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Older women in southwestern Ohio : long-term care needs and resources

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Ohio Long-Term Care Research Project

OLDER WOMEN IN SOUTHWESTERN OHIO: LONG-TERM CARE NEEDS AND RESOURCES

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May 1993

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Older Women in Southwestern Ohio: Long-Term Care Needs and Resources

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Executive Summary

The purpose of this project was to gain a better understanding of the long-term care needs of older women and to determine whether these needs were being met. The project focused on a five-county area in southwestern Ohio and used multiple research methods to gather information. We combined information from an existing needs assessment survey of older people in Butler, Clermont, Clinton, Hamilton, and Warren Counties in Ohio, from focus-group discussions with older women in each of these five counties, and from interviews with service providers in the area's aging network.

Older women in southwestern Ohio are similar to women nationally in marital status, living arrangement, and disability levels: 51% of Ohio women age 65 and over are widowed, 45% live alone, and 25% experience moderate or severe disabilities. Forty-one percent of older women in this Ohio region have incomes near or below the poverty level, compared with 32% of older women nationally.

A majority of women in the study had provided care to an older family member at some point in their lives; most also had relied on family and friends for help with their own disabilities in old age. More than half of the women who received help with daily activities relied on children and husbands as the major helper. Nearly one-quarter received help primarily from agencies or privately paid helpers.

Women's problems with the long-term care system included lack of information about the services available in their community, inability of lower-income women to pay for services, and gaps in available services in most communities. The following six areas of need were identified as unmet due to unavailability of services or long waits for assistance: 1) homemaker/ personal care, 2) home maintenance and repair, 3) transportation, 4) companionship, 5) respite care, and 6) counseling.

Limited funds for expansion of services and women's lack of awareness about community services were identified as two major barriers to service delivery and utilization. The study also revealed that these barriers are related: service providers are reluctant to advertise or otherwise promote services when they are already unable to meet the current demand.

The following actions are suggested to improve the availability and accessibility of long-term care services for older women:

* The development of a national policy to address the health and long-term care needs of all Americans;
* The inclusion of gender as a factor in targeting elders most in need of Older Americans Act services;
* Passage of state-level legislation to provide a continuum of long-term care services with cost based on ability to pay;
* Increased efforts by area agencies to improve communication with provider agencies in outlying geographic areas.

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Introduction

Long-term care is essentially a women's issue. Women live longer than men, experience higher rates of age-specific chronic disability, and more often live alone in old age; consequently they need long-term assistance much more frequently. Women also are the primary caregivers in our society, and as such are more likely to assist older people in need of help. As the primary consumers and providers of long-term care in this country, women are disproportionately affected by the degree to which an array of long-term care services is available and accessible.

Long-term care involves a continuum of health and social services to individuals with chronic disabilities. These services may be delivered in the home, in the community, or in institutions. The purpose of long-term care is to provide a variety of services from which an individual can choose, depending on the level of need. Such services can support independence while providing assistance with activities ranging from transportation to daily tasks such as meal preparation or personal hygiene (Koff, 1982). Although disabled individuals who receive formal long-term care services are generally viewed as the clients, caregivers to these individuals often benefit as well.

The goal of this project is to understand women's needs for long-term care. We focus on the long-term care delivery system in southwestern Ohio to learn how women perceive and use the system of services. The greater Cincinnati area is in many ways representative of medium-sized metropolitan areas in the United States. Therefore the findings of this project also contribute to our understanding of the needs of older women in many other areas of the country.

Background

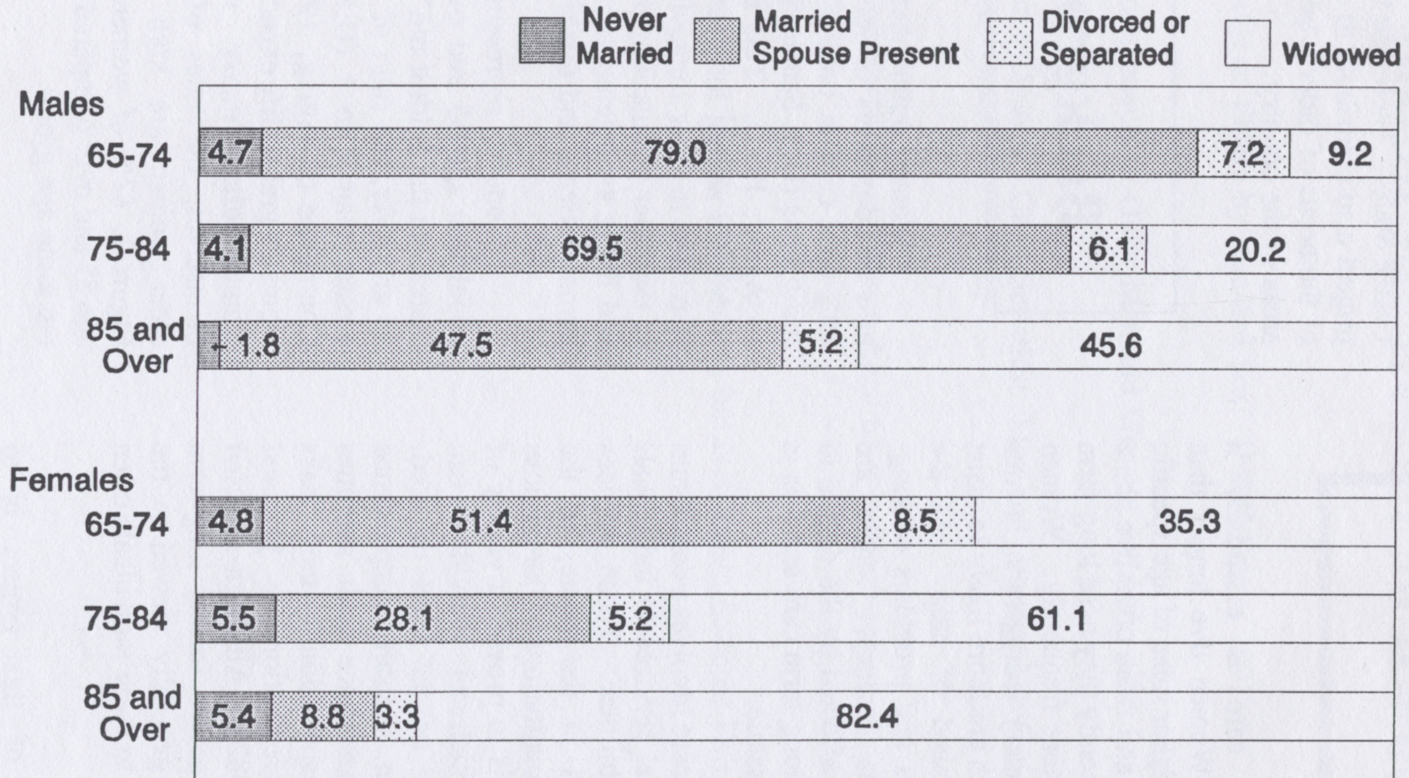
Women outnumber men by about 3 to 1 as consumers of formal and informal long-term care in both the community and institutions (U.S. Senate Special Committee on Aging, 1991). This overrepresentation of women among long-term care recipients is related to their longevity and proportion in the older population, their marital status and living arrangements, and their rates of chronic disease and disability.

Women represent 58% of the population age 65 and over in the United States. In the "oldest-old" group, those age 85 and over, the ratio of women to men is greater than 2 to 1 (U.S. Senate Special Committee on Aging, 1991). Because of women's greater life expectancy and because women often marry men older than themselves, the rates of widowhood for older women are high. As shown in Figure 1, 82% of women are widowed by age 85 and over compared to 46% of men in the same age group.

Some widows seek alternative living arrangements with family or friends, but a majority live alone. Indeed, women account for about 80% of all older people who live

Figure 1

Marital Status of Elders by Age and Sex: United States, 1991



Source: U.S. Bureau of the Census, 1992. "Marital Status and Living Arrangements: March 1991." Current Population Reports Series P-20, No. 461.

alone (Commonwealth Fund Commission, 1989). Research on elders' living arrangements has revealed that older people who live alone have lower incomes than those who do not, are only half as likely as older couples to receive help with daily activities if needed, and are at much higher risk of institutionalization if they have a disabling chronic illness (Branch & Jette, 1982; Commonwealth Fund Commission, 1989). Figure 2 shows the living arrangements of older women and men by age group. As shown, one-third of women age 65-74 and more than half of those age 75 and over live alone. Men in all three groups are more likely to live with a spouse than to live alone.

Women also suffer higher rates of disability due to chronic conditions than do their male counterparts (Verbrugge, 1984). The impaired older population in the United States is expected to grow from 4.3 million in 1990 to about 7.3 million in 2020. Although women represent 58% of the older population, they account for nearly 70% of the impaired older population (U.S. Senate Special Committee on Aging, 1991).

Most long-term care, both informal and formal, is provided by women. Most long-term care to older people is provided at home; about 80% of home care is given by family members, most of whom are women. Coward and associates (1992) found that older individuals in the community received help primarily from daughters (34%) and wives (23.6%). Formal long-term care services also are rendered primarily by females: the great majority of formal caregivers working as nurses, home health aides, and nursing home aides are women (Feldman, 1990).

For women, who have lower incomes than men and are more likely to require long-term care for an extended period, affordability of services is especially important. In 1989 the median income for women 65 and over was just above $7,600, only 27% above the poverty line of $5,947 for an older person living alone. Income for minority older women is even lower: 1989 median income was $5,259 for African-American older women and $5,543 for Hispanic older women (Malveaux, 1992).

Although most older people have health insurance (private coverage and/or Medicare) for conditions requiring acute care, a large portion of health-care costs must be paid out of pocket. These expenses take a high percentage of older women's income. In 1987 per capita out-of-pocket health care expenses (not including premiums for Medicare Part B or private insurance) equaled 23% of median income for older women and 13% of median income for older men (U.S. Senate Special Committee on Aging, 1991).

Very few older people have public or private insurance coverage for long-term care costs. Medicare coverage for long-term care is restricted to a limited number of days of skilled care. Medicaid covers long-term care costs for low-income individuals, but it protects only one-third of poor older people and 10% of the near-poor (U.S. Senate Special Committee on Aging, 1991). Although most long-term care under Medicaid is provided in nursing homes, home care is the most rapidly growing category of Medicaid expenditures (Reilly, Clauser, and Baugh, 1990). Private long-term care insurance policies are increasing in availability and quality, but it is estimated that fewer than 5% of older people had purchased these policies by 1989 (Luciano,

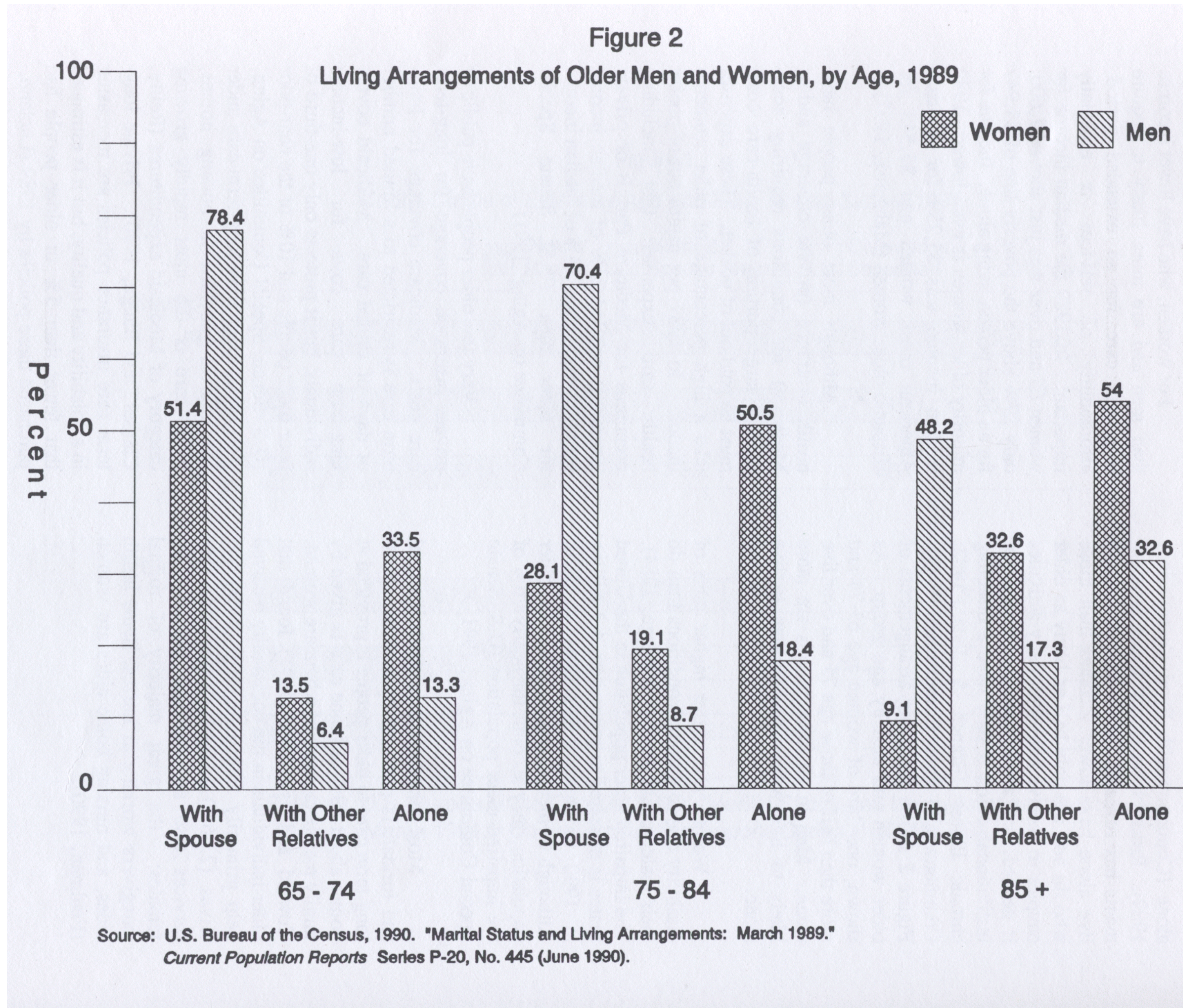


Figure 2
Living Arrangements of Older Men and Women, by Age, 1989

Source: U.S. Bureau of the Census, 1990. "Marital Status and Living Arrangements: March 1989." *Current Population Reports* Series P-20, No. 445 (June 1990).

1990). In a study of retired teachers, Ritchey, Atchley & Seltzer (1991) found that just over 20% of middle-income women had chosen to purchase long-term care insurance policies. Although private long-term care insurance may provide security for some older women, it remains inaccessible for many who can not afford the high cost of premiums.

In summary, women live longer than men, have lower incomes, and are more likely to experience chronic disabilities in old age. They are more likely than men to be widowed and to live alone. Women are less likely to be able to afford long-term care services. They provide most of the long-term care in both informal and formal settings. Whether long-term care services are available and accessible is critically important to women.

Methodology

The purpose of this project was to learn more about the long-term care needs of older women living in a five-county area of southwestern Ohio. Our overall questions related to the demographic characteristics of women in this area and to how these compare with men in the region and with women nationally. We sought to learn what these women's long-term care needs were and whether and to what extent these needs were being met. We were interested in learning whether older women are familiar with existing long-term care services, whether they are using them, and what barriers exist to the provision and use of these services.

We combined information from a previous needs assessment survey, from focus-group discussions with older women, and from interviews with service providers in the area's aging network.

We used multiple methods to obtain more extensive answers to our questions and a more complete picture of the situation. We combined information from a previous needs assessment survey, from focus-group discussions with older women, and from interviews with service providers in the area's aging network. We analyzed both quantitative and qualitative data -- the former to obtain statistical descriptions -- the latter to fill out the human picture. Each of these methods is discussed below.

NEEDS ASSESSMENT DATA

One component of this project involved secondary analysis of data from a needs assessment survey. The survey was funded by the Council on Aging, Cincinnati Area, and was conducted by Southwestern Ohio Senior Services, Inc. in December 1987. The data set contains a random sample of 1,264 individuals (65% women) age 60 and over who lived in Butler, Clinton, Clermont, Hamilton, or Warren Counties in southwestern Ohio. The survey was administered by telephone with a modified OARS Multidimensional Functional Assessment questionnaire. The data set includes information about respondents' social and economic resources, self-reported mental and physical health status, and needs and utilization of services.

The needs assessment survey data have certain limitations because of sampling and survey techniques. First, the random sample was drawn from a list of all individuals registered for the Golden Buckeye Card program, which is estimated to include 90% of Ohioans age 60 and over. It is probable that frail homebound older people, those least likely to benefit from this discount program, are underrepresented among Golden Buckeye Card holders. Second, 6% of the total sample (216 individuals) were reached but could not answer survey questions because of some type of impairment; thus the participation of disabled individuals was limited further. Finally, older women without telephones, who also are more likely to be poor, were excluded from the survey.

FOCUS GROUPS

Five focus group meetings composed of women age 60 and over were conducted, one in each county of the region. Focus groups allow researchers to observe group interaction in order to gain information about group members' experiences, perceptions, and points of view (Morgan, 1988).

The focus group participants were recruited through a variety of methods. Notices were posted in churches, physicians' offices, retirement communities, nursing homes, senior centers, and hospitals throughout the region. Two hospital membership programs printed notices in their newsletters. In addition, service providers in each county were asked to help identify women for discussion groups; they proved to be most helpful in recruiting. Fifty-two women participated in focus group discussions. Group size averaged 10 members, and ranged from seven to 12 participants.

The major limitation of the focus group sample resulted from our recruiting strategy. Because we were most successful at recruiting women through their connection to service providers, a majority of the focus group participants had some previous link with the service delivery system, even if only to be placed on a waiting list. Also, because focus groups were conducted in the community, those women who were too frail to leave their homes also were excluded from the focus group sample.

Focus group discussions were audiotape-recorded. The information from these discussions gave us the women's descriptions of their experiences, perceptions, feelings, and concerns, in their own words. Information obtained in this way adds an important human dimension to the numbers provided in the survey research.

INTERVIEWS

Face-to-face or telephone interviews were conducted with at least two providers in each county; 12 interviews in all were completed. The survey instrument for these interviews included questions about the services available in the county, areas of unmet need, and barriers to providing services. Interviews averaged one hour in length.

Table 1
Comparison of Selected Characteristics:
Men and Women Age 65+ in Southwestern Ohio

Characteristic	Women	Men
	Percentages	
Marital Status		
Married	40	81
Widowed	51	17
Divorced	5	2
Live Alone	45	17
Income		
Above 150% of poverty level	59	86
125-150% of poverty level	9	5
100-125% of poverty level	13	4
Below poverty level	19	6

Findings

CHARACTERISTICS OF WOMEN IN SOUTHWESTERN OHIO

Table 1 compares marital status, percentage living alone, and poverty levels for 305 men and 667 women age 65 and over in the study area. As shown, women were three times as likely as their male counterparts to be widowed and more than twice as likely to live alone. Most striking, perhaps, is the difference in men's and women's incomes. Forty-one percent of women in the region were poor or near-poor (with incomes 150% of poverty or below), compared to 15% of men. The 1987 poverty threshold was $5,012 for older individuals and $6,323 for older couples.

Women in the Ohio sample are similar to older women nationally in marital status, living arrangements, and disability levels. Older women in southwestern Ohio, however, are more likely to have incomes that fall into the poor or near-poor categories.

Table 2
Selected Characteristics of
Women Aged 65+ in Southwestern Ohio and Nationally

Characteristic	Southwestern Ohio	National
	Percent	
Marital Status		
Married	40	42
Widowed	51	49
Divorced/separated	6	4
Never Married	4	5
Living Arrangement		
Alone	45	41
With spouse	39	40
With other relatives	16	18
With nonrelatives	2	1
Income Level		
Above 150% of poverty level	59	68
125-150% of poverty level	9	9
100-125% of poverty level	13	9
Below poverty level	19	14
Disability Level		
Little or none	75	78
Moderate	18	10
Severe	7	11

National statistics on marital status and living arrangement from U.S. Bureau of the Census, Current Population Reports, Series P-2445. Income-level statistics from U.S. Bureau of the Census, 1991, as reported in Malveaux, 1992. National disability levels calculated from the National Long-Term Care Survey (1982).

Table 2 compares older women in this Ohio region with all older U.S. women. As shown, women in the Ohio sample are similar to older women nationally in marital status, living arrangements, and disability levels. Older women in southwestern Ohio, however, are more likely to have incomes that fall into the poor or near-poor categories. Forty-one percent of women in this Ohio region, compared to 32% of all U.S. women, had incomes 150% of poverty level or below.

DISABILITY

Disability levels reported in Table 2 were calculated for the 1987 needs assessment sample and the 1982 National Long-

Term Care Survey. These calculations were based on responses to questions about physical and instrumental activities of daily living (ADLs and IADLs). ADLs include eating, dressing, caring for one's own appearance, walking, getting in and out of bed, and showering or bathing. IADLs include walking distances, shopping, preparing meals, housework, taking medicine, and handling money. In this study, disability levels were defined as follows:

Little or no disability:
No difficulty with ADLs, and difficulty with not more than one IADL;

Moderate disability:
Difficulty with one ADL or with two or more IADLs;

Severe disability:
Difficulty with two or more ADLs.

As shown in Table 2, 25% of women in southwestern Ohio and 21% of women nationally experience moderate or severe disabilities.

The number of disabled older women in the five-county study area is expected to increase from 22,421 in 1990 to 30,717 in 2010 (Mehdizadeh et al., 1990). In view of this dramatic rise in individuals with disabilities, our challenge is not only to meet current needs, but also to anticipate and plan for increased needs in the future.

PERCEPTIONS AND EXPERIENCES WITH LONG-TERM CARE

The data presented thus far highlight the importance of long-term care as an issue for women, both nationally and in southwestern Ohio. In the following sections, information from the needs assessment survey and interviews with service providers are combined with the words of focus group members to provide a picture of older women's perceptions and experiences.

Women in the focus groups generally knew little about their home care options; they tended to consider help from families and nursing home care as the two major alternatives.

Preferences for Care

Most Americans prefer to remain in their own homes even when they become frail and require help with daily activities (Kane & Kane, 1987). The women in our focus groups were typical in this respect. Although they stated a clear preference for remaining at home, few had thought in advance about what they would do if they needed help to remain independent in their homes. Those who had used home services or had moved to a nursing home reported that they dealt with the situation when the need arose, often in a time of crisis. This lack of prior consideration is probably related in part to denial and the unpleasantness of dealing with possible future frailty, and also in part to a lack of awareness about services. Women in the focus groups generally knew little about their home care options; they tended to consider help from families and nursing home care as the two major alternatives. A large majority of focus group participants had an aversion to nursing homes as possible sources of care.

A majority of women in both the needs assessment sample and the focus groups reported that they had someone on whom they could depend for help if necessary. When asked whom they could rely on if they were to become sick or disabled, survey respondents mentioned children (47%), spouse (24%), other relatives (14%), and friends (12%). Only 3.5% mentioned paid help as a possible source of assistance.

Focus group participants received a great deal of support and assistance from their children. Yet even though they assured the group that children had provided assistance and were willing to help if necessary, many focus group members emphasized that their children led very busy lives.

> Well, I have a daughter that lives here in town with her husband and three boys, and she works eight hours a day, works at home all weekend...she tried to do what she could, but it wasn't enough and she absolutely did not have the time to do it. So that's when we felt compelled to get service someplace else.

* * *

> So we were pretty independent and able to take care of ourselves until my husband had a brain tumor, and when that happened one of our sons was able to help us out. And as of now I'm going to hire a little girl... to come in and, well, open the mail, take me to the store and this and that, just to relieve the family. I have three of my children living in town, but they have their lives to lead.

Women in focus groups who perceived continuing care retirement communities as an acceptable, affordable option were much more positive about long-term care facilities. Most of those who lived in such communities had made the decision to move while they were still relatively healthy, and had discussed the option with family members and/or physicians. Many of these women had friends living in these communities, and had visited a few facilities before making a decision. When we asked how they had learned about retirement communities, they replied that information and advertisements about such communities were everywhere. A few women who lived at home but who were on waiting lists for retirement communities said that simply were not yet ready to leave their current homes. Those who had chosen to move to retirement communities often stated that although it was difficult to leave their homes, they had adjusted quite well:

> I've got so I can call it (retirement community) home now. For a long time it was just a place to stay, but I'm very happy now.

* * *

> I think we gave our children the best gift we could by going to (a retirement community).

Eight focus-group participants lived in nursing homes at the time of the group discussions. In general, moves to a nursing home had been made necessary by rapidly failing health and increased disability. These eight women varied widely in their perceptions and degree of satisfaction. Like the women in retirement communities, some of the nursing home residents chose to live

in a nursing home to avoid burdening children with their care.

> The reason I'm where I'm at (nursing home), I was over-medicated by doctors. I'm not supposed to be here.... I feel that I'm in the wrong place, I don't need to be in there. I see so much sadness....We have wonderful nurses and aides, we have wonderful people but things really bother me -- where we have to take a shower, we have no place to dress....
>
> * * *
>
> Well, I just praise God every day that there's a place that I can be and have all the care I have. It's wonderful because I felt it was a burden to my children. Now I'm not a worry to anybody, because they just take care of me.

Experiences as Recipients of Care

Seventy percent of survey respondents with moderate or severe disabilities recently had received help with such activities as shopping, housework, bathing, dressing, or getting around. For all those who had received such assistance, the "major helpers" were children (36%), unrelated paid helpers (24%), husbands (20%), friends (12%), and other relatives (8%). As noted earlier, when survey respondents were asked whom they would rely on if they needed help, fewer than 4% mentioned paid or agency help. Among those who actually had received such help, as shown here, nearly one-quarter relied on agency or privately paid helpers as a primary source of care.

As noted, children were the primary source of care for survey respondents; this was true as well for focus-group participants. Some women lived with children from whom they received care; others relied primarily on children but used selected formal services as a supplemental source of help.

> I have one son, his wife and him have been a godsend. Until I got help she would come over and wash my hair, you know....My son comes and cuts the grass, asks me if I need anything from the store, anything like that. Course, you know, you wouldn't want your son doing your bath.... My son does the work outside my husband would do. The help from (an agency) pretty well rounds out things.
>
> * * *
>
> I live with my son. Oh, my son does everything for me. I had therapists that came to the house.... So I've been fortunate, my son has taken me to the doctor and done the things that I needed to have done.

Tables 1 and 2 reported the demographic characteristics of survey respondents age 65 for comparison with national demographic data. Because we are interested in the benefits of services to caregivers as well as to disabled older women, we used data for women age 60 and over, including women likely to be caregivers, when considering service utilization. Table 3 shows the percentages of survey respondents age 60 and over who used selected formal services, as well as those who needed but were not using certain services.

Table 3
Women Age 60+ Using, and Needing but Not Using,
Selected Formal Services

Service	Percentage Using	Percentage Needing but Not Using
Information and Referral	30.7	9.9
Social Functions/Senior Centers	24.6	9.9
Congregate Meals	22.3	6.6
Transportation	10.9	6.1
In-Home Medical Assistance	6.9	2.1
Homemaker/Personal Care (includes paid private help)	6.8	11.6
Home Repairs	6.1	8.8
Friendly Visitor	4.3	2.3
Counselor	4.2	2.1
Meals on wheels	2.3	2.8

The services used by the largest proportion of women in the survey were information and referral, senior center recreational activities, and congregate meal programs. For three of these services -- homemaker/personal care, home repairs, and home-delivered meals -- the percentage needing the service exceeded the percentage using that particular service.

Experiences as Caregivers

We were surprised not only by the high percentage of focus group participants who were or had been caregivers, but also by their strong preference for discussing their caregiving experience rather than their own long-term care needs. Three-quarters of the women who participated in the focus groups had provided care to an older family member at some point in their lives. A number of the women had paid for private help with these duties, and about one-third had sought help from an agency. Several women were providing or had provided care to a spouse or a parent (or both), and at the same time dealt with their own physical problems and/or disabilities.

I'm here because I take care of my mother. I've had, well, I just don't know where to go for help sometimes. She's able to take care of herself...sort of. She's forgetful and confused and she's got her problems. She manages to move around on her own fairly well. But I haven't known where to go to get help, for relief from being with her twenty-four hours a day.

* * *

I did take care of my mother for her last thirteen years. She had a stroke three years before she died and it left her blind, and yet her mental facilities were very sharp. So my problem there was to help her stay as independent as I could, even though she couldn't see. I didn't have any services; I paid a nurse aide who came into my home. She just came four hours a day while I was at work. And so I had that experience and it was difficult, but I didn't use services you were talking about.

* * *

During the time that I was taking care of my mother, I had to have a couple special surgeries and that really made it difficult, because while I was able to get someone to come in and change her bed and mine too for a while, and give baths and so forth, ...the matter of cooking meals and so forth was a <u>real</u> problem.

So much of what we do, when we need help, we have to do it by way of friends or by way of hit and miss. I think we need a service -- a resource person, someone that we can go to and say, "I have this need, who can help me with it?" Just listening to all of us, we're very ignorant about what is available and we don't know where to go for assistance, whether it is for our family members or for ourselves.

PROBLEMS WITH THE LONG-TERM CARE SYSTEM

<u>Awareness and Access</u>

> So much of what we do, when we need help, we have to do it by way of friends or by way of hit and miss. I think we need a service -- a resource person, someone that we can go to and say, "I have this need, who can help me with it?" Just listening to all of us, we're very ignorant about what is available and we don't know where to go for assistance, whether it is for our family members or for ourselves.

Lack of information about services is a major barrier to planning for the future as well as to finding appropriate services when needed. Information and referral services are critical both for caregivers and for frail older adults who are seeking assistance. About 25% of all survey respondents said they needed information about social or health services, but more than 40% of these women had received no such information in

the past six months. Focus-group members' knowledge about services varied greatly by county. Some of this variation was a result of differences in the group members' previous involvement with the service system, but county differences also appeared to be related to the availability of a well-coordinated, and well-advertised source of information.

Sources of information also varied widely by county or community. Some telephone books included a special "senior services" listing. Senior centers in all counties offered information and referral among their services; information also was available from other organizations such as general community service agencies and county health departments. According to the women in the focus groups, however, the quality of assistance from those organizations varied a great deal. The Area Agency for the region has an information and referral service that can provide information about resources in the entire five-county area. Yet although the concept of a planning and service area is familiar to service providers in the aging network, the women with whom we talked had no concept of such a geographic designation. Those in outlying areas did not consider Cincinnati, where the Area Agency is located, an appropriate place to call. They were most likely to look within their own communities for help. In general, the women seemed to receive the most helpful information and referral assistance from larger organizations in their communities that provided a range of services.

In nearly every county, the providers expressed reluctance to promote services when they were already serving the maximum number of clients possible and when waiting lists were very long.

Interviews with providers about raising community awareness of services revealed an interesting dilemma. In nearly every county, the providers expressed reluctance to promote services when they were already serving the maximum number of clients possible and when waiting lists were very long. These organizations regularly handled requests for help that they were unable to provide, and the staff members suggested that they believed it was unethical to promote a service that was not really available. This point implies that raising awareness of services may be difficult until organizations are able to serve greater numbers of clients.

Focus-group members and providers viewed financial issues as a major problem in trying to obtain or provide services. The women who appeared best able to handle the problem of obtaining services were those who perceived retirement communities as appropriate and affordable. Not all women desire this type of living arrangement, however, and few can afford to enter continuing-care retirement communities which generally set incomes of $25,000 and above as a criterion for eligibility. Indeed, in this study area only 8% of all female survey respondents age 65 and over, and 2% of those who lived alone, reported annual incomes in that range. Moderate- and low-income women who had no long-term care insurance coverage and did not qualify for

Medicaid found the cost of both home and institutional care well beyond their financial capacity. One woman, who had cared for her husband, stated:

> For five years I had him at home. I paid for therapists, I took complete care of him. If you have any funds whatsoever, forget it.... I called all kinds of agencies -- they would want me to guarantee $200 a day to come in and help me with my husband.

Areas of Unmet Need

If services are to be used, they must be available and accessible. We used information from our three data sources to learn about the major unmet needs of these older women. A need was considered unmet when focus-group participants or service providers noted that such services did not exist or required a long wait. For the needs assessment survey group, a need was considered unmet when at least one-third of those who stated they needed a service reported that they had not received such help in the past six months. On the basis of these three sources, we identified the following six areas as unmet long-term care needs for older women in the region:

Homemaker/Personal Care;
Home maintenance/repair;
Transportation;
Companionship;
Respite care;
Counseling.

Homemaker/Personal Care

Depending on the funding source, homemaker services (such as light housecleaning and errands) and personal care services (assistance with tasks such as bathing or dressing) may be provided by the same in-home worker or by different workers. Women in the focus groups who had received homemaker/personal care services in either of these two forms, were highly appreciative. Such services can enable a frail older woman to remain in her home instead of seeking an alternative living arrangement. This service, however, appeared to be unavailable to many women. Waiting lists were very long in some agencies. Some focus group participants who requested additional help were told that the agency simply did not have enough hours for everyone. Nearly 40% of the survey respondents who said they needed help with housework, preparing meals, or personal hygiene had received no such help in the past six months. One woman stated:

> I...had to wait a whole year on the waiting list (for a homemaker). I've had 24 or 25 surgeries so far.... I've really been through the mill with all kinds of stuff. But I waited a whole year.

Providers expressed frustration about the lack of capacity to meet the need for homemaker/personal care in their service areas. Waits for these services ranged from several weeks to two years, depending on the client's level of need. State budget cuts made before the interviews with providers had reduced the capacity to provide homemaker/personal care services in the region.

Home Maintenance and Repair

A number of women who were trying to remain in their own homes mentioned the need for home maintenance and repair services. Often the women said that not only were they physically unable to

do such work, but they did not know what needed to be done because they had not been responsible for such tasks when they were able. Indeed, women who lived in nursing homes or retirement communities often mentioned that before moving, their houses had become too much for them to handle:

> I had a two-story house and the yard gets to be too much, and in the winter it's snow and ice. There are so many things in a house...and my house wasn't a new house, and things begin to, you know, you need things done...and just was all of a sudden too much.

Only about one-third of the survey respondents who said they needed help with home maintenance or repair had received it. Affordability was a critical factor: the women stated that most repair or maintenance companies charged fees they could not afford. Several counties have programs to assist with minor home repairs, but most of these programs have long waiting lists, and some offer one-time-only renovations such as installation of wheel chair ramps.

> I think that one of the things that is desperately needed is someone to do things like...change filters for furnaces, air conditioners, appliances, and so forth. Someone that doesn't charge you $35-$40 to come out and then $20 every 15 minutes.

<u>Transportation</u>

Transportation was one of the most emotional topics raised in the focus group sessions. A number of women said that they felt they lost their independence when they gave up driving:

> I tell you...that's the hardest part of getting old. You just feel lost when you can't drive, and you've been driving since the 30s, and then all of a sudden they say "I don't think...you should be driving." It sure makes you feel old. Where I live we have all the services of getting to the doctor and getting groceries..., but the thing is, you can't go when you want to go.

* * *

> After I had surgery one of my biggest problems was transportation, and I ended up having to have some of my friends take me to the doctor or whatnot.

Many of the women in the focus groups depended on children and other relatives to help them with transportation. Others regularly used senior transportation services to travel to a senior center or to physicians' appointments. Some who used senior transportation services were frustrated with the lack of flexibility: some services could be used only for medical purposes; others had to be scheduled days or weeks in advance; some women could not cross a certain boundary (such as a county line) to visit a friend; and many could not attend church because the transportation service was not available on weekends. The availability of a flexible, user-friendly transportation system is important for women who may live for many years after giving up driving and who may not lose the desire to travel around in their communities.

Companionship

Not surprisingly, many older women, particularly those who were disabled, those living alone, and those without nearby family or friends, found lack of companionship a problem. Children and relatives provided company and conversation for some, and those who enjoyed senior center activities were able to meet their needs for companionship through relationships developed at the center. Yet some women still had unmet needs for companionship. One woman stated:

> Another thing you experience, especially when you live alone, is a sense of isolation...there's nobody that I can call. The people are busy, they're working and I don't have any support group even though I go to church and am in the missionary society and so forth, but there is no one that I can call and say, "Can you come over and chat for a while?"

Several companion programs exist in the region. Most programs use volunteers as companions; a number of these reported a shortage of volunteers, which limited their ability to meet the number of requests they received. Another very successful program that hires elders (primarily women) to serve as companions also had a waiting list for the companion service.

Respite Care

Respite care was mentioned in focus groups primarily by caregivers who, at some point, had needed relief from caring for a spouse or a parent and had been unable to find or afford respite services. Providers in every county mentioned respite as a major need; many noted either a lack of respite service or long waiting lists.

> I tried every service organization that I could think of (when caring for mother) and there was just no help to be found. I could not get any respite care. My family, I have a large family, only they were all working and they couldn't see that I needed the help. It was just one of those things...they were tired when they came home, too.

* * *

> Even the ones that advertise that they have a day care, or respite care, don't always have it. But I really haven't known where to get help. Anytime I'd call they'd say well, we can't help you but call...someplace else. I'd call there and they'd say we don't know anything about that, try someplace else, and I'd just get a runaround and I'd give up.

Counseling

Providers, rather than focus group participants, frequently mentioned a need for counseling, especially in-home counseling services for older women. Many of their older female clients were depressed and were dealing with loss; counseling was considered an essential but often unavailable service for these women. Although only a small percentage of survey respondents (5%) reported a need for counseling, 43% of those women had received no such help.

Summary and Discussion

Older women in the Ohio study area are similar to women nationally in marital status, living arrangements, and disability levels. Over half were widowed, 45% lived alone, and about 25% experienced some difficulty with daily activities. Projections of disability suggest that the number of disabled older women in the five-county study area will increase by about 37% between 1990 and 2010 -- from 22,421 to 30,717 women with moderate or severe disabilities.

Income levels for older women are lower in this region than nationally: 41% of the older women in southwestern Ohio had incomes at 150% of poverty or lower. Low-income women who do not qualify for long-term care coverage under Medicaid often experience difficulty in finding affordable care that will allow them to remain in their homes; most Medicaid-funded long-term care is available only to nursing home residents.

Women in this region prefer to remain in their own homes even if they become frail. Yet, unless they belonged to the small minority who preferred and could afford retirement community living, the women in this study were unlikely to have considered possible sources of help before assistance became necessary. This lack of planning appears to be related to 1) denial about one's possible future frailty, 2) perceptions that children and other family could be relied upon for help, 3) limited home- and community-based services in most communities, and 4) lack of awareness about the array of long-term care services that are available.

The primary problems experienced in the long-term care system included lack of awareness about available services; inability to pay for services not covered by private insurance, Medicare, or Medicaid; and gaps in available services.

Older women in southwestern Ohio rely heavily on family members for help. Children provide 36% of the care received, husbands 20%, and friends and other relatives 20%. About one-fourth of those who had received help, however, relied on unrelated help (hired privately or from an agency) as the primary source of assistance. Although women in the area know they can rely on children for help, they also are keenly aware that their children are extremely busy with their own lives. The formal services used most by female survey respondents included information and referral, senior center activities, congregate meals, and transportation through an agency.

The primary problems experienced in the long-term care system included lack of awareness about available services; inability to pay for services not covered by private insurance, Medicare, or Medicaid; and gaps in available services. On the basis of information from survey data, focus groups, and providers, we identified the following six needs as unmet because of lack of availability or long waits: 1) homemaker/

personal care, 2) home maintenance and repair, 3) transportation, 4) companionship, 5) respite care, and 6) counseling.

We need to know more about the group that providers call "hidden older women"; these are frail older women who have no contact with the long-term care system, and whom researchers are unlikely to reach in studies such as this.

This study identified problems with awareness and access to services in a sample of women who actually may know more about the system than the general older female population. As noted previously, a majority of focus group participants had some previous link with the service system, whereas the most frail community- dwelling women were excluded from both the survey and the focus groups. We need to know more about the group that providers call "hidden older women"; these are frail older women who have no contact with the long-term care system, and whom researchers are unlikely to reach in studies such as this.

From the providers' perspective, primary barriers to serving older women in the region included lack of funds to expand services and lack of coordination of home- and community-based services. Providers suggested that increased funding and collaboration among agencies in a given community would be a step toward eliminating these barriers. Indeed, the women who appeared to be best served lived in communities in which long-term care services were coordinated or housed primarily under an umbrella agency, and where services were well publicized.

Limited funding for meeting service needs appear to be linked closely with women's lack of awareness. Some individual awareness results from knowing friends and family members who use a service; word about such options does not spread, however, if very few individuals in a community receive formal assistance. Another way to increase awareness is through promotion of services -- in the media, by placing written information in prominent locations, or by speaking to groups about available services. Providers in almost every county mentioned a similar dilemma: they know the importance of educating the community about services but they are reluctant to promote programs that are unable to meet current demand. Thus, the lack of awareness about services may be linked directly to limited funding and to agencies' resulting inability to meet needs in their communities.

Our findings suggest that the characteristics and problems of older women in southwestern Ohio are similar to those of older women elsewhere in the nation. The findings also suggest that the concerns and difficulties of service providers in this area resemble those of service providers everywhere. Our conclusion -- that some of these problems are too vast to be resolved by individuals and/or single organizations -- leads to a discussion of the policy implications at the national, state, and regional levels.

Implications

National health and long-term care policy is a major issue of the day. Although a number of major bills addressing long-term care have been introduced in Congress in the past five years, no legislation has come close to being adopted as national policy. It seems probable that some new or revised legislation will be introduced and perhaps even implemented in the near future. Clearly, a national policy to address all Americans' health and long-term care needs would benefit persons of all ages who currently are underinsured or have no coverage. Improvement in health care and expenditure of a lower proportion of income on health care over the life course could improve both the health and the economic condition of women in their later years.

State and area agencies on aging are required by the Older Americans Act to target older people with the greatest social and economic needs. This Act specifies low-income, minority individuals as a group with a potentially high level of need. Currently, however, gender is not used as a factor to help identify such persons. In view of the dramatic social, economic, and physical disadvantages that women face in later life, gender should be considered in targeting those in need of Older Americans Act services.

The women in this region need expanded in-home services with cost based on ability to pay.

Ohio spends a larger percentage of long-term care dollars on institutional care than do most other states. The recent expansion of Ohio's Medicaid waiver program, which provides home care to low-income older people at risk of nursing home placement, was a major step toward redirecting long-term care funds. Unfortunately, in communities where this program is currently in place, the program funding is not sufficient to serve all older people who qualify. In addition, many women do not meet the income and disability qualifications for this program, even though they are considered low-income. The women in this region need expanded in-home services with cost based on ability to pay.

Two of the five counties in the study area have passed tax levies for senior services. The Clermont County levy for senior services was passed in the 1980s and renewed in 1991. In 1992, Hamilton County voters passed a $12 million levy to fund a program to provide home-delivered long-term care services with fees based on ability to pay. These local tax-funded programs represent major progress at the community level in addressing many of the problems revealed in this study. It is inefficient, however, to rely solely on county-level action to address Ohioan's needs for long-term care, and such reliance may result in lack of services for elders in the most rural communities. Coordinating a campaign for a tax levy requires a great commitment of time and expertise by

citizens and professionals. Such action may not be a reasonable expectation in less heavily populated counties in the state. Resolution of these problems in the long-term care system will require a major state-level commitment as well.

This project also resulted in suggestions for improved service delivery at the regional and community levels. Providers perceived great differences in levels of support from the Area Agency. Some suggested that the geographic distance from the Area Agency and a smaller size of the older population in their counties were related to the degree of support received. Others appeared to have little commitment to seeking either additional financial support or technical assistance from the Area Agency, even though services in their communities were among the most fragmented and least accessible. We suggest that a primary goal of the Area Agency should be to increase interaction with marginally involved communities. The addition of staff members who are responsible primarily for offering assistance to providers and educating community members about the services in their areas would be a step toward increasing support and community awareness in outlying areas.

This study revealed that women in communities with the most highly coordinated services were more likely to be able to negotiate the system and gain access to services. Providers suggested that collaboration between agencies would both improve service delivery and strengthen requests for funding and support. To improve long-term care service to older women in this region, efforts must be focused not only on increasing funds for expansion of services, but also on coordinating services at the community and county levels with specific, well-publicized points of entry into the system.

References

Branch, L., and Jette, A. (1982). A Prospective Study of Long-Term Care Institutionalization among the Aged. American Journal of Public Health. 72, 1373-1379.

Commonwealth Fund Commission (1989). Help at Home: Long-term Care Assistance for Impaired Elderly People Living Alone. Baltimore, Maryland.

Coward, R.T., Horne, C., & Dwyer, J.W. (1992). Demographic Perspectives on Gender and Family Caregiving. In Dwyer, J.W. & Coward, R.T. (eds), Gender, Families, and Eldercare. (pp. 18-33.) Newbury Park, CA: SAGE Publications.

Davis, K., Grant, P., & Rowland, D. (1990). Alone and Poor: The Plight of Elderly Women. Generations, Summer 1990, 43-47.

Feldman, P.H. (1990). Who Cares For Them?: Workers in the Home Care Industry. Westport CT: Greenwood Press, Inc.

Hess, B. (1990). The Demographic Parameters. Generations, Summer 1990, 12-15.

Kane, R.A. & Kane, R.L. (1987). Long-Term Care: Principles, Programs, and Policies. New York: Springer.

Koff, T.H. (1982). Long-Term Care: An Approach to Serving the Frail Elderly. Boston: Little Brown and Company.

Luciano, L. (1990). Should You Buy a Pay-Now, Save-Later Nursing Home Policy? Money, 19, 36-37.

Malveaux, J. (1992). The Economic Predicament of Low-Income Elderly Women. Project on Women and Population Aging, Southport Institute for Policy Analysis, Southport, CT.

Mehdizadeh, S.A., Kunkel, S.R., Atchley, R.C., & Applebaum, R.A. (1990). Projected Need for Long-Term Care in Ohio's Older Population, 1990-2010. Oxford, Ohio: Scripps Gerontology Center.

Morgan, D.L. (1988). Focus Groups as Qualitative Research. California: Sage.

Reilly, T.W. Clauser, S.B., & Baugh, D.K. (1990). Trends in Medicaid Payments and Utilization, 1975-1989. Health Care Financing Review, 1990 Annual Supplement.

Ritchey, L.H., Atchley, R.C., and Seltzer, M.M. (1991). To Buy or Not To Buy: Considerations in the Decision to Purchase Long-Term Care Insurance. Ohio Long-Term Care Research Project, Scripps Gerontology Center, Miami University, Oxford, Ohio.

U.S. Bureau of the Census (1990). Marital Status and Living Arrangements: March 1989. Current Population Reports. Series P-20, No. 445.

U.S. Bureau of the Census (1991). Statistical Abstract of the United States: 1991 (111th Edition). Washington D.C.: U.S. Government Printing Office.

U.S. Bureau of the Census (1992). Marital Status and Living Arrangements: March 1991. Current Population Reports. Series P-20, No. 461.

U.S. Senate Special Committee on Aging, American Association of Retired Persons, the Federal Council on the Aging, and the U.S. Administration on Aging (1991). Aging America: Trends and Projections.

Verbrugge, L. (1984). A Health Profile of Older Women with Comparisons to Older Men. Research on Aging, 6(3),291-322.