Winter 1982

"A nursing home ... not for my folks!": Families Caring for their Elderly at Home

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Gerontology Program

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"A NURSING HOME . . . NOT FOR MY FOLKS!"

-- Families Caring for their Elderly at Home --

Winter 1982

Prepared in cooperation with the
Massachusetts Association of Older Americans

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PREFACE

This booklet is the second in a series of reports about elderly issues. The first, entitled "The Elderly Have Spoken: Is Anybody Listening? The Impact of Fuel Costs on the Elderly," documented the impact of rising fuel costs on the elderly in Massachusetts. Each of the series reports seeks to capture the actual words, expressions, and feelings of elderly people and their loved ones. For the most part, the interviews were conducted by interviewers who are themselves 60 years old or older. We find that this age match provides greater insight and openness to the problems confronting the elderly in today's society.

In the following pages, you will find the stories of 68 families that have decided to care for their aging relatives in their own homes. Whenever possible, we have attempted to present the words of the family members themselves. These are telling words, unravelled in a moving document in which the authors' job was merely to serve as organizer and communicator of the experience.

FOREWORD

A serious societal problem is beginning to see the light of day: how to provide non-institutional care for frail elderly people who can no longer care for themselves.

The study in the following pages uses the eloquence of families' own love and pain as they tell of their desires to care for their aged relatives, and the frustrations encountered that block their ability to perform that task. The high cost of that care to the family--emotional, physical, and financial--is well documented in anecdotes from the 68 families interviewed.

It can no longer be assumed that families of these elderly dependent people have the required resources to give them adequate care. Other Western countries have come up with solutions; it is past time that American governments at all levels begin to provide ways and means.

American society through its governments must quickly address the problem. We can start with some solutions recommended in the study: assistance with transportation, subsidies for special equipment, funding for home medical visits and part-time home health care, and tax benefits for families caring for frail elders in their homes.

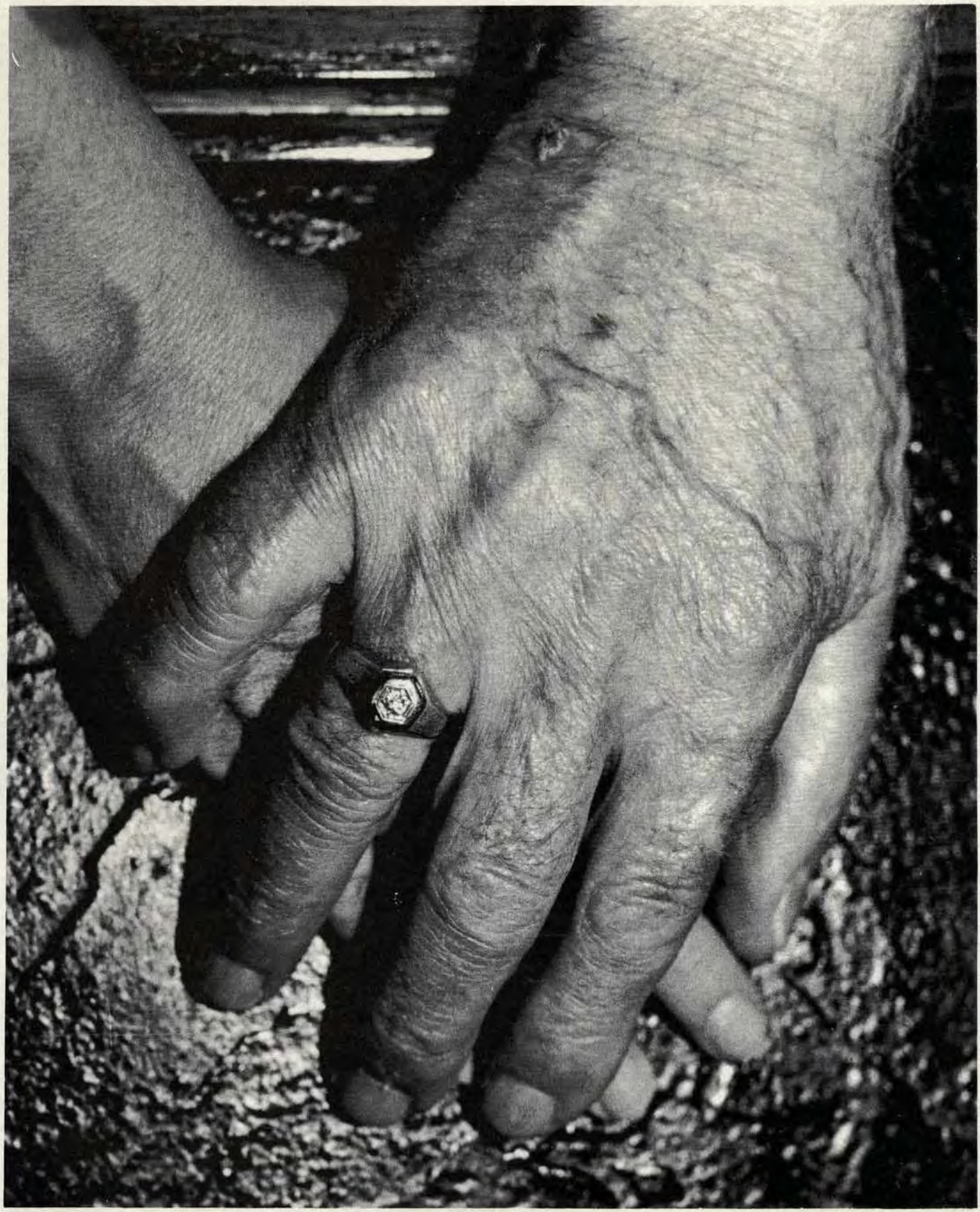
The study will be a useful resource for families approaching middle age, as well as for Members of Congress, state legislators, and local governments.

We live in an aging society, and to ignore that fact is to do so at our own peril.

Barney Frank

Barney Frank
Congressman
Massachusetts

TABLE OF CONTENTS



I. FAMILIES CARING FOR THEIR ELDERLY AT HOME

Robert and Edith M., age 55 and 51 respectively, live just outside of Boston, Massachusetts, in a small Cape home. Robert suffers from asthma and a heart condition and is only able to work part-time in an insurance business. Edith has worked in the past but has stopped working in the last year to help care for her aging mother, Helen. Helen, now 81 years old, previously maintained her own apartment in her hometown of Brockton, Massachusetts, but due to her failing health and the distance from her children was forced to move to her daughter's home. A room has been set aside on the first floor for Helen, who walks with the aid of a walker. According to Edith,

> My mother has always been a very strong, independent, and capable woman. As she has become older, these capabilities are failing her, no matter how hard she tries to keep them together. It is like losing pieces of a puzzle, one by one. It is heartbreaking to watch. No, I would not put her in a nursing home unless I absolutely had to.

This booklet outlines the story of people like Robert and Edith who are caring for an elderly loved one in their own home. We recognize the joy, the pain, and the dedication involved in such a choice. We have listened to the anger, the compassion, and the stress voiced by individuals caring for an older relative. During the course of preparing this report, in fact, both authors experienced the difficulty and frustration involved in deciding on the placement of an elder loved one. In one case, the elder was suffering from irreversible senility, called Alzheimer's Disease. When she moved into her son's home, it caused enormous disruption to routine activities established over a 30-year period. Her gradual physical and mental deterioration required 24-hour care, brought tremendous financial expense, and abruptly forced the family to confront the transformation of its one-time matriarch.

This booklet was prepared for people who are currently involved in such a caring relationship--whether as a recipient of care, as the caregiver, or as another household member--or who are about to become involved. In addition, we hope this booklet will be used by legislators and policymakers concerned for the welfare of our elderly and their families.

Our approach was to interview families who are involved as the primary caregivers for their elderly loved ones. From those interviews, we have sought to examine several questions. They are:

- What are the concerns and needs of caregivers?
- What is it like to care for an elder at home? That is, what are the demands, the joys, the sorrows, and the compromises?
- How can we be supportive of families that choose to care for their elders at home?
- What are the unexpected problems, if any, that these families face?
- How do families cope with the inevitable aging process of an older loved one?

We do not have answers to these questions; however, captured in these few pages is what 68 different families told us.

II. ATTITUDES - "My conscience would not allow me to put my mother in a nursing home."

Perhaps the most emotional discussion during the interviews was about the caregivers' attitude toward nursing homes. Specifically, caregivers were asked if they had ever considered placing their elderly relative in a nursing home. We were surprised to find that 82.3% of the respondents said, "No," they had not seriously considered sending their relative to a nursing home. Several of the comments from caregivers are worth reporting. For example, one caregiver responded:

> During these past years, I have visited many nursing homes, and they depress me. While my mother was in the hospital with pneumonia and a fractured hip, I talked with women in her room from nursing homes, and I was determined . . . this would never happen to my mother.

A suburban woman commented about her 85-year-old mother: "I work in a nursing home. It is a good one, but not for my mother. Some of the employees are of a very poor quality."

A 30-year-old black woman said she discussed a nursing home with her mother, but her mother refused to go.

A 52-year-old Hispanic suburban woman said: "I have considered a nursing home for my mother. However, cultural and moral obligations would not allow me to do so."

A 49-year-old black woman from Boston affirmed this belief: "My conscience would not allow me to put my mother in a nursing home."

A moderate-income white homeowner commented: "She is my mother. I could never put her in a home. She brought me up all my young days. I can take care of her in her old years."

One white woman said about her ailing 86-year-old father: "I would consider placing him in a nursing home when he is physically unable to keep himself clean. I shave him and cut his hair, but I can't bring myself to bathe him."

An Italian woman in her sixties from East Boston said: "My mother is senile and has lost control, so that we are forced to consider a nursing home. We are making the necessary arrangements for her now. But I would never do it otherwise!"

One Jewish woman caring for her sick mother offered this comment: "Yes, I have considered sending my mother to a nursing home. Sometimes I am so tired I don't have time for myself."

A man in his middle fifties told us that his own father is incapacitated and senile and is in a nursing home. He and his wife are caring for her mother in their home now. He said he would never consider putting his mother-in-law in a nursing home as long as they could care for her. He described his father's life at the nursing home as "living death."

An affluent homeowner, who has cared for her mother for the past ten years, stated:

> I have allowed my mother to become very dependent on me, which has made me very bitter. I don't even want my daughter to do the same for me. I would shoot myself first! We had my mother in a nursing home for three weeks once. It cost us $1,000 per week, and it was a disaster. I feel the government should take complete care of the elderly. Their children should not be burdened with the care of them!

Only 7.5% of the caregivers did not discuss this question in some depth with the interviewer. In almost all cases, responses were emotional and vocalized with some intensity. In one situation, the interviewer's very presence led the elder to conclude that this was an official from a nursing home coming to take her away. The resulting incident was very explosive, and the interviewer was forced to leave the home.

On the whole, the responses of the caregivers often conveyed an unrelenting determination to care in their own homes for their loved ones. Sacrifice of individual needs and concerns was not uncommon. As one woman told us:

> My mother is 90 years old and is comatose most of the time. She requires constant care. I am proud of her condition, because it shows that she has quality care. Mother has an air mattress and soft, clean sheets. We use lotions to protect her skin from the ravages of her long illness. We place cotton between her toes, and Mother's food is pureed. We use strained meat that is sold for babies. Mother has a vitamin every day. We use a Hoyer lift to turn her every two hours. . . . A few months ago, we were overjoyed when my mother managed to open her eyes and she seemed to look at a picture of the Madonna. We are sure that she said "Mádonna" before she closed her eyes.
>
> Also, we play Italian records at intervals throughout the day in the hope that she may hear the music and that it may comfort her. One day, she said a word or two from the records which we were playing. This was also a source of joy to us.
>
> I know that my mother is very tired. I know that she cannot live forever. However, I hope that our strength and funds will last because I fear that the trauma of leaving her home would somehow affect my mother. Any sacrifices that we make are well worth the effort. We could not live with ourselves if we did not do our duty at this time.

In one suburban household, the caregiving couple gave up their bedroom to her ailing 86-year-old father. The primary caregiver said:

> When my father came to live with us, we gave him our bedroom. We slept on a sofa-bed unit until we fixed ourselves a room in the basement. Once my husband mentioned that he felt guilty. When I asked him why, he said, "No one in my family could take care of my mother when she was old and sickly, so she died in a nursing home. Yet, here I am even giving up my bed for your father. That makes me feel guilty.

The caregivers' motives seem highly complex and far from uniform. Yet, continued determination and sense of responsibility to the elder is the common thread that runs through all their stories.

We found that, in about a quarter of the families interviewed, someone had to reduce his or her current employment to care for the elder. The reduction in some cases was from full-time to part-time employment; in other instances, one of the caregivers had to end employment altogether in order to take care of an ill elder.

As against this loss of revenue, financial contributions by the elders themselves ran between zero and $100 a month for 33% of the families, $101-200 a month for 30%, $201-300 for 20%, $301-400 for 11%, and $401-700 for the remaining 6%. In most cases, the contribution from the elder hardly offset the additional out-of-pocket costs for the household. And, for those who were forced to radically reduce their employment to assist in care for the elder, this lost revenue was rarely recovered.

Later in this report, we will consider the services that these families receive, or perhaps ought to receive, from government agencies and other sources of outside help. At this point, however, it is worth noting that these families are, in most cases, forced to "go it alone," with little help from relatives. Nearly 70% of the caregivers interviewed said they had other relatives living nearby. However, 73% said the relatives provided no periodic relief, and 93% said the relatives gave no financial aid.

This was the source of numerous negative experiences in the interviews. For example, one woman caring for her mother alone told us that she recently had an argument with her mother about money. One evening while they were talking together, the daughter mentioned how much things cost these days as a tactful way to get her mother to contribute to a very lean budget. Her mother responded by saying, "Oh, people always have worried about money--but we always get by." The daughter said she was angry that her mother was "so thick, but I guess that's because she doesn't get out into reality much. She has no idea about today's costs." The daughter dropped the subject with her mother because she saw she was not going to get anywhere. A few weeks later, she decided to remove $150 a month from her mother's account. She told us: "Mother never sees it; I do all the banking. Besides, I don't feel guilty one bit."

One woman in her late sixties told us of the lack of money to hire a sitter. Someone had to be around at all times to care for her aging mother, so this woman and her husband had almost no opportunity to be together outside the house. One night, the mother told the caregivers to go out--she would pay someone to stay with her. The daughter checked around and was able to get a neighbor's son to come over while she and her husband went to a movie. When they came home, her mother gave her 50 cents to pay the sitter. The daughter told us,

> She has no idea of the cost of things today. I had to give the sitter 10 dollars of my own money, rather than get into an argument with her. . . . I didn't tell her. If it makes her happy to keep money in her fist, that's what I'll let her do. But that's the last time we went out together . . . and that was six months ago. She keeps telling us to go out again, but I make up excuses. . . . We can't afford to pay a sitter.

In summary, the findings from the 68 families interviewed indicate substantial financial responsibility on the caregivers' part, with little relief from government, family, or other sources. About 25% of the families revealed that one caregiver had to give up paid employment to assist in caring for the elder. It was not uncommon to find the responsibilities of care placed on one member of the household, with little support from other members of the household or other immediate relatives. In addition to the emotional difficulty found in caring for an aging loved one, family situations were frequently compounded by physical and financial stress in caring for the elder.

In the upcoming sections, we will present, in the words of those interviewed, the most important experiences of caregivers since taking responsibility for their elderly relative. During the course of the research, we gathered a total of 181 different incidents from the 68 families. The 181 incidents presented by caregivers about living with their elderly relative ranged from very positive to very negative. More specifically, 43.1% of the incidents were of negative experiences, 27.1% were of positive experiences, 25.4% were a combination of positive and negative events rolled into one experience, and 4.4% were neutral. For the most part, 57.5%, the incidents conveyed to us were presented by the caregiver in a highly intensive manner, 34.8% were presented in a moderately intensive manner similar to social conversation, and 7.7% were presented in an unintensive manner by the caregiver.

We grouped the incidents into 12 different theme areas, as shown in Table 1. Not surprisingly, the highest number of incidents fell into the category of "interpersonal relations between elder and caregiver." The other themes that came up most frequently were: "health," "interaction (or lack of it) with other relatives," and "relations between elder and grandchildren." In the following section of this report, we give examples of the incidents that were recounted in each of these areas. These incidents illustrate the variety of patterns that exist in the caring relationship.

Table 1. RELATIVE FREQUENCY OF CAREGIVER INCIDENTS BY THEME AREA

Theme Area	Relative Frequency
Interpersonal relations with caregiver	32.6%
Health	17.1
Interaction or non-interaction with relatives	12.2
Interaction with grandchildren	11.0
Concern about leaving elderly unattended	6.1
Meals/cooking	4.4
Financial issues	3.9
Changes in social activities	3.9
Protective advice from elder	3.3
Relations with nonfamilial caregiver	2.8
Relief time	2.2
Transition of head of household	0.6
	100.0%

III. RELATIONSHIPS - "I feel like I'm getting to know my mother all over again."

Almost one-third of the incidents reported were stories of the interpersonal relationships between caregiver and elder. Overall, these incidents were slightly more positive and upbeat than the average for all incidents in the study. Almost all were riddled with emotion and intensity.

Specific incidents about relationships between caregiver and elder involve the unique combination of personality and situation. These factors become even more complicated when we introduce diminishing health and the dependence of the cargiving relationship. The following incidents dramatize the interaction between health and interpersonal exchanges:

> Mother has arthritis in her hands, arms, and legs. She has a great deal of pain. A series of normal events produced flashes of temper, and finally at dinner she erupted. I had prepared broiled scrod, a dish that she enjoys. It seems that on this day she wanted chicken, but how was I to know that? When she saw the fish, she pounded the table and screamed, "Fish again; I don't want that. Why don't you give me the food that I like?" I was dumbfounded. My heart skipped a beat and literally came up in my throat. I said, "Mother, I know that your arthritis is kicking up, and I think that you should take some Motrin and rest." She stormed out of the kitchen and went to her bedroom, slamming the door. I started to cry because this was the climax of many, many rough days.

The next incident describes a woman who is exhibiting some of the behavior associated with senility. The caregiver in this incident seems unaware and reacts to her mother with anger:

> My mother has become very defensive and secretive. She lies all the time, but she doesn't think that she is lying. For instance, I will ask her if she has given something away and she will first deny it, and then become very defensive about it.
>
> Last month, I came across a lamp in the cellar and I said, "What are you going to do with it?" My mother answered, "It was my mother's lamp, and I am not going to part with it!"
>
> A week later, she gave it to my sister. When I questioned her, she said, "I don't know what happened to it," but later admitted that she had given it to my sister and said, "What business is it of yours; I wanted to give it to her."

An incident similar to the prior one is revealed in this description of a family of limited financial means:

> Before my mother came to live with us, my husband and I were proud of our house. It was the right size for us and comfortable, and we enjoyed living here. But now Mother makes us see it in a different way, and I don't like it.
>
> All her married life, she had lived in a large, six-room apartment. We have a separate room for her, but it isn't as big as the rooms she was used to. We asked her to bring as much of her furniture as would fit into her room here; and everything in there now came from her own place. . . . But she missed the other things we didn't have room to move here. She has never said anything, but when we came home the other day, we found her poking around--she had been in the closets, the desk, the kitchen shelves.

When we asked her what she was looking for, she said, "I'm looking for my things--trying to find out where you have hidden them."

The following incident presents to the reader the sad reality of an elder who has progressed into her own reality in the latter years of her life:

> My mother, who lives in the same house with us, has her own room and bathroom. One evening, she told me that she wanted to wash her floor, and I told her it was too late and to go to bed. At 1:30 a.m., I heard her and I got up to check her. She was on her hands and knees scrubbing the floor with a little military brush that she has and a basin. "I had to get up and wash my floor," she said. It is a hardwood floor, and she was actually taking the shellac off; so I took the brush and basin away from her and got her back into bed.
>
> The next morning, I could see that she had finished washing the floor using her little potty and rags. She said to me, "I can't find my brush and basin. Do you know where they are? They seem to have disappeared."

Old habits and patterns of interaction between the elder and caregiver seem to continue to play themselves out with even greater intensity and magnification as the elder becomes sicker or disabled. For example, the following two incidents reveal

interactions between elder and caregiver where the caregiver feels infringed upon, yet continues the behavior pattern which has been built up over many years:

> My mother-in-law is a very demanding woman. She always has to have her way; she always has to win. I buy all her clothes, and I am always returning things because she is not satisfied with what I buy. She will say, "I never had anything like that in the old country. We always had the best clothes in the old country." I don't answer her; I just exchange them. I take the bus to Goren's in Chelsea, just to buy her stockings. They are the only ones that sell cotton stockings without seams. She has trouble with her feet and the seams hurt her, so I try to keep her happy.

In the following incident, the caregiver is 68 years old and is in moderately good health:

> My mother-in-law lives downstairs from me and is constantly calling for me to come down. I run up and down the stairs a dozen times a day, and I am not well myself. The other night, she woke me up with a banging on the pipes. I ran down, thinking that she was in trouble, but she wasn't. "I can't sleep," she said. "Get me something hot to drink." I could have screamed, but I didn't. I got her what she wanted, then went back upstairs. She takes a nap in the afternoon, but I am on the go all day. I need my sleep. I am exhausted.

As stated earlier, a number of incidents about the relationship between caregiver and elder were positive and upbeat. The moving in of the elder has allowed some families to grow

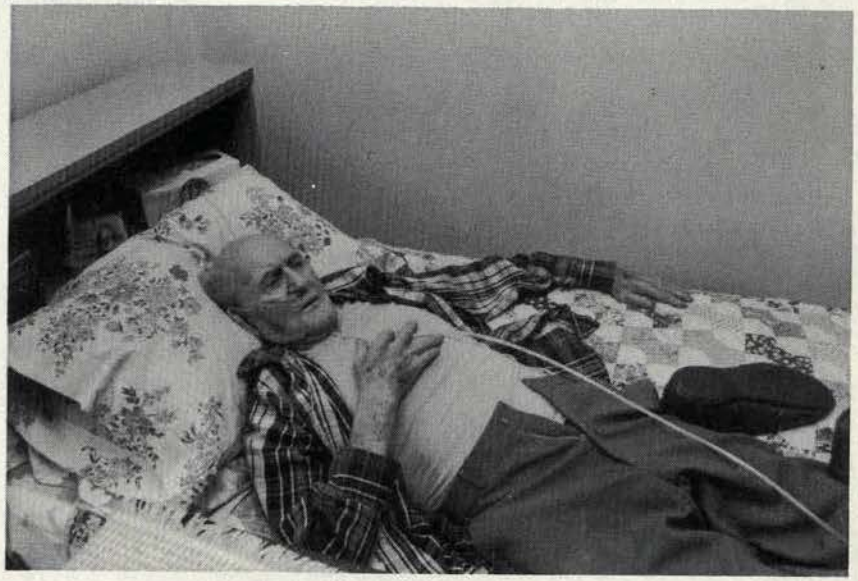
closer together and expand their relationships. Presented in serial format are a number of heart-warming stories about such relationships:

> My father and I have a wonderful relationship, and we really enjoy each other. We both know that he cannot live much longer, and we are both prepared for it, but in the meantime, we make the most of the time we have together. We laugh a great deal.
>
> The other night, I asked him to help me with something . . . I can't even remember what it was, and he said, "No." I said, "Why not?" and he answered, "Because I am a free man." We laughed and laughed and laughed. I dread the day that I no longer have him with me!

Another woman told us in a few words about her joys: "I looked from my window, and there they were--my husband and my mother--working in the yard to prepare this year's garden. I can't tell you why this made me so happy, but it did."

For this one caregiver, gardening was an important experience to share:

> I never know how much my mother knows about gardening--all my life my father did the garden. I just assumed my mother didn't care. Now I find she's got a real green thumb.
>
> Last week, Mother and I had an awfully good time down in the garden planting tomatoes--we chatted like schoolgirls.
>
> If I was young and my children still lived at home, I'd sure start a garden with them--it's brought my mother and I so close together.



Other unexpected common interests seem to emerge when a new boarder comes to the house, as revealed in this incident:

> I've found a common interest with my mother-in-law. When she first came here, I thought, "Oh, Christ, what a pain this will be." But now we watch all the hockey games together. Nobody in the house liked sports but me. Last week, she even made cookies just for the two of us to eat while watching the basketball finals. I can't get over it. It hasn't been bad at all.

Still other families have developed creative ways to keep the family together and share important events:

> A few months ago, I was not feeling well. I had the flu or something like that. My sister knew this. My children were in a Fesh (Irish step dance) out of state. It was the finals, and my mother wanted to attend with us. She told my sister that she would stay home with me. My mother didn't want me to be alone.
>
> My sister borrowed a camper for the day; she put my mother and I in the camper. My husband drove the children. My sister got permission to park the camper on the field so that my mother and I were able to see the Fesh. My mother confided in me that "We have such a wonderful family. I love to come with you and be with you all . . . and I don't feel like a burden."

Reports of stories in which the child and parent grow together are evidenced in this incident:

> My mother has only lived with us since my father died about a year ago. She won't go back into their house even though we only live a few miles away. One day soon after she came here, I found her crying in her room. . . . I didn't know whether to ignore it or not. Finally, I knocked on her door; I was glad she was in. She was looking at pictures of her family as we grew up. I had never seen her cry before.
>
> I went over and held her, and we hugged each other--we didn't even talk. After a while she started showing me pictures of myself when I was small. We talked about funny things I had done as a little girl.
>
> I feel like I'm getting to know my mother all over again.

Not all experiences between caregiver and elder are as pleasant and supportive as the previous incidents. It was not uncommon to hear caregivers talking about feeling guilty, or to listen to individuals discuss how caring for seniors has disrupted their lives. For example, a 63-year-old gentleman who earns less than $10,000 a year told us:

> When I was a young man, I had a steady girl-friend. I went into the service, and when I returned, both my parents were ill. I stayed with them and never married. She did get married.
>
> About a year ago, she called and told me she is now a widow. I really feel that I have devoted my life to caring for my parents and I deserve some happiness. I am enjoying myself, but every time I come home from being out with her, my mother has some complaint. . . . She couldn't prepare her meal, the apartment was too cold; something is alway always wrong. She's afraid I'm going to leave her, and she's always trying to make me feel guilty.

The issue of an elder making the caregiver feel guilty is also demonstrated in the following incident:

> My mother is completely dependent on me for everything. It has created a great deal of tension in the family, and has curtailed our social lives dramatically. I used to refuse invitations to stay home with her, but I don't do that any longer.
>
> Over the weekend, my husband, daughter, and I were invited to a reception. My mother was not

invited. She claimed she was ill and went to bed for the day. She plays the martyr to make us feel guilty so we will stay home with her.

One time when we had gone out and asked a neighbor to look in on her, she called the neighbor and said, "Call my daughter and tell her to come home. I need her." I came home immediately to find that she wasn't in need of anything. She just wanted me there.

In yet another incident, the caregiver seems to have shrugged off the shroud of guilt that was placed on her:

Two weeks ago was my birthday and, unknown to me, my husband and children had planned a surprise party for me at a local restaurant.

My husband planned to hire a home health aide to stay with my mother. As usual, I came home and prepared supper for my mother. My husband then asked me to get dressed because the rest of the family was going to meet at a local restaurant.

My mother must have overheard the conversation, as no sooner than I put my clothes on, my mother started to complain about how bad she felt, and that she should not be left alone at a time like this. I got angry and stated, "Mother, you are very selfish and I am very tired of you hanging on me; I cannot even enjoy my birthday."

Dependency in the caring relationship was mentioned several times. One illustration is:

She just won't let me out of her sight. I have friends who would sit with her, but she won't have it. She's become very dependent on me. More like a

two-year-old child would be. She is remarkably alert and in good spirits as long as she can see or hear me about. It's a good thing I never married. I couldn't do this if I had a family to care for.

Or, as a relatively young (30) black woman stated:

> I can't have company. My mother doesn't like the noise. I can't go out anywhere because I don't want to leave her alone, and she doesn't want to go with me.
>
> One day, a friend of mine dropped by, and we were talking in normal voices when my mother began complaining about our disturbing her. My friend became upset and left. I would like a larger apartment so that I can have some privacy.

Finally, there are situations between caregiver and elder which are heart-wrenching and leave little room for comment. Presented below are two such incidents:

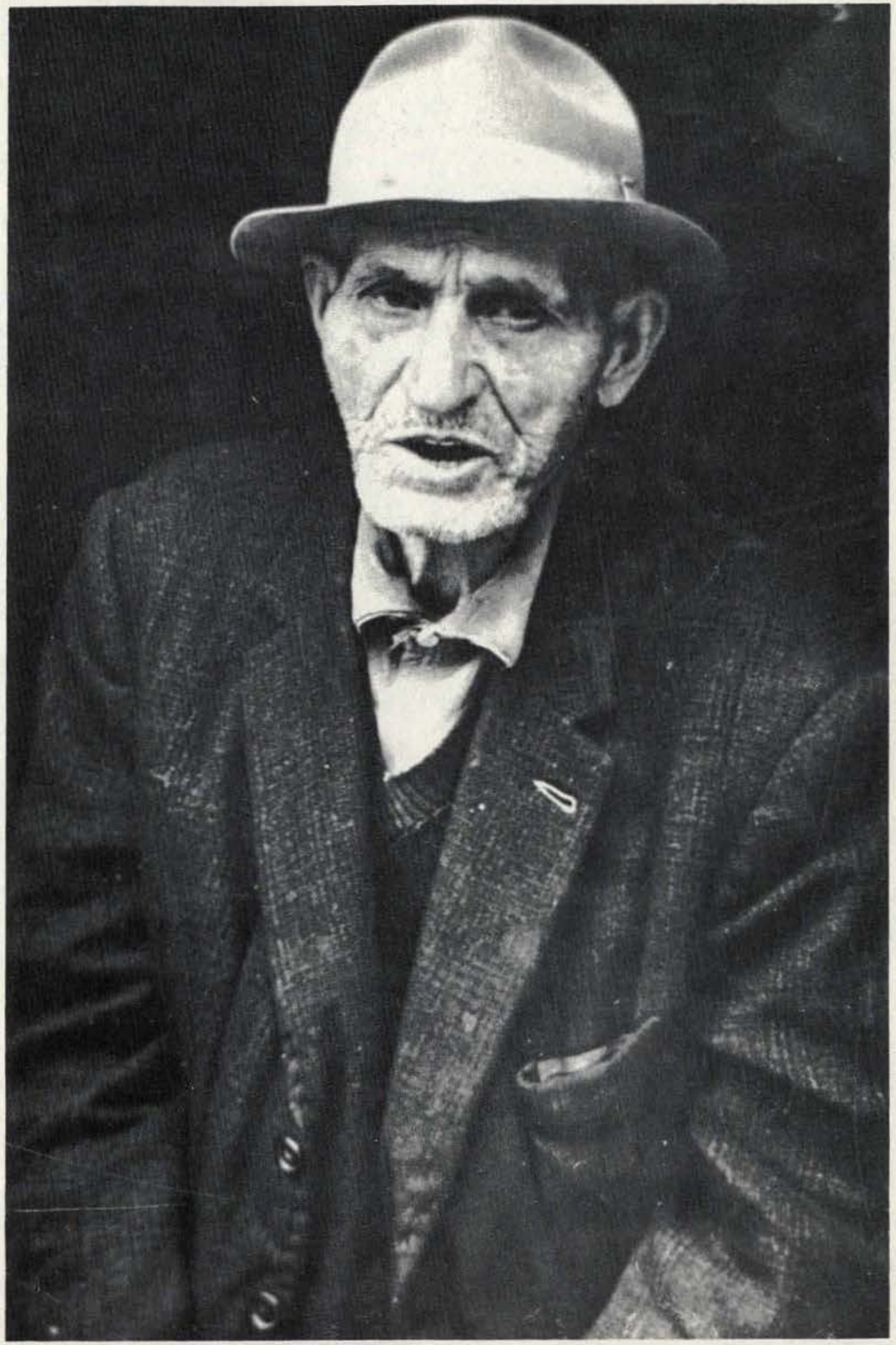
> When Mom's ninetieth birthday was coming up, the family got together and decided to have a large party for her. We decided to rent a hall and everything.
>
> When Mom caught wind of it, she said she didn't want it and would not even go even if we had planned it. We continued making plans, and her birthday finally came. I told her in the morning to pick out what she wanted to wear to the party and when I get home from work we'd get her all set.
>
> I arrived home, and she hadn't even taken a bath or picked out any clothes. I was furious, and had to

pick out her outfit and force her to take a bath. All the while she was saying, "I don't want to go . . . I don't want to celebrate getting old!"

A suburban woman told us of her 86-year-old father:

There has been nothing but sadness since my father came to live with us. When my mother died, he became depressed and withdrawn and still refused to talk reality. Very rarely does he respond when spoken to.

Once I said, "Pa, why don't you clean up your room? If Mama were here, you wouldn't be so messy." He looked at me and said, "If your mother was here, my whole life would be different!"



IV. HEALTH - "Mother always forgets . . ."

The second most frequently discussed topic was the health of the elder relative. This theme occurred in nearly one out of every six incidents discussed. Unfortunately, nearly half of the incidents concerning health were negative or unpleasant experiences, and these were generally related to the interviewers with great intensity and emotion.

It is not easy for many elders to reconcile themselves to the fact that their body is aging and declining even though their mind is still alert and clear. In some of the incidents reported, this self-deception has led to frustration for both the elder and the caregiver. In some of the incidents, the reverse has also been true: The body of the older person remains active, but the mind becomes cloudy and confused. Neither situation is pleasant, easy to describe, or subject to simple solutions.

The following experience typifies the lack of adjustment of many seniors to their health, as well as the anger and emotion it engenders in the caregivers, who must respond to the problem and all its ramifications:

> My uncle has one cold after another during the winter months. I worry because he has bronchitis attacks, usually triggered by colds. Also, I am the sole support of my daughter, and I cannot afford to stay home from work if I come down with this ailment. I do not like to have my daughter exposed to respiratory infections. I take many precautions to keep my uncle in good health, including warm clothing and nutritious food.
>
> Last December, during the frigid spell, I said, "Uncle Billy, I heard you coughing this morning. I hope you are not starting the bronchitis." Uncle responded crossly, saying, "For heaven's sake, I'm not a baby. Stop worrying about me." But, that day, he forgot his rubbers and raincoat. When he got home from work, he was quite wet. He had a high fever at night. I was frantic. I called the doctor, who was out of town. I called the covering doctor, who requested that I take my uncle to his office in town. Uncle said, "I'm not sick. Just give me a couple of aspirins." Then he began to draw his breath in great gasps. I was so alarmed that I tripped and fell down the stairs which lead to his bedroom. I did not know what to do. This attack seemed worse than the others. I called my mother, who is my uncle's sister, and she told me to call the police ambulance. I did. After an interminable wait, the police arrived and brought my uncle to the hospital. He remained overnight.
>
> The next day, as I drove home from the hospital, my uncle said, "I am truly sorry that I caused so much trouble for you. You have been so good to me.

For the rest of the winter, I will be sure to dress properly whenever I leave the house." Unfortunately, another incident occurred two months later around my uncle not taking his medication. I don't know what to do.

A tension similar to that in the previous incident exists within another family. The caregivers are currently providing for an elderly couple, a father who is 84 and a mother who is 77. Both seniors are in satisfactory health, and the primary caregiver is their daughter-in-law. She told us:

> My mother-in-law has been using a walker since she broke her hip two years ago, but she hates to use it. About a month ago, she got up at five o'clock to go to the bathroom and proceeded without her walker. She tripped over a chair and fell on the kitchen floor, fracturing two ribs. We screamed and hollered at her for not using the walker until she finally screamed back, "I do not need that damn walker."

An incident reported by a wealthy caregiver reveals the fear of what her unhealthy mother might unknowingly do to herself:

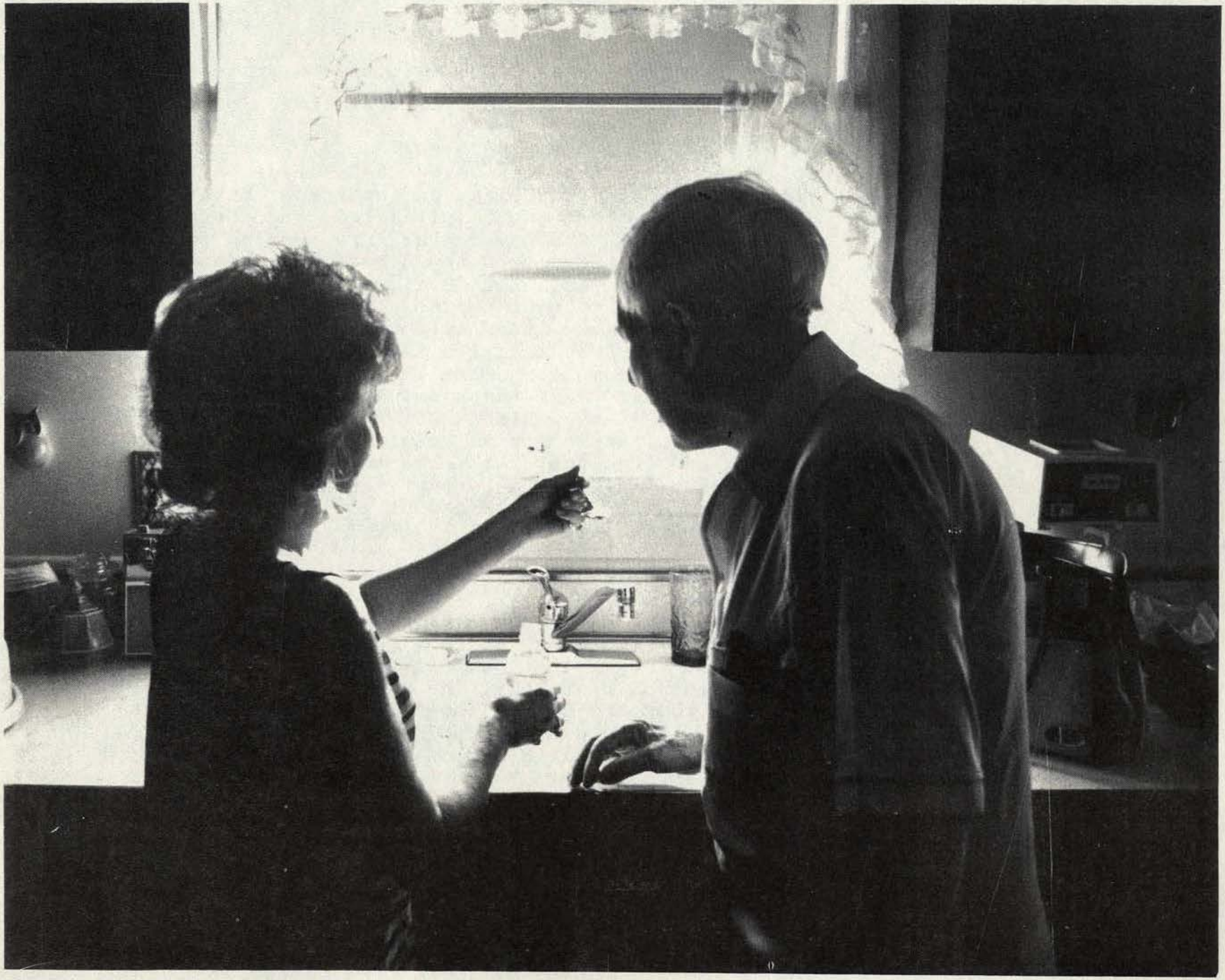
> When Mother first came to live with us, everything seemed fine. She adjusted and we adjusted, and we all felt we had made the right decision to have her come stay with us. But now that the novelty has worn off, I'm not so sure. It's getting so now that every day brings an incident to show she is not happy with us.

For instance: She is frail and has to have help washing her hair and bathing, so we have a routine we follow with her shampoo and tub bath. Recently, she began complaining that she doesn't have a tub bath every day, and two weeks ago she got herself into the bathtub in the middle of the night. She couldn't get out by herself, so she had to bang on the pipes to get us to help her out. I'm afraid she will do it again, and the thing that really worries me is that she might hurt herself in some way.

Other tensions exist between the elder's desire for continued independence despite illness on the one hand, and the constraints and compromises for the rest of the household on the other hand. The following incident describes how one family responded to this difficult issue:

Since Uncle Bob broke his leg, he has made a good recovery and walked very well when he returned home. However, his bedroom is upstairs. He can walk up and down stairs, but I am afraid that he might fall again. I insist that he remain upstairs unless my husband is in the house.

Uncle Bob is very upset by this. I don't think it is a hardship for him. He has everything that he needs upstairs . . . and I just can't take the chance of an accident, as I am here alone all day with two children. . . . The children run around very quickly and I am afraid that they might trip him and that he would fall again. The children are very active, and they have many toys that he might stumble over, and this would somewhat restrict the children's activities. He loves the children and they love him, but I do not want to prevent the children the freedom of their own home.



There are times when caregivers try to protect their loved ones from the full truth about their health. For example:

When my mother was 90 years old, she complained of soreness on the right side of her face. The doctor prescribed a mouthwash and medicine, but the pain persisted. Mother was hospitalized, and the prognosis was grave. She had cancer. The entire area was involved, and the doctor hoped that because of her age the growth would not develop rapidly, as usually happens with a younger person. However, the pain grew worse and swelling developed. The swelling interfered with my mother's eating and drinking. There were two more hospitalizations.

My mother was patient and cooperative. She accepted her fate, thinking that she had dental problems. I was apprehensive about telling her the truth, and it seems that I spent much time trying to keep the truth from her when friends or relatives visited. As the months passed, the situation was nerve-wracking, especially since I knew that the growth was spreading and soon would require radiation to reduce the swelling and make my mother more comfortable.

One day, the doctor recommended that my mother be taken to the Sidney Farber Cancer Center for treatment. My mother did not comment. After we had waited for half an hour, the nurse came into the waiting room and said, "Who is the victim?" I was frantic. Why did the nurse have to say that? I felt the perspiration come out on my forehead. The blood pounded in my head. I looked at my mother. She smiled wanly. She looked directly at the nurse and said, "I am the victim." Then she looked at me. She asked, "Do I have cancer?" I said, "Yes, you do have cancer." Mom said, "How long have I had cancer?" I said, "Two years." My mother replied, "I am glad that you did not tell me."

> I was so relieved. It seemed that a weight had been lifted from my shoulders. I was so tired of sham. I was tired of fibbing and trying to protect Mom. I knew that she had accepted the truth of her condition. From now on, no matter what happened, there would be less worry for me.

In the health-related incidents, it was not uncommon to find stories about relatives who were having difficulty with their hearing, their judgment, or their memory (and often some combination of these). The realities of these life stories are depicted in the following quotations from the interviews:

> My mother is hard of hearing, which is a constant source of aggravation . . . but part of the problem is she doesn't want to listen. She is too busy thinking of what she is going to say next. As a result, she just rattles on ceaselessly, and my husband will cut her off and say, "Nana, you've said that before. You're repeating yourself." But it doesn't bother her; she just keeps right on chattering.

Another individual relayed this incident:

> I felt like never taking her back to church. Sunday was Easter Sunday service, and my mother went with me. It was very crowded and my mother don't hear so good, so she started shouting out to me, "What did you say, what did you say," really loud, you know. So everyone turns around to look at her, as much as to say, "Shut up." She didn't even realize what they were saying and kept doing it. Oh, I felt like leaving that minute to take her home.

This incident further illustrates the problems caused by failing health:

> Mother always forgets. Last week, she was to go to the senior citizens' luncheon. Transportation and everything was arranged. She woke up at 2 a.m. worrying about what she thinks she has to do for the luncheon. She then calls the lady who made the reservations several times at that hour of the morning to find out if the lunch tickets were bought and reservations made. At that time of morning, the lady got real mad and wanted to cancel the whole thing. I had to go and see her in the morning and straighten out the whole thing for her. I was mad, too.

A similar point is made in this story:

> Last Thursday afternoon, a few of my neighbors came into my home for tea. We were having a pleasant conversation when my mother-in-law walked into the room. She said, "I'm glad you don't have a man in here!" I was shocked. My husband--her son--has been gone for ten years. I asked her what she meant by that. She said, "My Herbert has only been gone a short time, and it's not respectable for you to see men." I was embarrassed. My company became very quiet. My mother-in-law left the room in a huff, mumbling to herself.
>
> Later, she came back into the room and asked how everyone was feeling, and said, "I have a wonderful daughter-in-law." I realized then that she was becoming senile. I thanked her for the compliment and asked her if she would like to join us for tea.

Finally, a 41-year-old caregiver told us this of his 78-year-old mother:

> My mother, who has really become rather flaky, is still driving, which makes me very uneasy. When I question her about it, she tells me, "I have never had an accident in 40 years of driving." This is true of major accidents, but she is constantly having minor accidents. She will hit the door-jamb of the garage going in or out, and one time actually hit the house in backing up. I became aware of it because she had taken the paint off of the car. When faced with it, she said, "The driveway was not built big enough." Our driveway is a two-car driveway. It is 30 feet wide.

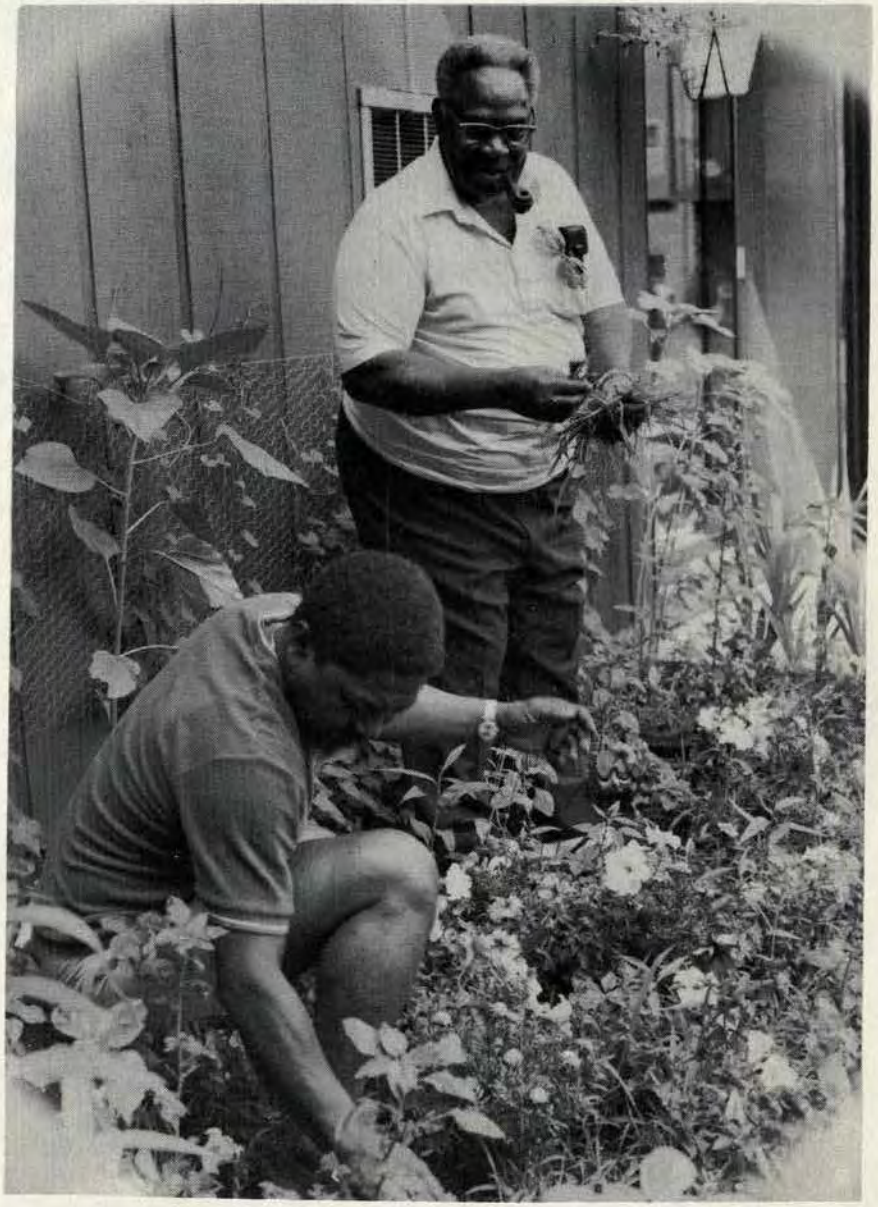
As evidenced in the preceding health-related incidents, diminished capabilities are something that everyone has a hard time adjusting to. The difficulty of fully understanding and responding to the diverse health problems associated with aging creates problems for both younger caregivers and aging adults. And, the complicated (and often unrelated) psychological forces that come into play between younger and older relatives can make objective decision making nearly impossible. Because of this complexity, generalities are difficult to draw. However, the sampling of experiences presented in this and other sections of this booklet touch familiar nerves that go beyond the 68 families in our study. These incidents simply illustrate experiences we have all shared or witnessed.

V. RELATIVES - "I didn't expect anything from them, and that's what I've got--nothing!"

What kind of help do relatives provide? Approximately one incident in nine had to do with the involvement of other relatives in helping to care for the elder. These were negative incidents on the whole: 54.5% were flat-out negative, another 31.8% had negative and positive elements combined, and only 13.7% were either neutral or positive. The incidents told in the open-ended portion of our interview were, as one would imagine, conveyed with intensity and emotion.

A very poor black woman from Boston told us this experience, which highlighted her anger and resentment toward her siblings:

> I have two sisters and a brother, but none of them help me take care of my mother in any way. None of them live in town, but they are all close enough to come over occasionally when things are going well. The day she had her stroke and was taken to the hospital, I called each one of them and told them how bad she was. Not one of them came to see her, so I knew then that it would be up to me to take care of her. After that, I didn't expect anything from them, and that's what I've got--nothing!



In talking to families, we found that the anger toward other relatives--those who seemed to ignore the aging parent --was like a wound that never healed. Every time it was touched, it would hurt and fester. The hostility and resentments would be harbored for years and would unceasingly gnaw at the caregiver. For some, the anger seemed to provide additional drive for further self-denial or even martyrdom. The loneliness of being the only sibling to care for a sick parent is reflected in the following statement:

> My mother is in a walker now and can move around a little. But, when she first came back from the hospital, she was bedridden and had to have constant care. I live alone with her, and I wouldn't ask my brother or sister for help because I thought they should offer it without having to be asked. None of them came forward to say they would help pay the bills or take on some of the nursing responsibilities, so I knew I was on my own. I couldn't afford a nurse, so I took a six-months' leave of absence from my job, and somehow or other we made it.

At times, a needy elder is invited into a home where hostile relations have existed for years between the caregiver and their relatives or siblings. The issue of support for the caregiver or visiting of the elder is compounded by the hostility. This may add to the caregiver's sense of isolation and further inflame their resentment and anger toward the relative.

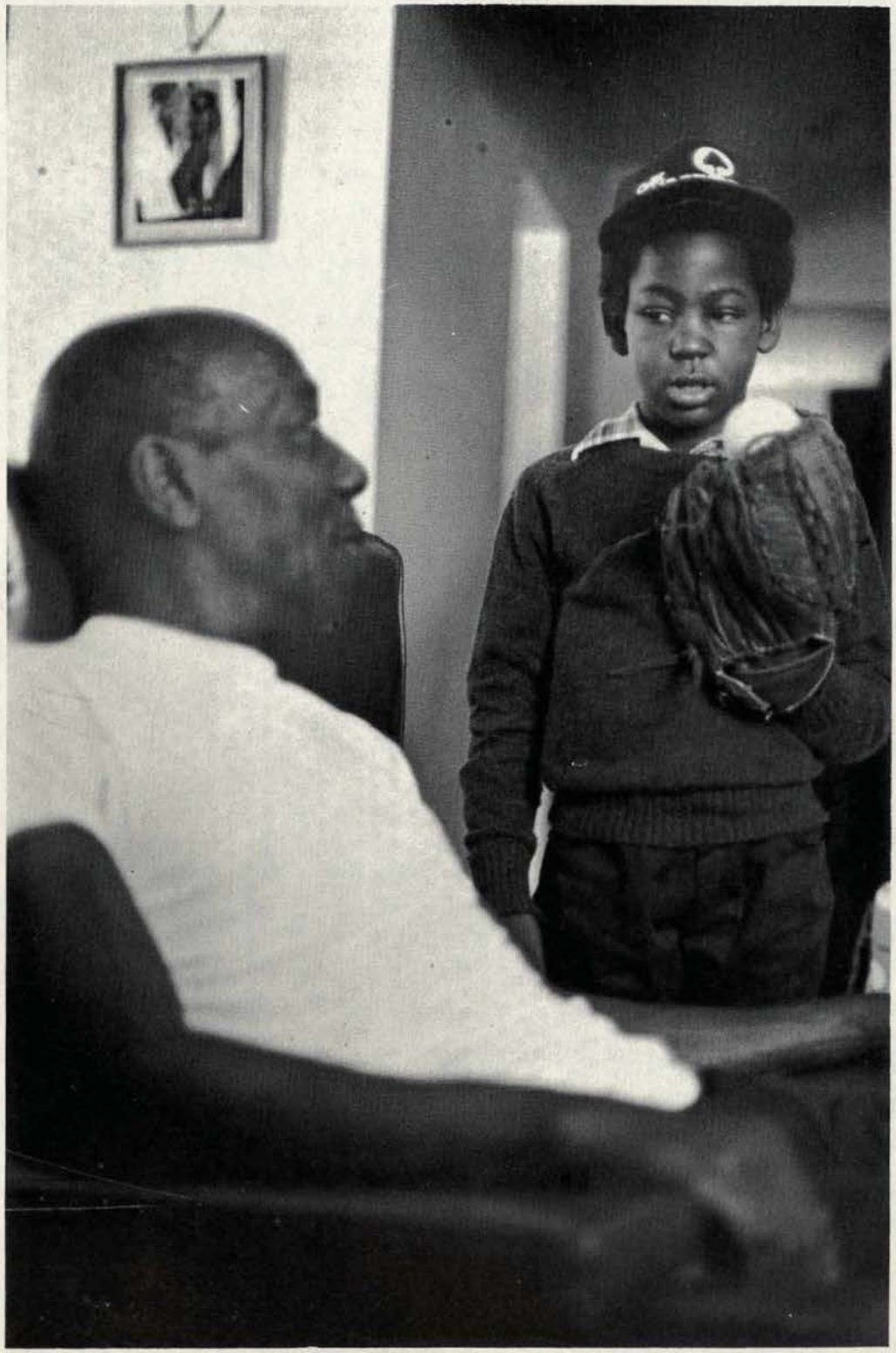
In the following incident, strained relations between sister and brother had a long history and were deeply entrenched. The way events unraveled required the sister to reach out to her brother for help:

> One night last December, Mama got sick and had to go to the hospital. I had no car; I could not get a taxi. I panicked so much I thought I would die. Finally, I had to call my brother to come and take her to the hospital. I don't know what I would do if Mama could not get help to go to the hospital; she may have died.

Finally, we have to remember that some of the relatives may themselves be elderly and somewhat dependent. In the following incident, the caregiver occasionally has company over on Sunday evenings to visit his mother. The incident describes a meal-time incident with an aunt, but it may seem to have been lifted from afternoon television:

> My mother passed the vegetables around the table, but when they were passed to Aunt Martha, she replied, "Oh, no thank you, I'm not hungry." Now, I know damn well she hadn't eaten a thing all day. I think she wanted someone to spoon it out for her. I whispered to my wife that I would be damned if I was going to do it for her; she is quite capable of doing it for herself. Soon, everyone had their plates full and was starting to eat, and then I noticed that Aunt Martha had nothing on her plate and that she was sitting back in her chair with her arms crossed. I finally asked her if she was going to eat. She said, "I can't reach it." I was so furious with her for being so stubborn, but I didn't want to argue with her in front of my mother. So I filled her plate and said nothing. My wife told me that I was looking at Aunt Martha with a face that would kill. She thinks that Aunt Martha does this because Mother is now here and gets a lot of attention, and we do not pay enough attention to her.

The need to care for an aging relative seems to take some very complicated relationships among family members and make them even more complicated.



RELATIVES

46

VI. GRANDCHILDREN - "Why doesn't Grandad respond as much to me as he used to?"

Approximately 11% of the experiences conveyed by the caregivers were interactions between their children and the elderly relative living in their home. For the most part, these incidents were more pleasant, and stated much more positively, than other incidents discussed in the interviews. Despite the positive nature of these incidents, not all were without some mixed emotions. For example, one female caregiver told us of her 89-year-old father's relationship with her brother's children. Within that description, which is considered a positive experience, there is still some sense of sibling rivalry and jealousy:

> I have a brother who lives in New Jersey who has two sons, the youngest of which is in college. My father dotes on both of them, but the younger one is his favorite. He calls his grandfather and tells him everything that he is doing in college--courses, grades, sports, girlfriends, etc. My father tells him stories of his boyhood days in "the old country." "Before I met your grandmother," he'd say, and tell of his experiences. "Boy, those were the good old days! I wish I were there with you; I would teach you a thing or two!"

The aging process is hard on all in the family. The gradual changes and, at times, the apparent lack of interest by the elder are difficult to understand. The following story was told by an urban caregiver of her 90-year-old father, who is in poor health:

> My daughter truly loves her grandfather. She is still fairly young and asks me many questions about why Grandad doesn't respond as much to her as he used to. "He doesn't pay as much attention to me as he used to," she said with tears in her eyes. I told her not to give up, but to talk to him. That day, she did not move from his side and just sat there chatting about this or that, anything so she could keep talking. That was a few months ago, and she still runs up to see him as soon as school is out.

A suburban woman whose father has recently died has taken her 78-year-old mother into her home. Her mother is in good health and provides additional support to the daughter. For example:

> The other day, I was rushing around doing errands and was worried that I wouldn't be home when my children arrived home from school. My mother said, "Listen, just go and do what you need to do. I'll stay here." When I arrived home late in the afternoon, my mother was baking cookies in the kitchen with the kids. The kids didn't even notice that I had come in, they were so busy with Nana. I didn't want to disturb them, so I took the chance to relax and read the paper. My mother says she doesn't believe me when I tell her how glad I am she lives with us.

Many of us remember the little things that loved ones used to do. For example, one caregiver reported:

> My mother used to crochet, but can't much now because of arthritis. A few years back, she made an afghan for my son's family, and they loved it. One day, my mother visited the great-grandchildren, and they were using it. They told her how nice and warm it was. She felt glad that they liked it so much. She said, "They appreciate." I asked her if it made her feel good that they appreciated it so much. She said "Yes" and then told me how good they were to her. She said, "They always say things to make me happy."

The following incident of an urban 91-year-old senior is an example drawn from a typical family situation which could have been problematic, but in fact was appreciated:

> Last week, my youngest daughter came home with her report card. We were not pleased with it. I was scolding her, telling her she didn't try hard enough, when my mother came into the room. She asked what was wrong, and we told her. She said, "I'm sure she will try harder next time." She gave my daughter a pat on the head and said, "Won't you, dear?" My daughter said "Yes" and left the room. My mother then asked us if we didn't remember when we were her age and that sometimes play is more important than school work. I then found my mother in my daughter's room talking to her about how important school work was and that "Mom and Dad really want the best for you." My mother is a diplomat. I wish I had that trait.

Unfortunately, not all experiences between children and their grandparents under the same roof were as positive. One affluent caregiver told of an incident involving her teenage son and her mother:

> My son, age 16, was to have been home by 9:00. My mother was babysitting for the other children, and we were out at a party. At 9:30, my mother called the police, all of his friends' homes, and the party we were at. Meanwhile, my son had come home and blew up at my mother. He screamed at her that he was old enough to take care of himself and she should stop embarrassing him in front of all his friends. By the time we came home, my mother was crying and my son had locked himself in his room.
>
> He's at that difficult age. He still treats his grandmother with a cold shoulder. I don't want it to be this way. . . . It hurts me to see how he treats her.

GRANDCHILDREN

52

VII. IMPLICATIONS

The task of providing care for frail elderly often involves tremendous compromise and self-denial. Caring for a failing elder can be a 24-hour responsibility which, in certain instances, can be very rewarding; in others, quite frustrating, costly, and depressing. In each family we interviewed, the situation was complex and varied. However, a common theme existed--the elder deserved decent care, care such as the elder had once provided for others; and there were few satisfactory alternatives to family-based care currently available.

It is clear, both from our interviews and from a look at overall social trends in the United States, that caregivers who look after elderly relatives in their homes need some outside help. The strains involved in the caring relationship come through clearly in the interviews. Moreover, the caregivers are finding the patterns of American family life changing around them. Over the past 30 years, the size and interconnectedness of the American family have changed. Children are more mobile, family size is smaller, and individual family members have become more self-sufficient. Of those over 65 years of age, 20% have no close surviving relatives; i.e., children. Less expectation is given to extended family responsibilities and more to career and personal growth.

Many of the caregivers, and many of whom are of retirement age themselves, represent the parents of the post-war population expansion. They worry, and some privately fear, "What will happen to me when I am old?" Their children may have moved to other cities and towns, and the closeness and expectation of family caring is simply not there. In one case, it became clear that one of the many motivations of a retirement-age couple to care for their dying father was their attempt to project the care that they would like to have when they are old. At the same time, we learned that this was impossible, due to their own family situation.

At this time, the future of extended care of elderly by families seems unclear. We are facing demographic and medical realities where more and more individuals are living on as sick and frail elderly who need constant care. (The average life-span has increased 2.8 years to 73.3 since 1967.) This demographic trend will accelerate over the next 40 years until the baby-boom generation of the 1950s has passed into the elderly boom of the 21st Century. Already, the U.S. Census Bureau predicts that the over-65 population in 1990 will exceed 30 million, or 15% of the population. The costs of such care to the economy will be staggering, imposing a heavy financial burden. The probability of individuals' being able to pay from savings for extensive long-term care is, at present, remote.

According to self-reports, the families that we interviewed are receiving surprisingly few outside services. However, experience indicates that families are the best advocates for obtaining services for a family member. It is estimated that 80% of the home health care is currently provided by relatives. Furthermore, the development of elderly social/health maintenance organizations and community supportive services holds out some promise for delivering cost-efficient care for the frail elderly.

Table 2 shows the services that are currently received or purchased by the families in our study and the ways they are financed. The most frequently purchased services were transportation (taxicabs, elderly shuttles, and the like) and part-time nursing care. Even in these cases, the percentage of families receiving these services was quite low. Most of the families, in other words, have taken almost the whole burden of care onto themselves. What should concern us about this fact is that a changing population and a changing family are making the burden harder and harder every year, thus restricting the number of families who will be able to provide in-house care for the aging, and perhaps altering the human interactions for those who seek to provide care at home.

Table 2. SERVICES CURRENTLY RECEIVED BY FAMILIES

Service	Percentage Receiving Service	Who Pays (Percentage)			
		Family	Elder	Gov't.	Other
Housecleaning	16.2	45.5	--	54.5	--
Laundry	8.0	83.3	--	16.7	--
Shopping	8.8	83.3	--	16.7	--
Meals-on-Wheels	4.4	--	--	100.0	--
Meal preparation	8.8	50.0	16.7	33.0	--
Food subsidy	5.9	--	--	100.0	--
Friendly Visitor program	7.4	--	--	60.0	40.0
Special equipment subsidy	11.7	10.0	--	80.0	10.0
Transportation	20.6	26.7	--	66.7	6.6
Home medical visits	16.2	7.7	--	84.6	7.7
Elderly legal services	3.4	66.7	33.3	--	--
Part-time nursing care	17.6	--	--	91.7	8.3
24-hour nursing care	--	--	--	--	--
Personal grooming	13.2	30.0	40.0	30.0	--
Clothing subsidy	--	--	--	--	--

When we asked caregivers to identify what role government should play in paying for the range of services, we found some very exacting responses. Specifically, we asked caregivers to state whether they felt government should provide direct financial support to the family caring for an elderly relative. The findings presented in Table 3 show careful review by cargivers across service categories and thoughtful response as to support needed.

Items such as transportation, part-time nursing care, home medical visits, and special equipment subsidy were requested for some form of government help (either tax credit or direct subsidy) by about nine of every ten caregivers. It is important to note that fewer than 15% of the families surveyed received government support for these services. In areas such as 24-hour nursing care, elderly legal services, food subsidies, and Meals-on-Wheels, we also found significant interest in government help; these are also areas in which families surveyed currently receive little or no government support.

Table 3. FAMILY INDICATION OF GOVERNMENT'S PREFERRED ROLE BY SERVICE AREA

Service	Provide Support	Offer Tax Credit	Provide No Support
Housecleaning	42.6%	19.1%	38.2%
Laundry	35.3	16.2	48.5
Shopping	47.1	7.4	45.6
Meals-on-Wheels	57.4	10.3	32.4
Meal preparation	42.6	14.7	42.6
Food subsidy	58.8	13.2	27.9
Clothing subsidy	40.3	14.9	44.8
Friendly Visitor program	55.9	5.9	38.2
Special equipment subsidy	70.1	20.9	9.0
Transportation	76.5	14.7	8.8
Home medical visits	75.0	11.8	13.2
Elderly legal services	66.2	13.2	20.6
Part-time nursing care	76.5	11.8	11.8
24-hour nursing care	64.7	13.2	22.1
Personal grooming	40.3	6.0	53.7

Many caregivers felt that there were certain areas where government support was not the preferred role for their situation, such as personal grooming, laundry services, shopping services, clothing subsidies, or meal preparation. Most of these families have identified a narrow range of government assistance which would help them in continuing to care for their elderly.

These targeted requests include:

- special equipment subsidy
- transportation assistance
- home medical visits
- part-time nursing care

The potential saving to taxpayers of a government program which supports and encourages elder care in their families' homes could be significant.

VIII. RECOMMENDATIONS

In conclusion, we have talked with 68 families who are currently caring for their elderly. We recommend:

1. Government assistance for families caring for their elderly at home, in the areas of:

- special equipment subsidies;
- transportation assistance;
- home medical visits; and
- part-time nursing care.

2. Education and peer support programs for people who are caring for their aging relatives and who could benefit from the results of research and training into the physical and psychological changes that come with aging and loss of independence.

3. Further research into the feasibility of developing low-cost support network systems for older Americans through congregate housing, shared living, respite care, and cooperative social support networks that supplement family support systems or replace them where no family exists.

4. Reshape Medicare and Medicaid programs to divert the flow of dollars away from institutional, long-term care placements and into increasing service for the home-bound.

5. Allowances for start-up costs for community elderly supportive services to develop as we currently allow for institutional programs.

6. Increased federal and state tax benefits for families caring for frail elders in their own homes.

APPENDIX

Research Methods

This investigation made use of two interview techniques. We asked closed-ended questions with fixed responses, but we also asked open-ended questions, allowing the caregivers to talk in depth about their experiences. Each of the two interview techniques has its advantages and disadvantages; used together, they can help us gain a good understanding of what the caregiving families were experiencing.

The closed-ended questionnaire involved 69 carefully defined questions. They covered areas such as age, ethnicity, income, the elder's health, involvement of relatives, employment, services currently received, types of government support felt to be appropriate, help from relatives, and the possibility of nursing home placement.

The closed-ended questionnaire gave us accurate computerized information about the 68 families we interviewed. This allowed us to get an overall picture of the 68 families as a whole. Of course, taken by itself, the questionnaire would not have been flexible enough to let the full range of the caregivers' feelings come through.

To complement the questionnaire, we used a sophisticated open-ended interview technique called the "modified critical incident technique." Originally developed in the 1950s, the technique has been used in international, national, and local studies to provide both qualitative and quantitative data. The idea is to let the interviewees talk about what is important to them, and then analyze the critical incidents that they bring up in the interview. These incidents are classified so as to discover the frequency of particular themes.

During an eight-week period, interviewers were rigorously trained at the University of Massachusetts/Boston, College of Public and Community Service, to conduct interviews on the experience of caring for elderly relatives at home. An average interview lasted one hour; however, the interviewer did not leave until the caregiver was finished talking (as stated earlier, some interviews ran as long as three hours).

Sampling

Because of the detail and length of the interviews, we limited the number of families in our study. Our sample of 68 families was constructed as a nonprobabilistic, random sample intended to reflect the Massachusetts population as a whole. We were careful not to create a "worst-case" analysis based on interviewing only families living in dire need. However, on the basis of our sample, we do not claim to generalize about all families that care for their elderly. Rather, we hope we have managed to shed light on how a small number of families are dealing with this important responsibility.

We tried to interview people who, taken as a whole, came close to being a cross-section of the immediate Boston area. About half of the families were from the city of Boston and half from the surrounding suburbs. About 81% of those interviewed were white, 13% black, and 6% Hispanic or other minority. Household incomes varied considerably: About 9% refused to answer the income question, 22% earned less than $10,000 in 1980, approximately 40% of the households had incomes between $10,000 and $25,000, just under 25% were between $25,000 and $40,000, and fewer than 5% reported incomes greater than $40,000.

The caregivers themselves were from 23 to 71 years old, with the average age being 51. In over 71% of the households visited, the elder was living with the daughter and her family, while only 15% lived with their sons, and 14% with a nephew, niece, grandchild, or some other relative. Over half of the elders were in their eighties, and the average age was 81, which is about the same age as the average nursing home resident in Massachusetts. In the great majority of cases--85%--the elder was female.

Among the families we interviewed, only one-third of the elders could be considered in good health; the others ranged from satisfactory to poor health. For the most part, the elder had lived in the home a long time--more than ten years in over half of the cases. In 26 of the households, the caregivers had children who also lived at home. The relation between elder and grandchild was the fourth most frequently discussed topic in the interviews with the caregivers and was the source of numerous positive experiences.

In order to attain as close a cultural match as possible between interviewer and caregiver, we chose interviewers who in most cases were over 60 years old. They were also assigned to neighborhoods with which they were most familiar. Although many of these interviewers had studied the problems of aging, and some had experience in caring for a sick elderly relative, many were initially reluctant to raise such sensitive topics with the respondents. However, once the interviewers established some rapport, they discovered a sense of isolation on the caregivers' part and a tremendous need to talk about their experiences. Several of the interviews lasted over three hours.