of treatment effect (at Global Deterioration Scale [GDS] 4) and treatment by linear GDS interaction; 2 log-likelihood ratio statistic =6.48 on 2 *df* (*P*=.04).

†Treatment effects calculated from the model at GDS levels other than 4.

‡After controlling for sex of caregiver, patient age, and patient income.

§Model 5 is a joint test of significance of treatment effect (at GDS 4) and treatment by linear GDS interaction; 2 log-likelihood ratio statistic =5.60 on 2 *df* (*P*=.06).

Effect of the Intervention

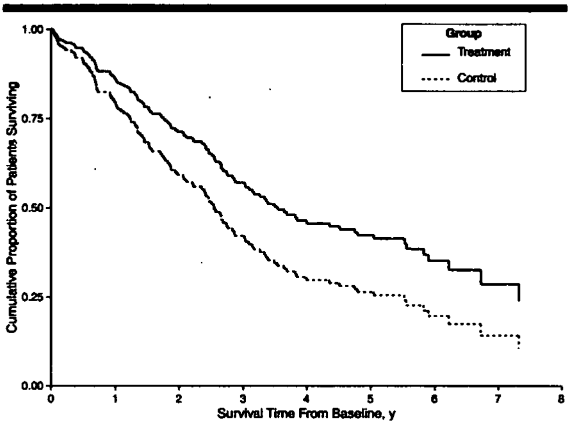
In model 1 (Table 4), we included treatment group membership, caregiver sex, patient age, and patient income. The risk of nursing home placement by treatment group caregivers was 65% of that by control group caregivers, only slightly different from the unadjusted estimate (67%). The Figure illustrates the survival functions for the 2 groups for time to nursing home placement, adjusting for sex, patient age, and patient income.

There was a significant interaction between treatment group and severity of dementia. Model 2 of Table 4 exhibits the Cox model regression coefficients for treatment group and treatment by GDS interaction, adjusting for sex, age, income, and severity of dementia. To summarize the finding, the estimated RR for the treatment group at GDS 4 was 0.18 and at GDS level 5 the estimated RR for the treatment group was 0.38. In other words, the intervention reduced the risk of placement between 2½ and 5 times at mild to moderate levels of dementia. At GDS level 6 the RR was 0.78, still conferring a 22% reduction in risk of placement, although not nominally significantly different from 0. At GDS level 7 the treatment group actually had a higher estimated risk of placement, although again not significantly different from 0. To estimate the overall statistical significance of the treatment effect, we compared the log-likelihood ratios associated with this model with a model including all the same variables except treatment and the treatment by GDS interaction. The difference in log-likelihood ratio statistic between these 2 models indicated that the joint effect of treatment and the treatment by GDS interaction was statistically significant (χ^2_2=6.48; *P*=.04).

Adding caregiver depression (model 3) and the index of the caregiver's reaction to the patient's troublesome behavior (model 4) to the variables in model 2 resulted in virtually no change in the coefficients. Both variables, when entered individually, were significant predictors of placement, over and above the effect of severity of dementia of the patient and treatment group membership of the caregiver. When depression and reaction to troublesome behavior were included simultaneously in the model (model 5), depression was no longer an independent predictor, and the treatment effect was diminished, but only slightly.

COMMENT

The NYU Spouse-Caregiver Intervention Study was designed to follow, as much as possible, the procedures of a classic clinical trial. Subjects were randomly assigned to a treatment or a control group and were assessed on an intent-to-treat basis. The study could not be blinded, but structured assessment instruments were used to minimize interviewer bias. In any case, the date of nursing home placement is not subject to interviewer bias. While it is theoretically possible that counselors might influence caregivers in the treatment group not to place their spouses in nursing homes, in practice, counselors more frequently influenced caregivers in the treatment group to place patients in nursing homes when it appeared to be in the caregiver's or patient's best interest (generally because the caregiver was abusing or neglecting the patient, or was too ill to continue to provide care). In the first year after baseline, 9 of the 11 caregivers in the treatment group who



Survival curves for time to nursing home placement, adjusted for sex, patient age, and patient income. Curves are from a Cox proportional hazards model and are depicted at the mean value of the covariates.

placed patients in nursing homes did so at the urging of the family counselors.

All of the counselors are clinicians, with master's degrees or doctorates in social work, gerontology, or psychology, and their primary aim was to help caregivers cope with caring for an AD patient. The control group in this study received support that was equivalent to or better than what was typically available to families of AD patients in the community. Since caregivers in the control group who asked frequently for advice from counselors or joined support groups were still analyzed as controls following the intent-to-treat principle, the differences between outcomes for the treatment and control groups were likely smaller than if the subjects in the control group had not had contact with the counselors in the NYU program.

An important strength of the study was our remarkably low attrition rate. With one exception, even after caregivers stopped actively participating in the study, they or their families were willing to provide information about the outcome for the patient.

The unifying theme of our intervention is that continuously available support and information can enable spouse-caregivers of AD patients to withstand the difficulties of caregiving and avoid or defer institutionalization of the patients. The primary focus of family counseling in this intervention is on diminishing the negative aspects of family involvement with caregiving while enhancing the positive supportive aspects, assuring that the caregiver's expectations are realistic and enabling them to be adequately met either by the family or by other resources. In addition, both the individual and family counseling provide caregivers and other relatives of the patient with information and management strategies that are relevant to their particular situation and responsive to their particular needs.

The intervention strategy has both structured and unstructured components. The most intensive part of the treatment, the scheduled counseling sessions, occurs at the beginning of the treatment process and enables the primary caregiver and other members of the family to establish a relationship with the family counselor. Once this relationship has been established, family members can ask for additional help, information, and advice when they need it. The "as needed" availability of counseling for the caregiver and other family members is an important component of the intervention, making it possible for counselors to respond to the changing effects of the disease and provide ongoing case management and crisis intervention. This also makes it possible for each counselor to provide support for a large number of families. Four counselors were each employed on the project 3 days a week, which is equivalent to 2.4 full-time counselors. Approximately 59 new caregivers enrolled each year, so each full-time equivalent counselor was responsible for about 25 new caregivers each year and each ultimately had a case load of about 86 patients (not adjusting for attrition).

To explore the possibility that our intervention could have directly affected the patients rather than the caregivers, we assessed use of medication by patients and frequency of troublesome behaviors. Use of medications in the treatment and control groups respectively were as follows: psychotropic medications, 26% vs 24%; prescription sleeping pills, 4% in both groups; and antibiotics, 3% vs 4%. Additional Cox proportional hazard analyses were run using psychotropic medications and troublesome patient behavior as time-dependent covariates (model 1). The odds of nursing home placement were not affected. These results support the conclusion that the effect of the intervention was on the caregivers and the way they responded to patient behavior, rather than on the patients themselves.

One of the goals of the intervention is to teach caregivers and family members behavior management techniques to minimize the effects of problem patient behaviors. It is the clinical impression of our counselors that caregivers in the treatment group learn to manage patient behaviors in such a way that the severity of some of these behaviors is decreased. Sometimes the troublesome patient behavior itself (agitation due to not being understood or being treated with impatience, for example) can be prevented by appropriate caregiver behavior. In other cases, the caregiver's management of the behavior makes the consequence of that behavior less difficult to live with. For example, although patient incontinence is an unavoidable consequence of neurologic deterioration due to the disease process, it can be managed in such a way as to be more or less noxious to the caregiver. Although we feel that a psychosocial intervention can help to minimize some of the effects of AD by teaching caregivers to manage behavior appropriately, we do not think that our intervention alters the course of the disease itself.

The NYU spouse-caregiver study is unique in several ways. The intervention strategy was based on the clinical experience of counselors who had been working with families of AD patients both individually and in support groups for many years. It has been tested empirically with a large sample of subjects for an extended period of time with many follow-up assessments. This provided a wealth of information about the impact of change in caregivers and patients on nursing home placement. To our knowledge, this is the first time that life-table methods with multiple time-dependent covariates have been employed to assess the effectiveness of a psychosocial intervention.

All the caregivers in this study were spouses of the patients, and most had been living with them for many years. This may explain the fact that caregiver age and physical health were not major factors in placement. Generally, these caregivers expressed the desire to keep the patients at home as long as possible, and even their own poor physical health did not motivate them to place their spouses in nursing homes.

Patient income was an important factor in the decision to place patients in nursing homes. Patients with higher incomes were likely to remain at home longer, perhaps because their spouses could afford to pay trained help at home and get new help if they were dissatisfied, or because they generally have more room in their living quarters so they could more easily gain physical distance from their demented spouse. This result reinforces the idea that state and federal policy can have a profound influence on the decisions of families about how to care for their elderly relatives. For example, in New York State, current Medicaid laws make it financially more attractive to place patients in nursing homes by paying all of the cost of caring for patients in nursing homes but only part of the cost of caring for patients at home.

The fact that male caregivers were able to keep their spouses at home longer than female caregivers deserves comment. Spouse-caregivers of AD patients are mostly from a generation that had stereotyped sex roles in which men were more accustomed to maintaining an independent life outside the home. Our clinical impression was that male caregivers were less enmeshed in the caregiving role, less exhausted by it, and therefore able to continue in it longer than female caregivers.

Not surprisingly, the severity of dementia of the patient had a substantial effect on the risk of nursing home placement. The intervention was most effective with caregivers of patients with mild to moderate dementia, for whom institutionalization is generally least appropriate.

If caregivers were more depressed, they were more likely to place patients in nursing homes. We found that depression had only a small effect on nursing home placement once caregiver reaction to troublesome patient behavior was accounted for, suggesting that the latter is a more proximal cause of nursing home placement than is the former. Additional counseling and training for caregivers and family members, designed to focus on specific troublesome patient behaviors when they begin to be a problem, may further strengthen the potency of the intervention. It can be argued that the greater propensity for treatment group caregivers of patients in the very severe stage to place patients in nursing homes is also a positive feature of the intervention, as the advantages to the caregiver of keeping the patient at home may have decreased by that stage and nursing home placement might, in fact, be appropriate.

The results of this study suggest that a short course of intensive social support and education on an individualized basis, followed by the opportunity for additional support as needed, can enable spouse-caregivers to maintain AD patients at home for a substantially longer period of time than would otherwise be possible. Because of the complexities of cost-effectiveness assessment, incorporating charges for home care and other related costs in addition to nursing home charges, we do not present a cost-effectiveness analysis herein, but an assessment of the impact of the intervention on cost and quality of life is under way.

The families who participated in this study were recruited from a variety of sources and represent a wide range of socioeconomic backgrounds. A challenge for the future is to persuade families of patients with symptoms of dementia who do not seek assistance to avail themselves not only of diagnostic evaluations, but also of counseling, education, and support. The NYU intervention study suggests that innovative techniques for disease management may provide effective alternatives to nursing home care.

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The NYU counseling team included Abby Ambinder, EdD, and Joan Mackell, PhD, in addition to 2 of the authors (E.S. and G.S.).

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Leonard L. Heston, M.D.

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Chapter 17

Effects of a Multicomponent Support Program on Spouse-Caregivers of Alzheimer's Disease Patients

Results of a Treatment/Control Study

Mary S. Mittelman, Dr.P.H.,
Steven H. Ferris, Ph.D., Emma Shulman, M.S.,
Gertrude Steinberg, M.A.,
Abby Ambinder, Ed.D., and Joan Mackell, Ph.D.

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Alzheimer's disease—which causes inevitable, progressive, cognitive, and functional deterioration—poses unique problems for family caregivers. Caregivers who are married to patients with Alzheimer's disease almost invariably want to keep their husband or wife at home rather than put their

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spouse in a nursing home. We set out to find out if we could help these caregivers.

For many years, counselors at the New York University Aging and Dementia Research Center (NYU-ADRC) had formed and led support groups and provided informal counseling to caregivers of NYU-ADRC patients (Ferris et al. 1985). These experiences induced us to develop a multicomponent intervention for caregivers of Alzheimer's disease patients. The goals of this intervention were to help the caregivers survive the illness and to postpone nursing home placement of the patient; the treatment program we designed successfully achieved both of these goals.

With support from the National Institute of Mental Health, we have conducted a longitudinal study to evaluate the potential benefits of this program since 1987. We restricted the study to spouse-caregivers—both because spouses are the primary caregivers for approximately two-thirds of Alzheimer's disease patients and because we felt that the impact of the illness would be different for husbands and wives of Alzheimer's disease patients than for other family members. Spouse-caregivers generally are elderly themselves, and they may no longer be in optimal physical health. Many elderly people rely largely on their spouses for companionship and become socially isolated when their spouses exhibit dementia. Unlike other family caregivers, most spouse-caregivers are living with the patient rather than in separate households.

Issues in Designing an Alzheimer's Disease Caregiver Treatment Study

The design of a caregiver treatment program must consider the nature of the illness. In particular, we had to consider the fact that Alzheimer's disease is a chronic illness that frequently lasts for many years. Previous studies of interventions for caregivers entailed treatment for a relatively short time. Haley et al. (1987), for example, compared education in groups, education and stress management in groups, and no treatment. The groups were time-limited (10 sessions), however, and after 4 months of follow-up, there was no evidence for the effectiveness of either treatment. This intervention might have been successful if it had not been terminated after such a short time.

Furthermore, with Alzheimer's disease the nature of the illness changes over time. Caregivers often report that the methods they use initially to cope with patient symptoms become useless after a short time, as these symptoms disappear and new symptoms replace them. Thus, caregivers need access to someone who can help them develop new techniques for patient management and provide them with information about appropriate resources.

Moreover, each individual caregiver has different specific problems and needs; to be effective, treatment must address these individual circumstances. An intervention that depends entirely on treatment in group settings cannot adequately address these individualized needs.

Many spouse-caregivers become homebound themselves either because of reluctance or inability to leave the patient alone or because of illness of their own. A study that requires caregivers to travel to a clinic for assessments as well as treatment probably would experience difficulty in recruiting and retaining caregivers in the study.

Although some form of control group is essential in assessing the effectiveness of treatment, psychosocial interventions generally are provided by members of caring professions such as social workers, family counselors, and psychologists. As a result, ethical considerations preclude the possibility of denying treatment entirely to anyone. In addition, preventing counselors from providing at least some assistance to every caregiver would be demoralizing. Moreover, caregivers who feel they are receiving valuable services have an incentive to remain in the study.

We incorporated several strategies to overcome the challenges we faced in designing and implementing a successful intervention study. Counselors were available on evenings and weekends so we could accommodate the schedules of caregivers and their families rather than requiring them to accommodate the schedule imposed by the typical working day. In addition, counselors went to the caregivers' homes, if necessary, for intake and follow-up assessments, as well as for individualized components of the intervention. We also designed the study to provide some basic support services to all study subjects.

The study design incorporated longitudinal follow-up to determine long-term outcome. Caregivers remained in the study throughout the course of the disease, whether the patient was at home or in a nursing home. We also interviewed caregivers 1 and 2 years after the death of each patient.

Components of the Treatment

All aspects of the treatment had a common aim: to provide support for the caregiver. Published studies, as well as our own clinical experience and research findings, indicated that the amount of support and assistance the caregiver receives from family members and others is one of the mos important factors in caregiver well-being (Cantor 1983; Ferris et al. 1987 Glosser and Wexler 1985; Gwyther and Blazer 1984; Gwyther and Matteson 1983; Kahan et al. 1985; Scott et al. 1986; Simons and West 1985; Teusink and Mahler 1984; Toseland et al. 1990; Wasow 1986: Zarit and Zarit 1983 Zarit et al. 1987). Furthermore, diversity and variability in caregiver problems emphasized the need for a multicomponent caregiver treatmen package, including elements designed to improve family support and provide group support, with the objective of alleviating the burden of caring for patients with Alzheimer's disease (Zarit et al. 1985a).

Increasing family and social support for caregivers was a major focus of our intervention strategy. According to Cobb (1976), social support is a mediator of stress in all phases of life from birth to death, and there is "strong and often hard evidence, repeated over a variety of transitions in the life cycle from birth to death, that social support is protective" against mental and physical disorder and improves an individual's ability to recover from illness.

Most families want to keep their impaired relatives out of institutions as long as possible. The well-being of the caregiver plays an important role in the decision to institutionalize the patient (Colerick and George 1986). Although our intervention focused on caregivers, we hypothesized that support for these caregivers also would enable them to maintain their spouse-patients at home for a longer time.

Our treatment program had three components. The first component consisted of individual and family counseling sessions. Before we designed this study, Simons and West (1985) reported that family support is an important buffer against poor health caused by stress. Zarit and Zarit (1983) proposed individual and family counseling as a clinical intervention to address problems that a group setting would not address effectively, including a caregiver's reluctance to ask for help and the involvement of potential supporters who have different ideas about what should be done.

Investigators also have suggested that individual and family counseling might improve understanding and communication between the caregiver and the family (Glosser and Wexler 1985; Teusink and Mahler 1984), resolve conflicts resulting from the impact of Alzheimer's disease on the patient's family (Gwyther and Blazer 1984; Wasow 1986), and convince family members of the need for caregiver respite (Scott et al. 1986). Prior research suggested that the extent of the burden on family members depends on their ability to cope with specific problems, their resources, and their responses to the patient's disabilities (Zarit et al. 1980). Individualized interventions address these problems most effectively.

All individual and family counseling sessions were task-oriented. These sessions had several major aims:

- Education to promote understanding of the nature of the disease and how it affects each person in the family.
- Promotion of communication, including listening, understanding, noncritical advice, feedback, encouragement, and praise where deserved, enabling family members to express and understand one another's needs.
- Problem solving: Because Alzheimer's disease is so overwhelming, we emphasized breaking problems into manageable pieces and informing the caregiver about available options. The counselor could help the caregiver choose among options and put them into practice to solve a particular piece of the problem. The counselor also would make the family and caregiver aware of all of the formal and informal services that were available and provide information about auxiliary resources at affordable prices, as well as where to obtain legal and financial advice.
- Patient behavior management: Counseling sessions incorporated role-play exercises to illustrate techniques for possible prevention or handling of difficult situations.
- Concrete planning to enhance caregiver support: This element included having family members other than the designated primary caregiver agree to an explicit plan to take over specific tasks to relieve the caregiver and getting the family to provide emotional support to the caregiver by scheduling activities with the primary caregiver but without the patient.
- Making families aware of the availability of psychopharmacological treatment to manage treatable dementia symptoms (e.g., depression, agitation, night-time wandering).

The second component of the intervention entailed ongoing support-group participation by the primary caregiver. These caregiver support groups were led by individuals experienced in working with caregivers and Alzheimer's disease patients, the family counselors conducting this study, counselors at the Alzheimer's Association, or counselors trained by or known to them.

A major focus of these group sessions was to provide a place for caregivers to express their feelings. Caregivers discussed how the illness affected their relationships with patients and other family members. Th process of learning how to cope with Alzheimer's disease and deal wit changes in patients who were becoming dependent on them helpe caregivers develop techniques for managing problems provoked by th illness. The caregiver support-group leaders provided education abou Alzheimer's disease and suggested appropriate resources for informatio and referral. These sessions also included discussion about financing lon term care, obtaining health care proxies, powers of attorney, and othe issues. Group members learned techniques from each other for how t manage the competing demands on their time from their own needs, th needs of other family members, and the need to provide care to the patient; how to hire and manage paid help for the caregiver; and how t cope with problem patient behaviors.

The third component of the treatment consisted of unlimited ad ho consultation. We did not originally formulate this element as a separat component of the treatment; as the study progressed, however, we became aware of the importance of the availability of the counselor to th caregiver and the family for help as they themselves determined the nee for it. Coming to terms with the fact that the Alzheimer's disease patient though physically unchanged, is no longer the person the caregiver onc knew is difficult—and takes time. Ad hoc consultation was a vital component of the intervention; it acknowledged and addressed the constantl changing nature of the disease and its demands on the family, as well a the necessity for ongoing crisis intervention.

Counselors were available for telephone consultation at any time including evenings and weekends in the event of a crisis. The need for a hoc consulting varied; it depended, in part, on whether the patient's dementia symptoms were stable or changing and whether the caregiver wa having conflicts with other demands or other family members. Counselors provided informal consultation for a variety of reasons, including changes in symptoms of dementia in the patient; physical problems o the patient and/or the caregiver; requests for and complaints about physicians, attorneys, aides, social services, nursing homes, and other individuals or services; miscellaneous family problems; the need for additional resource information; and changes in family composition and location.

The treatment schedule provided for individual and family counseling in the first 4 months after intake into the study. Treatment began with an individual counseling session; during that session, the counselor asked the caregiver to list family members he or she wanted to participate in subsequent family sessions. Four family counseling sessions followed, at times and places that were convenient for the caregiver and family members. These sessions could be held at NYU-ADRC, in the home of the caregiver or another family member, or at some other location specified by the caregiver. Treatment also included an additional individual counseling session with the spouse-caregiver.

The intervention protocol mandated that caregivers join a support group meeting weekly. Caregivers also were informed at intake into the study that consultation with the counselor was available to them and their families at any time. In addition, counselors provided resource information and referrals for auxiliary help, financial planning, and management of patient behavior problems.

Study Design

To be eligible for the study, subjects had to be married to a patient with Alzheimer's disease who had received a diagnosis from NYU-ADRC or another qualified medical facility. Caregivers had to be living with the patient at the time of intake into the study and to have at least one family member in the New York City metropolitan area.

The study was modeled after standard drug trial protocols. Caregivers were randomly assigned to a treatment group or a control group. All caregivers who agreed to participate completed an extensive structured intake interview. After the interview, the counselor opened a sealed envelope containing the caregiver's group assignment.

Each caregiver in the treatment group underwent all of the interventions. and each was provided with support for an unlimited time. Regular follow-up interviews of all caregivers contained all measures used in the intake interview. These follow-up interviews were conducted every 4 months for the first year and every 6 months thereafter.

This schedule was maintained when a patient entered a nursing home. The schedule was modified, however, when a patient died: in that case, the caregiver participated in two short, unstructured interviews—for the purpose of maintaining contact only—6 and 18 months after the death of the patient, and two structured interviews (eliminating the elements that dealt with patient care) 1 and 2 years after the patient's death.

Although the intake and follow-up interviews included structured instruments, counselors conducted these interviews informally, listening carefully to the caregivers' problems. Caregivers have told the counselors that they considered these sessions helpful.

The study design mandated that caregivers in the control group receive resource information and help on request only; these caregiver received no formal treatment. In reality, however, we provided some services to all caregivers. In fact, we received many letters of appreciation from caregivers in the control group, thanking counselors for their help Caregivers in both groups reported that one of the most important thing we provided was someone to listen to their problems. Moreover, we did not differentiate between treatment and control group caregivers if the asked for help in emergencies.

We provided resource information to any caregiver on request. In addition, NYU-ADRC publishes regular newsletters, which include tip about patient care, as well as other information about the latest advance in Alzheimer's disease research; we sent these newsletters to all caregiver in the study. We also sent birthday cards to all caregivers. These birthda cards were a symbol of the caring attitude we wanted to convey to ou patients and caregivers, and caregivers frequently called us to thank u for remembering them.

One major difference between the support we provided to caregiver in the treatment and control groups involved counselors' response to caregivers' telephone inquiries: treatment group caregivers received active help, whereas control group caregivers received only the information they requested. For example, if a caregiver in the control group telephoned to ask a counselor about hiring an aide, the counselo would provide the caregiver with the names and phone numbers of several agencies or aides they felt comfortable recommending. If a caregive in the treatment group called with the same request, however, he or sh would receive information on how to hire and train an aide; in som cases, counselors visited the homes of treatment group caregivers and trained the aides themselves.

Another important difference between the two groups was that th treatment group caregivers and their families took part in six forma scheduled counseling sessions; no one in the control group received formal counseling. As a result, the counselors knew and interacted with th families of patients and caregivers, as well as caregivers themselves, i the treatment group; in the control group, however, they knew only th caregivers. Family members of treatment group caregivers frequentl called counselors for advice or help with problems they were havin with the primary caregivers or with the patients, whereas family member of control group caregivers never had contact with the counselors. Thus, the level of support provided to caregivers and their families was far greater in the treatment group than in the control group.

The emphasis placed on participation in a support group also was quite different between the two groups. Such participation was required of treatment caregivers, who agreed in writing to join a support group at the time of intake into the study. Of course, control group caregivers could initiate support group participation on their own, but the counselors did not urge them to do so.

Caregivers in both groups completed a large, comprehensive battery of structured questionnaires at intake and at each follow-up interview. All primary caregivers of NYU-ADRC research subjects complete the caregiver questionnaire as part of the standard patient evaluation protocol; caregivers recruited from elsewhere completed this questionnaire on entry into the study. All caregivers completed the entire caregiver assessment battery. This battery evaluates several dimensions of caregiver well-being including psychological, physical, financial, and environmental problems and social support. It also includes an evaluation of patient and family problems, with particular emphasis on issues and problems relevant to caregiver well-being and the precipitation of institutionalization.

The caregiver assessment battery included several elements:

- Caregiver questionnaire (developed at NYU-ADRC); readministered if more than 1 month had elapsed between entry into the study and previous administration
- Caregiver physical health questionnaire, adapted from the physical health questionnaire in Older American Resources and Services (OARS) (Duke University 1978)
- Patient physical health questionnaire, adapted from physical health questionnaire in OARS (Duke University 1978)
- Social network list, including satisfaction scale (Stokes 1983)
- Family cohesion, from Family Adaptability and Cohesion Evaluation Scale (Faces III) (Olson et al. 1987)
- Short Psychiatric Evaluation Scale (SPES) (Pfeiffer 1979)
- Affective Rating Scale (Yesavage et al. 1983)
- Burden interview (Zarit et al. 1985a)
- Memory and Behavior Problems Checklist (Zarit et al. 1985b)
- Caregiver home evaluation (safety checklist developed at NYU-ADRC)
- NEO Personality Inventory (Costa and McCrae 1985)

Results

Recruitment into the original study (Mittelman et al. 1995) ended in February 1991 with the enrollment of 206 caregivers. (We currently are enrolling a second group of 200 caregivers.) Table 17–1 presents some characteristics of the study subjects. Of the caregivers, 58% were women, and 42% were men. At intake into the study, 32% of the patients had mild dementia (Global Deterioration Scale [GDS] 4), 40% had moderate dementia (GDS 5), and 28% had moderately severe dementia (GDS 6) (Reisberg et al. 1982). We have continued the intervention with the original group of caregivers, evaluating all subjects at regular intervals to assess the long-term consequences of the intervention and caregiving in general.

The results of our study indicate that caregivers in the treatment group benefited greatly from the intervention. Most spouse-caregivers were reluctant to place their husbands or wives in institutions; a primary benefit of the program was that it enabled caregivers in the treatment group to maintain their spouses at home.

Effect of Intervention on Nursing Home Placement and Death of Patients

As of August 1, 1995, 25.2% of treatment group patients were still at home, compared with 12.6% of control group patients. Moreover, caregivers in the treatment group postponed placement of patients into nursing homes considerably longer than caregivers in the control group. Since the beginning of the study, 52 treatment group caregivers and 65 control caregivers had placed patients in nursing homes (see Table 17–2). Furthermore, caregivers in the treatment group kept patients who eventually were placed in nursing homes at home for an average of 194 days

Table 17–1. Study variables at baseline

Variable	
Caregiver gender	Female = 58% Male = 42%
Severity of patient dementia (GDS)	Mild = 32% Moderate = 40% Moderately severe = 28%

(approximately 4.6 months) longer than caregivers in the control group. Many more patients in the control group died (67) than patients in the treatment group (45), and virtually all of the excess deaths occurred among patients who had been placed in nursing homes: 25 patients in each group died while living at home, whereas 42 patients in the control group died after nursing home placement versus 20 patients in the treatment group.

Because caregivers were randomly assigned to the treatment and control groups, and there was no significant difference in GDS or physical health status at intake in the two groups, the higher number of deaths among control group patients cannot be attributed to the fact that one group had more severe dementia than the other at intake. The fact that the time from nursing home placement to death was less among control group patients than among treatment group patients may indicate that patients in the control group were more physically ill at the time of nursing home placement than those in the treatment group. Although our intervention strategy was not designed specifically to maintain the physical health of patients, the extra education and counseling that the treatment group caregivers and their families received may have provided an unintended benefit in this regard.

The effect of our intervention strategy on nursing home placements was particularly striking in the first 12 months after intake into the study (see Table 17–3). During this period, 35 patients were placed in nursing homes. Fewer than half as many treatment group patients (11) were placed in nursing homes as control group patients (24), however ($\chi^2 = 5.8$, $P < .05$) (Mittelman et al. 1993).

Table 17–2. Effects of intervention: average number of days from intake to outcome

Outcome	Treatment group Days	Treatment group *N*	Control group Days	Control group *N*	Difference (days)
Patient placed in nursing home	810.2	52	640.5	65	169.7
Patient died	1,032.8	45	1,025.4	67	7.4
After nursing home placement	1,366.8	20	1,053.8	42	313.0
While living at home	765.7	25	977.8	25	–212.1
Caregiver died	1,479.9	12	807.6	11	672.5
Total time patients have remained at home	1,087.4	103	893.5	103	193.9

We also used hierarchical logistic regression to assess the effects of treatment and other predictors on nursing home placement. We entered caregiver gender, caregiver age, patient age, patient income, and caregiver difficulties with patient behavior into the multiple predictor model, one at a time, as covariates. We then estimated the effect of treatment group membership over and above the effects of these covariates. Being in the treatment group rather than in the control group had a statistically significant effect ($\chi^2 = 4.4$, $P < .05$). Controlling for caregiver sex and age, patient age, income, and need for assistance with activities of daily living, the odds of nursing home placement for treatment group patients were less than half those for control group patients (odds ratio = 0.40).

Effect of Intervention on Depression in Caregivers

Researchers have frequently documented the negative effects that living with and caring for a family member with Alzheimer's disease have on the mental health of caregivers. Previous systematic studies of interventions for caregivers of patients with dementia (e.g., Haley et al. 1987; Kahan et al. 1985; Lawton et al. 1989) have demonstrated little or no effect on depression.

We examined the effect of our intervention strategy on depression reported by caregivers ($N = 206$) in the first year after intake into the study (Mittelman et al. 1995). We hypothesized that caregivers in the treatment group would become less depressed or remain stable, whereas caregivers in the control group would become more depressed.

Table 17–3. Outcome 12 months after baseline

	Treatment group (*N* = 103)		**Control group (*N* = 103)**		**Total (*N* = 206)**	
Status	***n***	**%**	***n***	**%**	***n***	**%**
Patient at home	83	80.6	74	71.8	157	76.2
Patient placed in nursing home	11	10.7	24	23.3	35	17.0
Patient died before nursing home placement	9	8.7	5	4.9	14	6.8
Patient died after nursing home placement	0	0.0	4	3.9	4	1.9

We measured caregiver depression at intake and all follow-up evaluations with the Geriatric Depression Scale (Yesavage et al. 1983), a 30-item symptom checklist ($\alpha = .94$). At intake, more than 40% of the caregivers (50% of the women and 30% of the men) had scores of 11 or higher, indicating possible clinical depression; this cutoff has a sensitivity of .84 and a specificity of .95 for clinical depression (Brink et al. 1982). The mean score at intake was 9.8 (SD = 6.5).

Overall, the intervention had a positive effect on depression among caregivers (Mittelman et al. 1995). Because a multivariate analysis of covariance found a significant positive interaction between time and treatment group membership, we conducted three hierarchical multiple regression analyses, corresponding to the change from baseline to the three follow-ups (4, 8, and 12 months) in the first year after intake (see Table 17–4). The difference in the amount of change in depression between the treatment and control groups increased from the 4-month ($b = -.71$, $F = 1.25$, not significant) to the 8-month ($b = -1.35$, $F = 5.02$, $P < .05$) to the 12-month follow-up ($b = -2.91$, $F = 15.94$, $P < .001$); the control group became more depressed, while the treatment group remained stable. By the 12-month follow-up, the average difference between the treatment and control groups was almost three points.

Not surprisingly, depression at baseline was a significant predictor of depression at follow-up, although the effect of baseline depression on follow-up depression decreased with time. Although analysis of baseline data suggested that female caregivers entered the study with significantly more depressive symptoms than male caregivers ($b = 3.13$, $t = 3.5$, $P < .001$), the caregiver's sex was not a significant predictor of change in depression from baseline to follow-up. Increase in severity

Table 17–4. Predictors of depression at follow-up

		Months from baseline		
Step	**Predictor**	**4 ($n = 192$)**	**8 ($n = 181$)**	**12 ($n = 173$)**
1	Depression at baseline	.83[a]	.80[a]	.67[b]
2	Caregiver female	.75	–.37	.61
3	Increase in severity of dementia in patient	2.26[a]	.60	.54
4	Treatment group	–.71	–1.35[c]	–2.91[a]

Note. Figures are unstandardized regression coefficients.
[a]$P < .001$; [b]$P < .01$; [c]$P < .05$

of patient dementia was a significant predictor of increase in symptoms of depression in the caregiver only from baseline to the 4-month follow-up (b = 2.26, $F = 9.17$, $P < .001$); this factor was less predictive and not statistically significant at later follow-ups. Further exploratory analyses showed that differential improvement in satisfaction with social networks in the treatment and control groups accounted for about half of the difference in change in depression between the two groups.

Changes in depression were small for most caregivers, but 21% of caregivers ($n = 44$) changed more than one standard deviation (7 points or more) between baseline and 12-month follow-up. Moreover, 71% of treatment group caregivers who changed substantially became less depressed, compared with 30% of control group caregivers. These findings suggest that the NYU-ADRC intervention has the potential to alleviate some of the deleterious effects of caregiving on mental health.

Effect of Intervention on Social Support for Caregivers

Which aspects of the intervention contributed to the effectiveness of the treatment? Many researchers have theorized that social support mediates the stress of caring for a patient with Alzheimer's disease (Pearlin et al. 1990).

We examined the effect of our intervention strategy on caregivers' social systems to help explicate the effects of the treatment on depression in caregivers. We conducted two sets of hierarchical regression analyses. The results showed that caregivers in the treatment group experienced greater family cohesion (as measured by scores on FACES III) than those in the control group. The intervention also had a marked effect on caregivers' satisfaction with their social networks, which increased from baseline to the 4-month follow-up and still further from baseline to the 8-month follow-up.

We inferred that family counseling, which occurred in the first 4 months, and participation in a support group, which began after the 4-month follow-up, each added to the satisfaction of caregivers with their social support. Caregivers frequently included family counselors in their lists of members of social networks with whom they felt close. Thus, by directly providing caregivers with social support in their relationships with family counselors, the intervention increased caregivers' satisfaction with their social networks. The difference between the treatment and control groups did not diminish with time—predictably, because the availability of family counselors and support groups also remained constant.

The intervention enhanced social support for caregivers within 4 months of intake into the study (see Table 17–5), whereas its effect on caregiver depression became substantial only at later follow-up points. Social support was a significant predictor of depression cross-sectionally at baseline. This finding provides evidence to substantiate the theory that social support mediates between the primary stress of caregiving, as well as outcomes such as depression.

Conclusion

The results of the NYU-ADRC caregiver study indicate that the intervention achieved both of its goals. It significantly improved the ability of spouse-caregivers to cope with Alzheimer's disease and thereby significantly postponed nursing home placement.

The results of this study demonstrate that a multicomponent intervention can be effective in improving social support for the primary caregiver, largely by increasing the involvement of other family members in addition to the spouse. At follow-up interviews, caregivers in the treatment group reported increased family cohesion and greater satisfaction with the informal support provided by family and friends. This increase in social support appears to have a substantial effect on depression among some caregivers.

The intervention also was instrumental in enabling caregivers to postpone or avoid placing patients in nursing homes. This finding is especially

Table 17–5. Predictors of caregiver satisfaction with social network at follow-up

		Months from baseline		
Step	**Predictor**	**4 (*n* = 192)**	**8 (*n* = 181)**	**12 (*n* = 173)**
1	Satisfaction with social network at baseline	.73^{a}	.59^{b}	.58^{a}
2	Caregiver female	–.22	.02	.05
3	Increase in severity of dementia in patient	–.23	–.09	.24
4	Increase in family cohesion	.02^{c}	.03^{c}	.04^{b}
5	Treatment group	.48^{a}	.66^{a}	.68^{a}

Note. Figures are unstandardized regression coefficients.
$^{a}P < .001$; $^{b}P < .01$; $^{c}P < .05$

notable: if a pharmacological treatment produced equivalent effects on time to institutionalization, it would be hailed as a major breakthrough.

Clearly, the broad application of strategies similar to those embodied in the NYU-ADRC intervention would be likely to have a major impact on the social and economic cost of Alzheimer's disease. We are currently conducting research at NYU-ADRC to determine the economic cost of caregiving and the economic benefit of the intervention.

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The CHAIRMAN. Dr. Levy.

STATEMENT OF DR. DAVID LEVY, CHAIRMAN AND CEO, FRANKLIN HEALTH, INCORPORATED, UPPER SADDLE RIVER, NJ, AND CAROL WEINROD, REGISTERED NURSE, FRANKLIN HEALTH, INCORPORATED

Dr. LEVY. Thank you. Chairman Grassley, members of the committee, thank you for initiating this important discussion and inviting us to share our experiences with you.

My name is David Levy. I am a family physician and epidemiologist and the founder and chief executive of Franklin Health, Inc. Franklin Health's complex care management program was inspired by two simple observations. First, a very small number of patients have complex medical requirements that disproportionately drive expenditures. In fact, among those under 65, we estimate that the sickest 1 percent of the population, whom we call "complex patients," drive about 30 percent of total health care costs.

Second, standard benefit packages, including that of Medicare, lack the flexibility to treat these complex patients, and traditional cost management strategies such as precertification and utilization review often leave patients and their families feeling not only ill-served, but confused, frustrated and angry.

In coordinating the care of patients with complex and multiple needs, we strongly believe that the patient and his or her family—not hospitals, not doctors, not even case managers—must be at the center of the system; that, given good information and individualized support, patients and their families will make the right treatment decisions for themselves. The heart of our complex care management program lies in personal contact with patients and families, empowering them with knowledge and choices and supporting them in their communities.

Today, I have asked Carol Weinrod, a registered nurse who is one of our full-time professional care managers, to talk about our program.

Carol.

Ms. WEINROD. Thank you, Dr. Levy.

Let me begin by briefly describing two patients—Ruth and Lynn—and then talk about how I managed their care. Ruth, a widow in her eighties, was hospitalized with the latest of several hip fractures when I was called into the case by her Medicare managed care plan. She had been hospitalized twice previously for problems relating to heart disease and a chronic pulmonary disorder. Physical examination and blood work during this inpatient stay suggested a probable cancerous mass on a kidney.

With multiple doctors involved in her care, and certain that she could not be safely maintained at home, the hospital planned to discharge Ruth to a nursing home. Her only family support was a stepdaughter who was very much committed to her but could not see any way to effect Ruth's fervent wish to return to her home of more than 40 years. The stepdaughter lived some distance away and worked full-time. Although she had been through several years of her mother's declining health, the stepdaughter had a very limited knowledge of the health care system and potential resources and simply did not know where to begin.

In her mid-fifties and with a previous history of cancer when I met her, Lynn was hospitalized with pneumonia secondary to ALS, commonly known as Lou Gehrig's disease. Although stabilized in the hospital, she required skilled nursing care, including frequent suction and oxygen support. While her husband and two sons were devoted to her care, each worked full-time, and the family could not afford the daily nursing coverage necessary for Lynn to be discharged home. While her disability would make her eligible for Medicare within a year, the family was extremely reluctant to seek additional assistance from the State Medicaid program in the meantime.

Faced with these kinds of complicated situations, what do family caregivers need? They need someone who can help identify appropriate, realistic, individualized goals, someone who can track information across the continuum of care and who can facilitate effective communication between the family and the hospital, the nursing facility, outpatient clinic, home health, and other services. They need an advocate, a consultant, an educator. In short, they need someone who will support their individualized needs and who will work with them toward putting in place a system of services that meets their loved one's needs and wishes.

For instance, with Ruth's stepdaughter, I spent a great deal of time educating her about home health and hospice services, made sure that physical therapy was initiated before her mother's discharge, and assisted in finding and interviewing private-pay home health aides. I arranged a case conference between the stepdaughter, the hospital discharge planner, the attending physician, and a nearby hospice agency. When Ruth was discharged, I made sure that everyone met her at home—the durable medical equipment supplier, a nurse from the hospice agency, the home health aide, and the stepdaughter. Throughout Ruth's final illness, I remained available for after-hours discussions with the stepdaughter to discuss her mother's physical, emotional and spiritual needs. With all the services she needed in place, Ruth, as the daughter gratefully reported, got her wish and was able to die peacefully at home.

With Lynn's family, my tasks were quite different. First, I advocated with the insurer to flex the standard benefit package, allowing an increase in home health services and the coverage of additional durable medical equipment in return for clear savings over the costs of a nursing home placement. Because her husband was deeply in denial about her ALS, I turned to another caregiver—a son who not only became proficient with his mother's nursing care, but was emotionally able to pursue supports I identified that his father could not, including legal aid to explore Medicaid assistance as well as ongoing contact with the local ALS foundation chapter.

In this case, as in many others, one of my most important roles was to serve as a liaison and sometimes mediator between the family caregivers and the home health agency. Given her deteriorating course, Lynn's family was deeply pleased that she was able to remain out of the hospital for the entire 8 months that I worked with the family.

Dr. LEVY. As the patients that Carol has described, perhaps nothing is as frustrating and difficult for families as the rigid application of coverage limitations or narrowly drawn treatment protocols. Simply, utilization review and cost monitoring are not the same thing as real care management. The barriers to cost-effective care erected by some health plans and insurers are terribly shortsighted. By providing intensive help to the patients whose needs are the greatest, our complex care management system provides one answer to this problem. We take the time to assess the patient face-to-face, not by telephone; we identify treatments, needs and choices in collaboration with the patient, the family and the providers, not by applying a "cookbook" solution. We have strong evidence that by putting the patient at the center of the health care system, the results significantly improve quality of life for all of these patients as well as taking a significant amount of cost out of the system. In particular for the Medicare system, it is estimated at about $10 billion per year, annual and recurring.

Thank you very much, and we would be happy to answer any questions later on.

The CHAIRMAN. Thank you very much.

[The prepared statement of Dr. Levy and Ms. Weinrod follows:]

Testimony Presented by

David Levy, M.D.
and
Carol Weinrod, R.N.
of
Franklin Health, Inc.

before the
Senate Special Committee on Aging

September 10, 1998

Dr. Levy: Chairman Grassley, Senator Breaux, Members of the Committee, thank you for this opportunity to discuss the impact on family caregivers of our intensive case management program, which expressly focuses on the needs of the sickest, most medically complex patients. As you have heard, family caregivers are integral to the care of millions of aging and chronically ill individuals, yet often go unrecognized by the health care system, and seldom receive the education and individualized assistance necessary to support the multiple and essential roles they play.

My name is David Levy. I am a family physician and epidemiologist, and Chairman and CEO of Franklin Health, Inc. In 1987 I founded the company to assist employers and other payers in addressing two significant weaknesses in our system of health insurance:

- While health insurance provides adequate coverage for a majority of the population, a very small number of patients require intensive medical care and thus disproportionately drive expenditures. These individuals – who we call "complex care" patients – have: a significant primary diagnosis, such as metastasized cancer, that may be terminal; significant co-morbidities, which might include diabetes, congestive heart failure or pulmonary disease; multiple specialists and other providers of care; and a range of other concerns, including disruption of family relationships and fear of financial ruin. In the under-65 population we estimate that this sickest one percent account for approximately 30% of health care expenditures. As you know, the often-quoted figure in Medicare is that 10% of beneficiaries account for 70% of program costs.

- Benefit plans are not designed for these patients. In our experience no two complex care patients ever want to be treated in exactly the same way. Yet standard benefit packages, including that of Medicare, lack the flexibility to treat each case as unique and traditional cost management strategies, such as pre-certification activities, utilization review and limited provider panels, frequently leave patients and their families feeling not only ill-served but confused, frustrated and angry.

From the beginning our Complex Care case management program has been driven by certain core values:

- First, that the patient must be at the center of the care system. Faced with difficult choices among treatment options, including the weighing of risks and outcomes, the preferences and decisions of the patient, along with his/her family, must take precedence over the concerns of benefit managers or the convenience of physicians and other providers or even the "best" treatment plan devised by a case manager. Patients accept the realistic limitations of insurance coverage in a less than ideal world, and understand the consequences of their decisions; particularly for those facing multiple and complex illnesses, the right to choose the care they want must be fully respected.

- Every patient deserves information and education about his/her treatment options. This right to knowledge must be accompanied by a right to privacy and full respect for the patient's relationship with his/her physician(s). When Franklin Health was founded we were confident that given good information and individualized support, patients would make good decisions about their own care needs; today we have several years of outcomes data showing that patient-centered decision-making leads to genuine changes in treatment plans and better quality care, increased patient and family satisfaction with services, improvement in quality of life, and incidentally produces significant savings when applied to appropriately targeted individuals with complex care needs.

The heart of our Complex Care case management lies in personal, face-to-face contact with patients and their families. Today I have asked Ms. Carol Weinrod, a registered nurse who is one of our full-time case managers, to talk about the impact of those interventions on the family caregivers of extremely sick, medically complex patients.

<u>Ms. Weinrod</u>: Let me begin by briefly describing the kinds of complicated and difficult situations that patients and their families face every day.

Case Example 1: Ruth, a widow in her 80s was hospitalized with the latest of several hip fractures when I was called into the case by her Medicare managed care plan. In the previous three months she had been hospitalized on two other occasions for problems relating to heart disease and a chronic pulmonary disorder. Physical examination and bloodwork during this inpatient stay suggested a probable cancerous mass on a kidney, but Ruth refused further and invasive procedures that would have confirmed this diagnosis. Having been in nursing homes on previous occasions, her Medicare skilled nursing facility (SNF) benefit days were nearly exhausted. With multiple doctors involved in her care and certain that she could not be safely maintained at home, the hospital was anxious to discharge Ruth to a nursing home. Her only family support was a stepdaughter who was very much committed to her, but could see no way to effect Ruth's fervent wish to return to her home of some 40 years. The stepdaughter lived 45 minutes from Ruth's home and worked full time. Though she had been through several years of her mother's declining health the stepdaughter had a very limited knowledge of the health care system and potential resources and felt overwhelmed by her mother's needs. As with most cases, multiple questions need to be answered: what were Ruth's medical needs and how could these be matched with her wish to return home?; what resources could the daughter access or bring to bear, given the limitations imposed by the demands of her own life?; what education, assistance, support, coordination could I provide to both Ruth and her stepdaughter?

Case Example 2: In her mid-50s, Lynn had faced serious medical problems for a number of years. With a previous history of cancer, when I met her Lynn was hospitalized with pneumonia secondary to ALS (Lou Gehrig's disease). Although stabilized in the hospital, she required skilled nursing care including frequent suction and oxygen support. While her husband and two sons were devoted to her care, each worked full time and the family could not afford the daily nursing coverage necessary for Lynn to be discharged to home. The standard, employer-provided health plan specified maximum coverage of 4 hours per day of home health services. Lynn's husband could see no way to take her home with such limited medical support. While her disability would make her eligible for Medicare within a year, for a variety of reasons, including pride and a real belief in self-reliance, the family was extremely reluctant to seek additional assistance from the state Medicaid program in the meantime. Again, there were multiple questions: how should Lynn's complicated care needs and self-management training be provided and coordinated?; which family member would be the primary caregiver during this episode of care?; what would be the most cost-effective approach and could this be implemented?

Case Example 3: With family caregivers including his wife and daughter and several grandchildren, Angelo wanted to return home after a skilled nursing facility stay. Having been in and out of hospitals, he seemed to have made some peace with the cancer that would ultimately end his life but his family was extremely angry about what they saw as inconsistent and inadequate care. They were strongly opposed to hospice services, which they viewed as giving up on Angelo. During his stay in the nursing facility, Angelo developed a bedsore, a gaping wound, on his backside; because of strong feeling about Angelo's dignity and their own impending loss, none of the family members could perform the wound care that would be necessary to maintain him at home. Again, there were many questions: how could Angelo's medical needs be met in the home?; would the family reconsider hospice services?; how should the family's emotional needs be addressed?

As these case examples begin to suggest, family caregivers are asked to assume multiple roles within an unfamiliar, seemingly impenetrable health care and social services system, in an emotionally charged atmosphere that often evokes fear and disorder. As each of us who has faced the serious illness of a parent or child or spouse knows, not infrequently family caregivers are asked to be:

- The interpreter or liaison, the one who connects the patient to the explanations, directions, decisions of physicians and other providers,
- The decision-maker who considers and helps choose among treatment and service options,
- A direct caregiver, who must learn and be responsible for providing nursing and other functions, and
- The coordinator of other caregivers, ranging from the scheduling of other family members to arranging needed transportation, nutrition, social, financial, and other services.

In most cases, family caregivers are asked to fulfill these roles even while maintaining full-time employment and attending to other important persons in their lives.

From my perspective, the varying roles of family caregivers can be matched by the varying functions of the case manager on an individualized basis. Case management might then include:

- Providing acknowledgement and support for the family caregiver as a integral member of the health care team;
- Offering information and assistance to the decision-maker, both in respect to identifying treatment options and resources, and by facilitating the process of identifying and respecting the patient's wishes, as well as the family caregiver's feelings about the choices the patient makes;
- Furnishing training and education regarding the patient's illness and in regard to specific caregiving skills;
- And establishing a trusting rapport that supports the caregiver while coordinating the execution of the patient's treatment plan across all dimensions of care.

So, what do the family caregivers of the complex care patients with whom we work need? In every case they need someone who can track information across the continuum of care – from hospital to nursing facility to outpatient clinic and home health service, and around again – and work with them toward arranging the care system to meet the patient's needs and wishes. And at the outset each patient, along with his/her family, needs a face-to-face assessment to identify the appropriate, individualized goals of care. But how the case manager facilitates movement toward those goals depends on the patient's needs and wishes and the circumstances of the family – there is no single answer.

Case 1: With Ruth's stepdaughter I spent a great deal of time educating her about the differing capabilities of home health and hospice services, made sure that physical therapy was initiated before her mother's discharge from the hospital, and assisted in the interviewing of home health aides. I arranged a telephone case conference between the stepdaughter, the hospital discharge planner, the attending physician, and a nearby hospice agency that had a local hospital hospice bed should Ruth require re-hospitalization at some point. When Ruth was discharged from the hospital, I ensured that the people representing all the services she needed met her at home: the durable medical equipment supplier, a nurse from the hospice agency, the home health aide, and her stepdaughter. Ultimately, the hospice physician agreed to become Ruth's primary care doctor and followed her with home visits. I remained available for after-hours discussions with the stepdaughter to discuss her mother's care. Ruth, as the daughter gratefully reported to me several weeks later, got her wish and was able to die peacefully at home.

Case 2: With Lynn's family my tasks were quite different. First, I advocated with the insurer to flex the standard benefit package, allowing an increase in home health services and the coverage of durable medical equipment in return for clear savings over the costs of a predictable future hospitalization or nursing home placement. Because her husband was deeply in denial about her ALS, over time I needed to identify the family caregiver who could be realistic and of greatest help to Lynn – this turned out to be one of her sons who, along with his mother-in-law, became the central contact person. The son was able to pursue supports I arranged that his father could not, including an attorney and a legal aid organization to explore Medicaid assistance, as well as the local ALS foundation chapter which provided great emotional and educational support to both Lynn and the family. In this case, as in many others, one of my most important roles was to serve as a liaison, and sometimes mediator, between the family caregivers and the home health agency. An important observation to make here is that families, especially at the outset, are often intensely ambivalent about the need for home health services – angry and reluctant about giving over the care of their loved one to a "stranger" but aware that they cannot possibly meet all of the patient's needs and aware, too, that their own lives have to continue. Given her deteriorating course, Lynn's family was deeply pleased (as was I) that she was able to remain out of the hospital for the entire eight months that I worked with the family.

Case 3: Anger was in some ways the predominant emotion among Angelo's family caregivers. Given their own emotional incapacity to perform Angelo's wound care, they were angry that the health care system did not offer the package of services they needed: traditional home health coverage plus daily nursing care. Over time what we were able to put in place was a kind of simulated home hospice, including arranging a primary care doctor who would act as a hospice physician, prescribing stand-by medications and following Angelo at home. The anger and neediness of Angelo's family could be overwhelming at times and, again, I frequently had to mediate between the family caregivers and the home health personnel to prevent total alienation between the two. Arranging pastoral care was important for this patient and his caregivers, as were extra social work visits. While the family never entirely conquered their anger, they were very pleased about being able to allow him to die at home, as he wished. In a moment his daughter described to me as "sacred," Angelo died with his family around him, his dignity intact.

When it comes to putting the patient's needs and wishes appropriately at the center of the care system, perhaps nothing is as frustrating to family caregivers – and case managers – as the rigid application of coverage limitations or 'allowable' treatment protocols or, at worst, the active avoidance of costs on the part of an insurer or health plan. (In fact, it is the insistence on forcing the square pegs of patients with complex needs into the round holes of standard benefit packages that, at least in part, has fueled a significant public backlash against the perceived excesses of managed care.) But utilization or cost monitoring or benefit reduction is not the same as real care management and the barriers to cost-effective care erected not only by private insurers but also by the Medicare program are terribly shortsighted. We all know of the example that until recently Medicare would pay for an amputation secondary to diabetes but did not cover diabetes self-management education or supplies. The answer, however, cannot be simply to expand benefit packages, and thereby explode costs – we must implement a care management system that ensures that appropriate services can be provided to patients, and their families, whose care needs are complex, costly and can be only partially met by even the most committed family caregivers.

Let me give an example of the case manager's role in devising a cost-effective treatment plan that actually fits the case. As you know, skilled homecare is a covered Medicare benefit, while custodial care is not covered unless attached to a skilled visit under supervision of a homecare professional. In reality, many patients fall somewhere in the middle of this neat distinction and there is considerable room for interpretation as to the "medical necessity" of the service. Often, the coverage decision is made by a distant reviewer who has no first-hand knowledge of the person's needs. (In our experience, a Medicare risk contractor may tend to cut off services quickly, labeling such care custodial, while a homecare agency may stretch the service past the time of needed skilled care.) Having taken the time to assess the patient face-to-face, having identified his/her needs and wishes and the family caregivers' abilities and concerns, our case managers help make such judgments. Our job is to put the <u>patient</u> at the center of the health care system: a system which <u>should</u>, and – in our experience – <u>can</u>, if given reasonable flexibility, meet the needs of patients and their families with a range of services that are necessary, appropriate, cost-effective and, perhaps most importantly, well-coordinated.

Thank you. Dr. Levy and I will be pleased to answer any questions.

The CHAIRMAN. Ms. Weinberg.

STATEMENT OF MYRL WEINBERG, PRESIDENT, NATIONAL HEALTH COUNCIL, WASHINGTON, DC

Ms. WEINBERG. Mr. Chairman, I am pleased to have the opportunity to testify today, and I want to commend the committee for taking such time and devoting this amount of energy to such an important issue.

The National Health Council's mission is to improve the health and well-being of individuals with chronic diseases and/or disabilities. As we have already heard today, most people with chronic conditions receive care not only through the formal health care system, but also from family members and friends. This need for family caregiving is only going to increase with time, as will its financial implications. Unless this informal system of care is supported, expanded and sustained through public policies, we will face an unprecedented crisis in long-term care, shifting demands and costs to both the public and private insurance markets. That is why today's hearing is so important.

In order to avert such a crisis, public policies should be adopted to support family caregivers and the services they require. A one-size-fits-all Government-run program probably is not the solution, nor is it politically feasible at the current time. However, local, State and Federal policies can do much to bolster and expand existing programs and create incentives within the health care system to meet the growing needs of caregivers and future demands for caregiving services.

There are three basic areas where caregivers require support. First, when the initial health care crisis occurs, caregivers need information about the diagnosis and course of the disease. They need training about the medical treatments they will be expected to provide and administer to the care recipient, and they need to be recognized as a key participant on the health care team.

Second, caregivers need support to meet the day-to-day long-term care needs of the care recipient, such as respite care, a blend of home care and other interventions. Furthermore, as you have heard this morning, it is critically important that caregivers are prepared for the impact this role will have on their own lives.

Finally, caregivers require financial support. One cause of great stress to caregivers is the financial insecurity that comes with a chronic or disabling illness requiring full-time long-term care.

I would like to spend just a couple of minutes on each of these three areas.

First, support is needed when the initial health care crisis occurs. Often, medical care must be provided in the home, such as giving injections and monitoring and maintaining medical equipment—care that once was provided solely by doctors and other health care professionals. Much of this shift has been the result of efforts to reduce health care costs. That is why it is imperative that caregivers are adequately trained to take on this role and that they are recognized as an important member of the health care team.

Public and private insurance plans and managed care plans should offer expanded benefits and services to train and support caregivers for their role on the health care team.

One interesting idea that some provider organizations have already begun is popular mini-medical schools for the members of their communities. They recognize that consumers want this health information, and these programs should include courses that are focused on the area of long-term care. Some have suggested that health care providers be reimbursed for such training and counseling services.

The second area relates to caregivers' need for support to meet the day-to-day long-term care needs of the care recipient. Historically, much attention has been paid to the traditional issues related to caregiving, such as respite care and support groups. However, as this informal care system grows, more programs and new approaches are needed. Currently, many caregiver support services are provided by local chapters of national voluntary health agencies, many of whom are our members, such as the Alzheimer's Association, or by community hospitals. These services range from adult day care to support groups to training to education and referral services. But many of these programs serve only a very small number of families due to limitations on resources and/or restrictions on eligibility. It is important that public policies seek to expand these types of local, community-based programs so that more individuals can be served and future needs be met.

Currently, State governments administer most home and community-based services for people with chronic diseases and/or disabilities. Typically, the States have been leaders in developing strategies to provide more appropriate, integrated and flexible services to meet long-term care needs and to identify methods to contain costs. Experience has demonstrated the providing flexibility is the best way to meet the diverse needs of individuals and communities. This flexibility requires a new and different Federal role, working in close partnership with the States.

As you already know, work and family demands often conflict with caregiving responsibilities. To maintain both roles, caregivers identify work schedule flexibility and information about community services for those with chronic diseases as the most useful services employers can offer. These types of benefits are not only humane, but they are good business and should be viewed by employers are recruitment and retention tools.

In addition, we agree with earlier recommendations to expand the Family and Medical Leave Act, and further suggest that the definition of "family member" be expanded to include more than just children, spouse and parents, since in many instances, the primary caregiver is a grand-daughter, niece or daughter-in-law.

Finally, the public policy that will most support family caregivers is a policy that protects families against overwhelming long-term care costs. We must design various income supports to address the financial needs and insecurities of long-term care. As you heard earlier, one way to help protect against the cost of long-term care is through access to affordable, private long-term care insurance. Public policies should encourage individuals to purchase such long-term care insurance, and employers should be encouraged to offer group policies.

However, I must again stress that access to long-term care insurance does not address current or near-term challenges, since most people today in need of long-term care cannot afford to buy policies due to their age or medical status.

You have already heard that some States have developed very targeted programs to address the different income needs of caregivers and the different types of individuals providing caregiving. I want to mention just one additional program.

Soon, a four-State demonstration program will begin in New York, New Jersey, Florida and Arkansas to provide all people with long-term care needs a cash benefit so that they can seek out the programs that they believe will best meet their needs. Enabling care recipients to exercise their independence may result in better outcomes, both physically and emotionally.

I must note that the Government alone should not be expected to support and sustain the caregiving system. The entire health care community, including the for-profit and not-for-profit sectors, must work together with Government to address this pressing issue. To that end, in December, the National Health Council with the National Family Caregivers Association, National Alliance for Caregiving, and other Council member organizations and non-member organizations, will hold a Consensus Development Conference on Caregiving. We will bring together representatives of all the stakeholders dealing with this important issue.

The goal of the conference is to develop consensus around and set into motion a series of concrete steps—an action plan—that can be achieved within the next 3 to 5 years to address key issues facing family caregivers, with the ultimate objective of better integrating the family caregiver into the formal health care system. The Council and I look forward to working with you and members of the committee on this critical issue.

Thank you.

[The prepared statement of Ms. Weinberg follows:]

NATIONAL
HEALTH
COUNCIL

1730 M Street, NW
Suite 500 • Washington, D.C. 20036-4505
(202) 785-3910 • Fax (202) 785-5923

Testimony of

Myrl Weinberg, CAE
President, National Health Council

Before the
United States Senate Special Committee on Aging

September 10, 1998

"75 Years of Putting Patients First"

Myrl Weinberg, CAE

President, National Health Council

Before the
U.S. Senate Special Committee on Aging

September 10, 1998

Mr. Chairman and members of the Committee, I am Myrl Weinberg, President of the National Health Council. I am very pleased to have the chance to testify today on the critical issue of caregiving and I commend the Committee for devoting such time and energy to raising awareness about this important issue.

To put my testimony in context, I would like to briefly describe the National Health Council. The Council is a private, nonprofit umbrella organization of more than 100 health-related organizations. The Council's core membership includes over 40 of the nation's leading voluntary health agencies, such as the American Cancer Society, Alzheimer's Association, Easter Seal Society and National Multiple Sclerosis Society. Other Council members include such organizations such as the National Family Caregivers Association, American Association of Retired Persons, American Medical Association, and private businesses such as Pfizer Inc., Amgen Inc. and Aetna U.S. Healthcare Inc.

The Council's mission is to improve the health and well-being of those individuals with chronic diseases and/or disabilities.

As of 1995, there were nearly 100 million people in America with a chronic condition, according to a Robert Wood Johnson study, "Chronic Care in America: A 21st Century Challenge" (August 1996). And that number is growing as the population ages and as medical research continues to find ways to extend life. By 2020, it is projected that 134 million Americans will have at least one chronic condition. For example, the Arthritis Foundation estimates that by the year 2020 more than 60 million Americans, or 20% of the population, will suffer from arthritis.

As we have already heard today, most people with chronic diseases and/or disabilities receive care not only through the formal health care system, but also from family members or friends. In fact, these informal caregivers often are the first "line of defense" for persons with chronic diseases and/or disabilities, providing the majority of day-to-day assistance required. Surveys indicate that there are more than 22.4 million family caregivers in the United States – a three-fold increase over the last ten years. And, as previous speakers have already demonstrated, the financial value of caregiving is tremendous, accounting for approximately 20% percent of national health care expenditures or nearly $200 billion annually.

The need for family caregiving is only going to increase with time, as will the financial implications of caregiving. Unless this informal system of care is supported, expanded and sustained through public policies, we will face a long-term care crisis, shifting demands and costs to both the public and private insurance markets. That is why today's hearing is so critical.

In order to avert a long-term care crisis, public policies should be adopted to support family caregivers and the services they require. A one-size-fits-all government-run program is probably not the solution, nor is it politically feasible at the current time. However, local, state and federal policies can do much to bolster and expand existing programs and create incentives within the health care system to meet the growing needs of caregivers and to meet future demands for caregiving services. The development of such public policies must be the basis for additional discussion and debate.

There are three basic areas where caregivers require support. First, when the initial health care crisis occurs caregivers need information about the diagnosis and course of disease. They will need training about the medical treatments they will be expected to provide and administer to the care recipient, and acknowledgment that they will be a key participant on the health care team. Second, caregivers need support to meet the day-to-day, long-term care needs of the care recipient. Families and friends willingly become caregivers, but respite care, and a blend of home care and other interventions are needed to provide additional supports. Furthermore, it is important that caregivers are prepared for the impact this role will have on their own lives. Guidance must be offered and a support system should be in place to prevent emotional and physical "burn-out" that can cause caregivers to become care recipients themselves. And, lastly, caregivers require financial support. One cause of great stress to caregivers is the financial insecurity that comes with a chronic or disabling illness requiring full time, long-term care.

I would like to spend just a few minutes on each of these areas. As I do, I will offer suggestions of some existing programs that can be expanded or improved, and will highlight some innovative programs that are working today.

First, support is needed when the initial health care crisis occurs, and continues throughout the crisis. Often, medical care must be provided in the home, such as giving injections and monitoring and maintaining medical equipment – care that once was provided solely by doctors and other health professionals. As fewer people are admitted to nursing homes and hospitals, and as hospital stays grow shorter, families and friends are taking on an unprecedented role in providing these medical services. Much of this shift has been the result of efforts to reduce health care costs. That is why it is imperative that caregivers are adequately trained to take on this role and that they are recognized as an important member of the health care team.

Although a number of innovative programs have been developed to address this particular need, these programs must be expanded. In addition, public and private insurance plans and managed care plans should offer benefits and services to train and support caregivers for their role on the health care team. Some have suggested that health care providers be reimbursed for such training and counseling services. Others have suggested that caregiving issues should become part of the medical and nursing school curriculum. We must act quickly to address this issue, because the need is overwhelming as cost-containment strategies are implemented and as medical technologies grow more complex.

The second area is the need to provide support to meet the day-to-day, long-term care needs of the care recipient. More attention historically has been paid to the traditional issues relating to caregiving such as respite care and support groups. However, as this informal health care system grows, more programs and new approaches are needed.

Many caregiver support services are provided by local chapters of national voluntary health agencies, such as the Alzheimer's Association, or by community hospitals. These services may range from adult day care, to support groups, to training, to information and referral services. But many of these programs serve only a very small number of families due to limitations on resources and/or restrictions on eligibility. It is important that public policies seek to expand these types of local, community-based programs so more individuals can be served and future needs be met.

Currently, state governments, through their respective state agencies on aging and Medicaid agencies, administer most home- and community-based services for people with chronic diseases and/or disabilities. Typically the states have been leaders in developing strategies to provide more appropriate, integrated, and flexible services to meet long-term care needs and to identify methods to control costs. Experience has demonstrated that providing flexibility, typically through the Medicaid waiver process, is the best way to meet the diverse needs of individuals and communities. This flexibility requires a new, different federal role, largely one of partnership with the states in designing and managing programs. But I must stress that the federal government must provide the necessary leadership in this area.

Work and family demands often conflict with caregiving responsibilities. To maintain both work and caregiving roles, caregivers identify work schedule flexibility and information about community services for those with chronic diseases and/or disabilities as the most useful services employers can offer. These types of benefits are not only humane, but good business and should be viewed by employers as recruitment and retention tools.

In 1993, Congress passed the Family Medical Leave Act, which offered working caregivers an option of 12 weeks of unpaid leave to take care of a new baby or ill family member. We have seen the benefits of this policy and should consider expanding it to include employers with 50 or fewer employees and also to include definitions of family member as more than just children, spouse, and parents. The primary caregiver in many instances may be a granddaughter, niece, or daughter-in-law, relationships not currently covered by the Family and Medical Leave Act. I must add a caveat, however, to my remarks about the Family and Medical Leave Act. Studies have shown that few people utilize the Family Medical Leave Act for caregiving purposes, so we should not rely solely on this program to address caregiving needs in the workplace.

Finally, the public policy that will most support family caregivers is a policy that protects families against overwhelming long-term care costs. We must design various income supports to address the financial needs and insecurities of long-term care. One way to protect against the cost of long-term care is through affordable, private long-term care insurance. Public policies should encourage individuals to purchase long-term care insurance and employers should be encouraged to offer group long-term care insurance. However, I must stress that access to long-term care insurance does not address current or near-term challenges, since most people today in need of long-term care cannot afford to buy policies due to their age or medical status.

Some states have developed very targeted programs to address the different income needs of caregivers and different types of individuals providing caregiving. For example, some states provide a monthly cash benefit to the older and disabled person who, in turn, may choose to pay any person, including relatives and friends, to provide in-home care, such as assistance with activities of daily living.

Similarly, other states have looked at the unique needs of younger people who require long-term care services. Studies have shown that younger people frequently desire a level of independence often not desired by older care recipients. A four-state demonstration program will begin shortly in New York, New Jersey, Florida, and Arkansas to provide all people with long-term care needs with a cash benefit so they can seek out the programs they believe will best meet their needs. Enabling them to exercise their independence may result in better outcomes, both physically and emotionally.

Other state programs reimburse caregivers up to a certain amount for respite care and related services and for consumable items, such as "Depends." Medicaid reimbursement for consumable items is available when an individual is in a nursing home, but typically not available when care is provided at home. A few states even provide a one-time grant for home modifications and health care devices.

I must note that the government alone should not be expected to support and sustain the caregiving system. The entire health care community, including the for-profit and not-for-profit sectors, must work together, with government, to address this pressing issue. To that end, in December the National Health Council, with the National Family Caregivers Association, National Alliance for Caregiving and other Council members and nonmember organizations, will hold a Consensus Development Conference on Caregiving. We will bring together representatives of all the stakeholders dealing with this important issue. The goal of the conference is to develop consensus around, and set in motion, a series of concrete steps -- an action plan -- that can be achieved within the next three years to address the key issues facing family caregivers, with the ultimate objective of better integrating the family caregiver into the formal health care system.

I look forward to working with you and the members of the Committee on this critical issue. Thank you for the opportunity to share my views with you today.

The CHAIRMAN. Thank you, Ms. Weinberg.

You will remember I told you we might have a vote at noon. That vote has been put off until 1:45, but this room has already been scheduled for another use at 2 o'clock this afternoon, so I am not going to ask questions of you, although we may submit some for answers in writing, I would appreciate very much if you would respond that way and understand that even though we are not going to have the roll call vote, that there are other things that have to go on in this room on this very subject this afternoon, when we are holding a forum.

Before I close, I want to ask each of you on your own initiative—do not necessarily wait for my staff to contact you—to keep in touch with us on this very important subject, particularly those of you who have studies ongoing and also for the previous panel. It is very necessary for us to keep up on that information.

Also, not because of Ms. Levine's admonition about accommodating public services to family caregivers, rather than having it be the other way around, but following on what you said, I have already organized a forum for September the 18th which will hear about a Johnson Foundation project that tries to facilitate family patient direction of public moneys in the provision of care or services for those families that do it themselves. The focus of the forum will be older caregivers caring for disabled children. The forum will be held on September the 18th in the other Senate Office Building, Hart 216, and it is going to be held in the morning.

I want to close by thanking all of our witnesses for being here today. Your testimony offers keen insight into informal care delivery systems which are so crucial to the well-being of our Nation's elderly. I believe that today's hearing provides an important first step in understanding what can be done to address certain challenges facing millions of Americans today, particularly as we think in this committee about caring for our elderly, and of course, I believe that Congress is only just beginning to really understand the implications of increasing demands for long-term care services, including those affecting family caregivers. It is important that we in Congress continue looking ahead, and that is a very important role for this Committee on Aging.

As chairman of the committee, I am going to keep doing my part to explore and examine the financial challenges of long-term care for individuals and families, as well as what increasing long-term care demands means to public programs of Medicare and Medicaid, and obviously, that is my intent. Sometimes, we fall short of intent, and I ask anybody in this room or anybody who is listening to help me keep this in the forefront of the Aging Committee.

I have a chart up here that lists tips for family caregivers, and I am going to make this available as much as possible to individuals and organizations involved in caregiving. It can also be found on the Aging Committee's web site. These tips encourage family caregivers to be informed, to be persistent and to be smart with money. This list offers suggestions for each of these points, and I think all of these tips can be valuable for family caregivers. Also I think it is especially important for family caregivers to consider planning ahead financially.

As I mentioned at the start of the hearing, I am introducing a bill today to help Americans prepare for the financial demands associated with long-term care. This bill will benefit both the caregivers and the care recipients by helping to minimize the burden of financial hardship when faced with long-term care needs.

I look forward to working with colleagues here in the Congress on this important piece of legislation which has also been introduced in the House of Representatives by a Connecticut Congresswoman, Nancy Johnson.

Also before closing, I would announce, as I previously alluded to that this Aging Committee will hold a congressional forum this afternoon at 2 p.m. in this room. Secretary Jeanette Takamora, the Commissioner of the Administration on Aging, will be moderating the forum, and representatives from a number of successful caregiver programs around the Nation will make presentations and answer questions about their programs. Many others have traveled from various States to listen and participate in this forum, and I am sure it will be a worthwhile discussion of best practices I would urge all of you here and others, to carry new information you gather from the forum back to your States and communities.

Before closing, I must give a special thanks to those of you who are here today, who are part of the family caregiving network, that we have heard so much about today. Your active involvement in the care of someone, particularly the elderly, is certainly a significant commitment that you make, and we have seen attempts to quantify that which make it even more meaningful. I commend you for your efforts and your dedication to working to improve the quality of life for elderly family members and friends.

The meeting is adjourned. I thank you all very much for participating.

[Whereupon, at 12 p.m., the committee was adjourned.]

APPENDIX

American
Academy of
Home Care
Physicians

STATEMENT OF THE
American Academy of Home Care Physicians
to the Senate Committee on Aging,
September, 10, 1998

President
Peter Boling, M.D.
Richmond, VA
804/828-4624

Immediate Past President
Allen I. Goldberg, M.D.
Maywood, IL
708/327-9113

President-Elect
George Taler, M.D.
Baltimore, MD
410/328-5141

Secretary/Treasurer
C. Gresham Bayne, M.D.
San Diego, CA
619/687-5815

Executive Director
Constance F. Row, FACHE

WHO WE ARE

The American Academy of Home Care Physicians is the only professional society for physicians who have an active, professional interest in home care. Undaunted by lack of medical education emphasis and low reimbursement for the last generation, the physicians of the Academy, have for the last decade, worked to promote the art and science of home care medicine, for the benefit of patients, and their many family caregivers.

Uphill battle it has been, and still is. Only recently have pilot programs been instituted to teach physicians how to care for patients in the home as part of the medical school curriculum. It was not until last January that reimbursement levels made making house calls feasible. Despite these obstacles, Academy physicians have been developing house call model programs, and offering access in selected areas of the northeast, mid-Atlantic, south, mid-west and west.

FAMILY CAREGIVING and HOUSE CALLS

The physicians of the Academy interact with care givers on a daily basis. They know their issues, and their problems. They believe that physicians can help, and be part of the solution to the problem if more physicians were willing to make house calls, thereby assisting relatives in caring for their homebound relatives, and relieving them of the responsibility for transport of the patient to the doctor's office.

The frail elderly, the chronically ill child--all of these greatly prefer that doctors come into their homes.

Home visits can assist patients in achieving what they want--to be cared for at home, and avoid institutionalization. The Treasurer of the Academy, a San Diego physician, cared for Dr. Benjamin Spock during his declining years. Both Dr. Spock and his wife were the grateful beneficiaries of his rare, but important specialty house call program.

P.O. Box 1037 ■
Edgewood, MD 21040-1037 ■

Phone: (410) 676-7966
Fax: (410) 676-7980

The AAHCP President, and President-Elect, both offer outstanding house call programs in Richmond, VA, and Baltimore, MD, respectively.

Dr. Tom Cornwell, a community physician in Illinois was the Academy's Housecall Physician of the Year, receiving his award at the Academy's Annual Meeting. Another Board Member who is at one of Harvard's teaching hospitals in Boston, described the cost savings associated with having house calls as part of a comprehensive geriatric practice at our Annual Meeting. An upcoming brochure called "Making Housecalls Part of Your Practice" will soon be sponsored with a generous grant from Ross Laboratories, and sent to physicians to encourage their consideration of making house calls.

The Academy continues to interact with and support the national organizations who, in turn support family caregivers. We only wish we could answer the telephone as family members wish—with the name and address of a physician in their area who will make house calls. With proper support, however, we do believe more physicians can be encouraged to provide this important support to caregivers.

Thank you for the opportunity to share the view so the Academy with your readers.

Suzanne Geffen Mintz

President/Co-founder, National Family Caregivers Association

Written Testimony Presented to the
U.S. Senate Special Committee on Aging
as part of its
Hearings on Caregiving, September 10, 1998

Mr. Chairman and members of the Committee, I am Suzanne Mintz, President and Co-founder of the National Family Caregivers Association (NFCA). During the hearings you heard from many expert witnesses about various aspects of caregiving, about the impact of caregiving on our society, about interventions striving to help caregivers and about suggested ways we can do more. But you have not heard from an organization that actually represents caregivers, an organization whose members are providing care to loved ones day in and day out. For that reason I have prepared this written testimony.

The mission of NFCA is to improve the overall quality of life of America's family caregivers by providing information and education, support and validation, public awareness and advocacy. Our members care for spouses, children, aging parents and other loved ones. The majority care for someone over the age of 50, and have been providing care for five years or more. They are also providing "intense" levels of care. This is defined as helping a loved one with more than two activities and being involved with caregiving responsibilities for more than 21 hours a week. NFCA's members are typical of the eight to nine million Americans who are providing extensive care at home to our neediest citizens.

The National Family Caregivers Association defines a family caregiver as any individual that provides non-compensated care to a family member or partner who is chronically or terminally ill or disabled. The care may take any number of forms including physical assistance, paramedical services, financial aid, legal guidance, care management and/or emotional support. At this time there is not a national consensus on the definition of who is a family caregiver. In fact many individuals who are fulfilling the role of family caregiver do not identify with the term. That is one of the reasons it is so difficult to get a comprehensive understanding of the full scope of caregiving's impact.

One thing is clear. Family caregivers are underpinning our health care system by providing 80% of all home care services. As you heard from Peter Arno, the market value of these services is approximately $200 billion a year.

At a time when the nation is concerned about the rising cost of health care, it becomes increasingly more important to understand the invisible role that family caregivers play in our health care delivery system. and to do something to support it. This is particularly true because family caregivers are now being asked to take on new challenges and additional caregiving responsibilities, at a time when it is more difficult for families to do so. The reasons for this are well known and include advances in medical technology that extend and prolong life, changes in Medicare reimbursement laws, the rise of managed care, changes in the traditional family, the mobility of Americans, and the rise of the 85 years + population.
With 100 million people, virtually half of the population, in this country having chronic conditions, and with the number of persons available to potentially serve as caregivers projected to decrease from a ratio of 11: 1 in 1990 to 4:1 in 2050, the need to find ways to support family caregivers is becoming increasingly critical.

Studies have shown that family caregivers are a population at risk, that they are prone to depression and illness themselves. We do not need to go over the data here, but I do wish to refer you to a recent survey of intense caregivers, the

National Family Caregivers Association/Fortis Report: Caregiving Across the Life Cycle, a copy of which was sent to each of you some weeks ago.

Understanding the problem is not complicated. Finding solutions is. Caregiving circumstances are diverse and extremely personal. No two stories are exactly alike. Caregivers at different stages of their journey need different things. Caregivers dealing with different illnesses or disabilities have somewhat different problems. But despite the differences, there is a common bond among all caregivers and that is their intense isolation, feelings of frustration, and financial sacrifices that we as a nation must strive to minimize.

Caregivers need help from multiple sectors of society. There is a role for government (national, state and local), for the healthcare system, for employers, for community, and of course for other family members.

On the federal level we must begin to acknowledge the role of family caregivers in our healthcare system and make provisions for supporting them by including assistance for family caregivers in the Medicare, Medicaid, and Social Security programs. As these programs are currently being reviewed to determine how we can "update them" and sustain them in the 21st century, it is imperative that the changes that have occurred in our society since their inception be taken into account.

When Medicare was established many of our nation's elderly were in their 60s and they were dealing with acute care problems. Today's seniors are living well into their 80s and are now dealing with chronic care problems. Persons with chronic problems require a very different type of medical care than those with acute medical problems. Caregiving is not a long-term issue when dealing with acute healthcare needs. It is a major issue when dealing with chronic healthcare needs. It is no wonder that Medicare is no longer meeting the needs of many of today's seniors and why home care expenditures have risen so dramatically.

What is scary, however, is that current HCFA policy does not support seniors who are chronically ill. The Balanced Budget Act of 1997 increased the burden of caregivers when it reduced home care payments and instituted the Interim Payment System. Depending upon the outcome of efforts to redefine the term homebound, caregivers and their loved ones could be hurt even more. Congress must intervene and make Medicare a program that addresses today's and tomorrow's realities and that includes provisions for assessing the health of family caregivers and their ability to provide care. It must include funding for training family caregivers and meaningful coverage of respite for family caregivers providing significant levels of care. If we expect families to be part of the healthcare team, we must give them the support, the education and the means to do so. Respite for caregivers is not a luxury. It is a medical necessity. We must remember that dollars spent on supporting caregivers saves many more dollars in healthcare costs.

Medicaid is America's current answer to the problems of long term care, but Medicaid has a built-in bias toward institutional care, this despite the fact that the vast majority of the ill and the elderly are cared for at home and prefer to stay in community. We must develop a long-term care policy that reflects these realities. Studies have shown that caring for someone in the community is much less expensive than in an institution, yet we continue to force families to make painful decisions about a loved one's care while simultaneously destroying a family's financial well-being. Medicaid must be revamped to provide access to more community-based long-term care options that support a caregiver's ability to provide care, and that assists them in transitioning a loved one to institutional care if and when that becomes necessary, without putting their own well being in jeopardy. Caregiving families whose loved ones are Medicaid-eligible are saving our nation millions of dollars.

Social Security, the third and oldest of the government's major programs for the elderly, does not take into account the work value of caregiving, but that work value has been shown to be extremely high. Caregivers who cut back on hours, who leave the workplace, or indeed who never enter it, are penalized for their service to loved ones because they are not accruing credits toward their own social security benefits. They are thus putting their own old age at risk. In addition by leaving the workplace, many caregivers, are cutting off their own health insurance, thus adding to the possibility that they will suffer from physical and mental health consequences of caregiving. Caregivers who are not covered by work-based health insurance, who are themselves not yet eligible for Medicare, need some healthcare insurance, especially because they are at greater risk for illness than the normal population.

As stated earlier, family caregivers need help from all major sectors of our society, but the role of the federal government in setting policy and legislating change is critical if family caregivers are to get the recognition and support they need. Family caregivers are a natural resource that needs to be protected. Family caregivers are an irreplaceable part of our social service and healthcare system. Current government policy acts as if family caregivers do not even exist.

It is a tribute to the leadership of this committee that these hearings were held. It is our heartfelt wish that the testimony provided will result in new legislation to help America's family caregivers.

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