

Informal Caregivers: 2002

Phone Survey

Forward

Acknowledgments

This project was made possible through a combined effort between the North Dakota State Data Center at North Dakota State University (NDSU) the Child Development and Family Science Department at NDSU, the North Dakota Center for Rural Health at the University of North Dakota (UND), the North Dakota Department of Human Services (ND DHS), Aging Services Division. It was funded by monies made available through an appropriation under the Older Americans Act, Title III, Part E, National Family Caregiver Support Program and administered through the North Dakota Department of Human Services, Aging Services Division.

We would like to thank the following individuals: Dr. Greg Sanders, Marlys Bratteli, and Tammy Irion from the Child Development and Family Science Department at NDSU; Dr. Richard Ludtke from the Center for Rural Health at UND; and Nancy Shantz from the ND DHS, Aging Services Division, for their assistance and partnership throughout the course of this study.

We also would like to express our appreciation to Jane Strommen, Administrator, Arthur Good Samaritan Center and Brian Arett, Executive Director, Fargo Senior Commission for making arrangements for our focus groups. A special word of thanks goes to the informal caregivers and senior service workers who took part in our focus groups.

Finally, we would like to express our gratitude to the many informal caregivers who were willing to share their experiences and insights with us. It is our hope that this investigation will help uncover ways in which we can better serve them.

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Executive Summary

Introduction

A survey of households in North Dakota was conducted in the Spring of 2002. The purpose of this study was twofold. First, it was used to estimate the number of informal caregivers that lived in North Dakota. Second, it served to provide preliminary insight into the barriers to informal care. This initial study was the first of two surveys used to gather information regarding informal caregiving in order to assist policy makers in exploring ways to improve caregiving and the lives of those who provide informal care. A broad definition of informal caregiving was used to collect the data. In brief, the definition of informal caregiving that we used to determine who should be included in the data set was:

*An **informal caregiver** provides needed care on a long term basis to a **care recipient**, who is most often a relative, friend, or neighbor. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group), or those who provide care as a career. Long-term care often involves assisting the care receiver with personal hygiene, getting dressed, using the bathroom, or household tasks such as preparing meals. It does not include recovery from an injury after which the recipient no longer needs care. Currently we are interested only in those recipients of care who are at least 60 years of age.*

A random sample of 10,000 households was used as the sampling frame for data collection. A total of 2,625 households were successfully contacted. Roughly 6.5 percent of these households reported having informal caregivers. This resulted in 144 completed surveys which were analyzed for this report. The interview instrument was divided into six sections and gathered information on: characteristics of informal caregiving, informal caregiving difficulties/concerns, services available to the informal care recipient, services available to the informal caregiver, services provided by the informal caregiver, and demographics.

Characteristics of Caregiving

- Results indicate that nearly 46 percent of caregivers are caring for their mother or mother-in-law.
- The top two reasons why the care recipient needs services are the aging process and physical disabilities.
- Approximately 78 percent of caregivers indicated they do not receive monetary compensation for their caregiving services.
- Of those caregivers who live with the care recipient, more than 40 percent of caregivers said the care recipient can not be left alone.
- Of those caregivers whom do not live with the care recipient, approximately 81 percent of caregivers live less than 20 minutes away from the care recipient.
- Nearly 28 percent of caregivers said they spend more than 20 hours per week on average providing care.
- Approximately 39 percent of caregivers indicated they have spent one to three years caregiving.

Caregiving Difficulties/Concerns

- Caregivers indicated that having no consistent help from other family members, emotional aspects, and having the responsibility for making major life decisions for their care recipient are serious difficulties they experience when providing care.

- Nearly a quarter of caregivers agreed that it is difficult for them to find support or assistance when caregiving and it is difficult for them to accept support or assistance when caregiving because it is their duty to provide care.
- Approximately 40 percent of caregivers indicated there are not other informal caregivers who provide care to the care recipient.
- The two most common reasons why others are not providing care are because they live farther away and/or had full-time jobs.

Services Available to Care Recipient

- More than three-fourths of caregivers indicated that homemaker services/home health aides and congregate meal settings are available to their care recipients.
- At least half of caregivers said the following services are not available to their care recipient: pet service, parish nurse, adult day centers, outreach programs, and shopping assistance.
- If the service was not available to the care recipient, more than half of caregivers indicated they would like outreach programs and homemaker services/home health aides to be available to their care recipient.
- Regardless of the type of service, the most common reason the care recipient does not use the service (if it is available to them) is because they do not need it.
- In the instances where the service is available, adult day centers and escort/transportation services are the top two services care recipients will not use.

Services Available to Caregivers

- More than 62 percent of caregivers indicated that information about available services is available to them.
- On the other hand, at least half of caregivers indicate that respite care, caregiver training or education, individual caregiver counseling services, and caregiver support groups are not available to them.
- In instances where the service is not available, the top three services that caregivers would like to have available to them are information about available services, respite care, and assistance with accessing available services.
- When the services are available, more than half of caregivers indicated they are using assistance with accessing available services and information about available services.
- Regardless of the type of service, the most common reason the caregiver does not use the service (if it was available to them) is because they do not need it.
- The most utilized service is assistance with accessing available services. Approximately 72 percent of caregivers utilize this service.
- More than half of caregivers indicated that other information or services that would be valuable to caregivers, now or in the future, are information about the care recipient's condition or disability, info-line, and someone to help them arrange for services or assess the situation.

Services Provided by Caregivers

- At least 90 percent of caregivers report they provide companionship, listen to the care recipient and/or are someone for them to talk to, and assist with errands/shopping.
- Although contributing financially is the service provided least by caregivers, more than half had done so.
- The services caregivers provide on a daily basis most often are assisting with medicines (85.6 percent), assisting with meals/nutritional needs (81.2 percent), providing companionship (80.9 percent), and listening to them (care recipient)/(being)someone for them to talk to (79.3 percent).
- The services the highest proportion of caregivers provide weekly are assisting with errands/shopping (55.1 percent), providing transportation/getting places (44.0 percent), managing finances (25.0 percent), and providing phone contact (20.0 percent).
- The highest proportion of services caregivers provided monthly are communicating with medical providers (26.1 percent) and managing finances (17.0 percent). However, it is more common for caregivers to communicate with medical providers on occasion (44.3 percent). They also report managing finances on an occasional basis as much as they do on a weekly basis (17.0 percent).
- The service that the highest proportion of caregivers report providing on an occasional basis is help with legal assistance (75.3 percent).
- At least half of caregivers indicated they would like help assisting with household tasks (60.7 percent), assisting with maintenance/repair (52.1 percent), and administering personal care (50.7 percent).
- Thirty percent of caregivers reported they have had time conflicts between working and caregiving and had taken off work early or arrived to work late because of caregiving.

Demographics

- Approximately 46 percent of caregivers reported they have spent an average of \$0 to \$1,000 within the last year caring for the care recipient.
- Nearly 29 percent of caregivers are between the ages of 65 and 74. Approximately 21 percent are between the ages of 55 and 64.
- Nearly 69 percent of caregivers are married or living with a partner.
- Approximately 68 percent of caregivers do not have children residing in their household.
- Approximately 29 percent of caregivers indicated the highest level of education they have reached was high school diploma or GED. Thirty-five percent of caregivers have some college or have graduated college.
- Nearly 41 percent of caregivers are retired. Thirty-five percent of caregivers work full-time.

- ❑ Nearly 28 percent of caregivers had a household income in 2001 before taxes of \$20,000 or less.
 - ❑ It is interesting to note that according to the 2000 Census, the median household income in North Dakota was \$34,604 (Source: US Source: US Census Bureau, 2000 Census, SF3 Table P53).
- ❑ The majority of caregivers are white (Non-Hispanic).
- ❑ Approximately 99 percent of caregivers indicated their principle language is English.
- ❑ Nearly 74 percent of caregivers are female.
- ❑ Approximately 57 percent of caregivers indicated their place of residence is rural.

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Introduction

Study Objectives

The purpose of this study was twofold. First, it was used to estimate the number of informal caregivers that lived in North Dakota. Second, it served to provide preliminary insight into the barriers to informal care. This initial study was the first of two surveys used to gather information regarding informal caregiving. The study was conducted in order to assist policy makers in exploring ways to improve caregiving and the lives of those providing informal care.

Methodology

A two-staged stratified sampling design was used based on housing units. First, the state was divided into two categories representing those counties classified as urban (i.e., having a city with at least 2,500 residents) and rural (i.e., without a city of at least 2,500 residents) counties. Roughly half of the state's households fall into each of these two categories. Thus, half of the sample was apportioned to each of these two categories. In the second stage, the urban counties were segmented into two components, a) households inside cities greater than 5,000 population and b) all other households in urban counties. A proportional sample was drawn from these two components and comprised the urban county sample. Similarly, a proportional sample of households from each of the rural counties was drawn which comprised the rural sample. This process ensured a representative sample of households was contacted from both cities and rural areas and produced a generalizable sample for the state. Interviewers were drawn from a pool of trained surveyors and supervised by North Dakota State Data Center staff. A computer assisted telephone interviewing (CATI) system was used to reduce coder error and ensure consistency in responses.

A random sample of 10,000 households was used as the sampling frame for data collection. A total of 2,625 households were successfully contacted. Roughly 6.5 percent of these households reported having informal caregivers. This resulted in 144 completed surveys which were analyzed for this report. The interview instrument was divided into six sections and gathered information on: characteristics of informal caregiving, informal caregiving difficulties/concerns, services available to the informal care recipient, services available to the informal caregiver, services provided by the informal caregiver, and demographics.

Analysis

The analysis was conducted in a three-step process. Data was entered into CATI by telephone interviewers and transferred into SPSS. Next, frequencies for all questions with the exception of open-ended questions were computed. Survey items that were incomplete were excluded from the calculation of means. Finally, the open-ended data was thematically coded by the NDSDC staff.

Interpreting the Results

These data were collected for the purpose of establishing prevalence rates of informal caregiving in North Dakota. Due to the difficulty of identifying and contacting informal caregivers, this sample is not large enough to be generalizable. As such, this data should be interpreted with caution. It is meant to be used as a guide to the experience of providing informal care in North Dakota.

Recommendations

The findings from the 2002 North Dakota Family Caregivers Support project are very compelling with regard to the urgent need to address informal caregiving in North Dakota. The recommendations we offer are organized into three parts. First, we address the broad overall policy concerns. We feel these major themes should serve as the foundation for an effective action oriented approach to addressing informal caregiving in North Dakota. Second, we provide a chart that outlines our suggestions for targeted legislation or agency specific initiatives. This chart is intended to serve as an illustration of the kinds of legislation or initiatives that are needed to create positive movement with regard to caregiving in North Dakota. Finally, we offer some ideas and insights from the research literature regarding initiatives and legislation that have been attempted. The intent of this section is to offer illustrations and some perspective regarding the success of other programs.

I. Broad Policy Recommendations

- The findings from this research suggest there are three broad policy directions that should be considered. First, a sustainable initiative should be established that monitors the changing demand for caregiving in the state.
Rationale: Results from this study indicate that informal caregiving is occurring in more than 6% of the households in the state. This translates into more than 16,700 households. For perspective, this is equal to all the households in the state's smallest 17 counties. More importantly, demographic forecasts indicate that the demand for caregivers in the state will rise sharply in the near future. Currently, 14.7 percent of the state's total population is 65 years of age and older. By the year 2020, that percentage will jump to 23 percent. The distribution of this exploding senior population will vary greatly throughout the state, creating an uneven demand for caregivers. For example, nearly two-thirds of the state's 39 rural counties already have senior populations that exceed 20 percent. By 2020, seniors will represent nearly one in three residents in these rural counties. In contrast, only one of the 14 urban counties in the state has a similar concentration of elderly. Nonetheless, nearly two-thirds of the state's elderly (i.e., those persons 65 years of age and older) live in the 14 urban counties of the state. Equally important is the fact that the state's oldest seniors, those in most need of caregiving, are the fastest growing segment of North Dakota's population. Currently, North Dakota has the highest proportion (2.3 percent) of residents 85 years of age and older in the nation. This population is projected to nearly double by the year 2020, expanding from 14,726 to 24,258.
- Second, priority needs to be given to providing support services that will enhance the abilities of current and potential informal caregivers.
Rationale: The state's extremely tight labor market combined with the low wages for in-home care creates a significant demand for caregivers. It is in the best interest of the state to encourage those who are currently performing voluntary informal caregiving to continue doing so. One way to create a conducive environment for caregiving is by providing an effective support system. Findings from this research demonstrate there is an important need for continued support for those providing informal caregiving. For example, 3 out of 4 caregivers report having access to information about available services, and nearly 70 percent say they receive assistance in accessing information. However, of those who do not have access to information, over two-thirds say they desire such access. The type of services needed and desired varies widely. This is probably due to a lack of exposure or insight into various forms of services. For example, less than 20 percent of caregivers report they have counseling or caregiver support groups available to them. Although only one-third of the caregivers desire such services, the greatest amount of concern among caregivers relates to emotional difficulties.
- Third, significant cost savings in elder care can be gained through enhanced support of family caregiving. Therefore, public and private incentive programs should be vigorously explored.
Rationale: Informal caregivers contributed an estimated market value of \$196 billion in Long Term Care services within in the U.S. in 1998. For perspective, the cost of home health care during that same year was estimated at \$32 billion and the cost of nursing home care was approximately \$83 billion. The savings to the state for having an effective informal care system are obvious and compelling. Therefore, public and private support for an integrated

statewide informal caregiving system should be a high priority. The active informal caregiving program, facilitated through the Aging Services Division of the North Dakota Department of Human Services, is an important starting point. However, legislative action is needed to create effective incentives for participation in informal caregiving. This includes a targeted campaign aimed at employers to encourage them to provide benefits for those who provide care. Research indicates that the kind of services employed caregivers find most useful include: a) flexible work schedules, b) unpaid family leave, c) help locating services, and d) assistance with insurance paperwork. The following chart offers an overview of specific recommendations for policy initiatives by these three target areas.

II. Chart of Recommendations for Targeted Legislation or Agency Initiatives

Target Areas for Legislation or Initiatives	Policy Initiative	Objectives of Policy Initiatives	Targeted Agencies for Administration of Policy Initiatives
<i>A. Monitor changing demand for caregiving and create corresponding training programs for caregivers</i>	Create on-line tracking and referral system for caregivers	<ul style="list-style-type: none"> Provide monitoring system to assess changing demand for caregivers by region 	<ul style="list-style-type: none"> Administration on Aging
	Create comprehensive programs that coordinate volunteers with the professional workforce	<ul style="list-style-type: none"> Provide a more desirable and comprehensive service module for a better quality of life for elderly at lower costs 	<ul style="list-style-type: none"> Administration on Aging Statewide integrated task force Department of Human Services
<i>B. Integrated support system</i>	On-line caregivers website	<ul style="list-style-type: none"> Provide cost effective and reliable 24-hour access to informal caregiver resources 	<ul style="list-style-type: none"> Department of Health Administration on Aging ND State Data Center DHS/Aging Services
	Distance education programs targeted to caregivers	<ul style="list-style-type: none"> Reduce training costs for caregivers and increase skill levels and/or available specialty sources of education 	<ul style="list-style-type: none"> Department of Health Department of Human Services
	Create educational programs that assist elderly or caregivers in understanding health issues, insurance, and caregiving	<ul style="list-style-type: none"> Increase awareness for elderly and caregivers Decrease end-of-life costs for families and hospitals 	<ul style="list-style-type: none"> Department of Human Services Department of Health Senior Health Insurance Counseling Program
<i>C. Incentive programs</i>	Long-term care health insurance	<ul style="list-style-type: none"> Get public to participate in long-range financial planning for elder care 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services Statewide Grants
	Tax breaks for caregivers	<ul style="list-style-type: none"> Retention incentives to enhance the caregiver pool to eliminate current shortages 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services
	Tax breaks for employers who provide elder-care assistance	<ul style="list-style-type: none"> Promote employer based caregiving assistance 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services

III. Research Support of Policy Initiatives

1. Volunteer Services

The legislature should promote community-based programs that tap the professional and volunteer services of local residents to assist in elderly caregiving. A model program using this approach is the Elderberry Institute's "Living at Home/Block Nurse Program" which is widely used in Minnesota and in Oregon. Its philosophy is to utilize resources within the community that are not fully utilized to assist in elder care. For example, the program facilitates the use of professional and volunteer services of local residents to provide nursing, companionship, and chore services to senior residents, allowing them to remain outside a formal institution. The program identifies capabilities of individuals and their families and coordinates resources in the community to provide care and support for particular needs of seniors. This collaborative approach is based on the recognition that community residents realize the need for interdependence and are willing to act in ways that benefit others. Volunteer services include counseling, training for family caregivers, and in-home support programs such as elder daycare.

Program Advantages:

- Care is more fulfilling because it builds on the "spirit of community" to meet families' needs.
- Maximizes self-reliance and minimizes the use of costly professional services.
- Focuses on early intervention and treatment, prevention and recovery, and coordination and integration of services.
- Fees may be charitable contributions.

Program Implications:

- Model successfully implemented in 30 communities in Minnesota, Texas, and Colorado.
- Estimated cost of program is 24% less than the minimum cost of a nursing home stay *before* nursing services.
- Increases and enhances family and community involvement in the care of elderly.
- 85% of Block Nurse Clients would be forced to enter nursing homes if home care was not available.
- Strong data indicate that Medicare/Medicaid dollars are being saved as a result of these programs.
- In 1997, 15 programs reported a total of 379 people kept out of nursing homes for estimated savings of \$4,700,040. During this time, 35,307 volunteer hours were contributed.

2. Equipment Stipends

The legislature should fund equipment stipends which allow elderly or caregivers to purchase equipment that facilitates independence. These stipends promote caregiving by easing its financial burden. Greater use of informal caregivers reduces the long-term care cost to both the family and to the state. In addition, subsidies such as equipment stipends will assist middle-income families who are the hardest hit financially. These families cannot afford nursing home care or home health care, nor do they qualify for Medicaid or other public health programs because their incomes are too high.

3. Distance Education

North Dakota should focus resources on advancing distance education as a way to assist rural communities in providing support services to caregivers. The Caregiver College is one such example of a successful program. This program was formed by a multi-disciplinary group of rehabilitation professionals to provide free community health education to informal caregivers of the elderly. Classes can be conducted anywhere that has appropriate videoconferencing facilities. North Dakota is a leader in telecommunications, and its videoconferencing capabilities are rapidly spreading, making this a viable policy option. Results from over 700 people receiving "certificates of completion" from the Caregiver College found no significant difference in knowledge gained between students using videoconferencing technology and other methods (<http://tie2.telemed.org>).

4. Incentives

The legislature should fund caregiver incentive programs. Examples from other states include:

- New York's Health Care Reform Act of 2000 authorizes the establishment of a state-funded health insurance initiative specifically targeted to uninsured home care workers. The New York Association of Homes and Services for the Aging, the state association for non-profit Long Term Care (LTC) providers, has recommended that all workers in home care, nursing homes and residential care settings across the state be covered.
- In 2000, California appropriated \$25 million for its Caregiver Training Initiative, designed to improve recruitment and retention of entry-level staff.
- Created incentives for long term care insurance: New York, Minnesota, and Washington have health insurance initiatives that assist small employers, including LTC providers, in gaining access to coverage for themselves and their employees.
- Providing funding for community-based well-being programs that include daily monitoring of elderly through phone calls and/or visits from community volunteers: this improves senior involvement with the community as well as opportunities for social interaction. One model program, "Walk in My Shoes" (<http://www.urbanext.uiuc.edu>), is aimed at orienting new staff at nursing homes, senior care groups, and agency personnel to the needs and limitations of older adults.

5. On-line Computer Assistance

There should be ongoing support for an on-line resource assistance website for caregiving. The benefits of this resource includes:

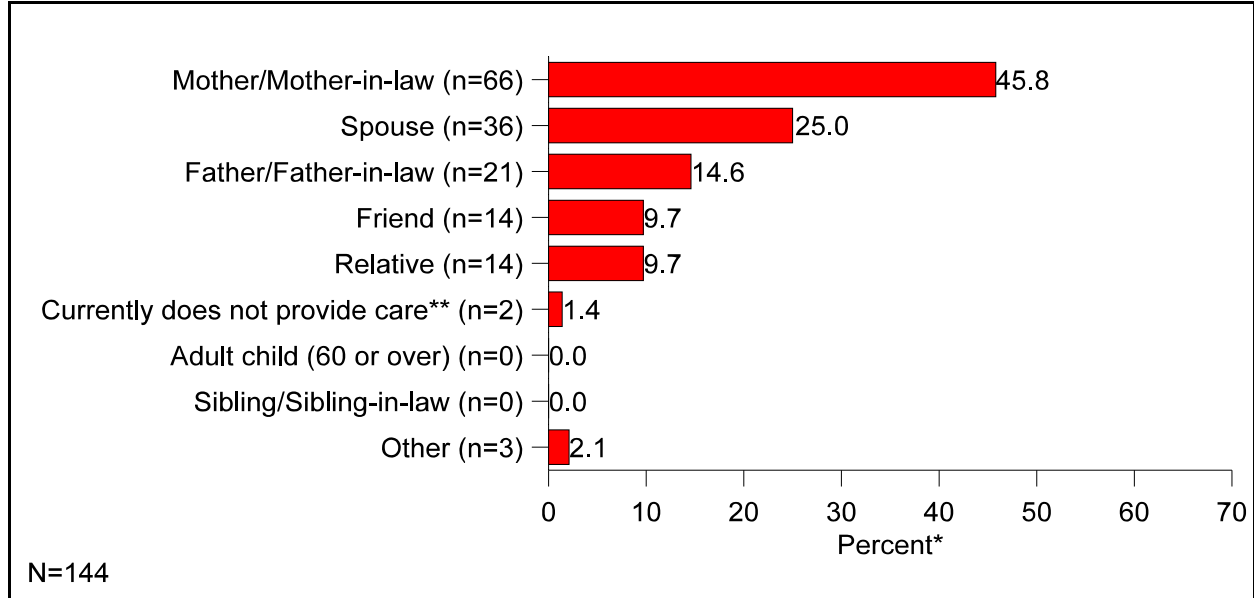
- cost effective way of delivering information, resources, training, and monitoring activities
- provides social anonymity which increases candid communication
- creates social interaction while decreasing social isolation, especially for those in very rural areas
- provides access to peers, services, and health care professionals
- easy 24-hour access

SURVEY RESULTS

Characteristics of Informal Caregiving

- ▶ Results indicate nearly 46 percent of caregivers are caring for their mother or mother-in-law. An additional 25 percent of caregivers are caring for their spouse (Figure 1, Appendix Table 1).

Figure 1. Relationship of Care Recipient to Caregiver

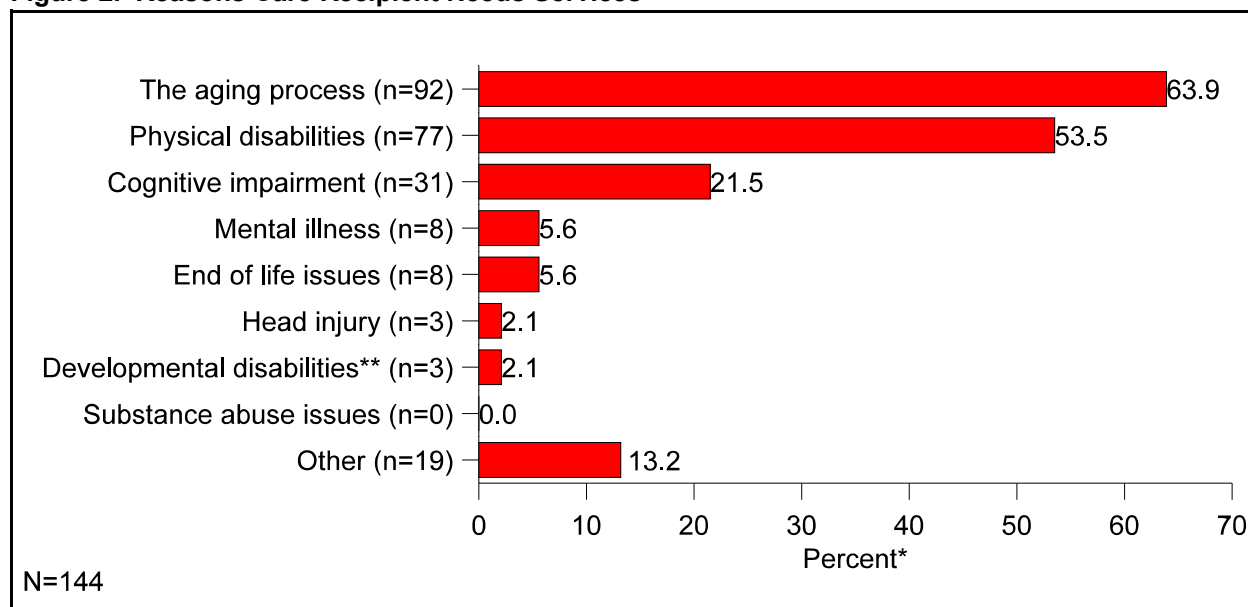


*Percents do not always add to 100.0 due to multiple responses; N=144.

**Full response category states: "I currently do not provide care, but have done so within the last year."

- ▶ Nearly 64 percent of caregivers indicate the care recipient needs care because of the aging process. More than 53 percent of caregivers indicate the care recipient needs care because of physical disabilities (Figure 2, Appendix Table 2).

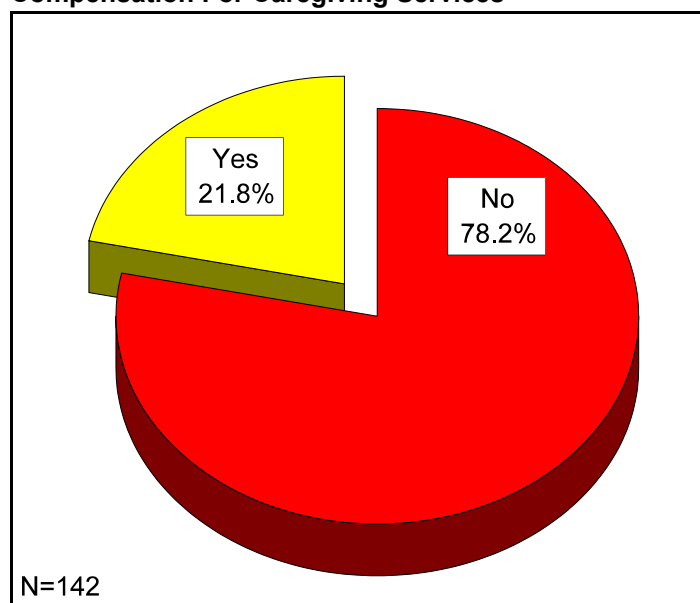
Figure 2. Reasons Care Recipient Needs Services



*Percents do not always add to 100.0 due to multiple responses; N=144.
 **Full response category states: "Developmental disabilities/mental retardation."

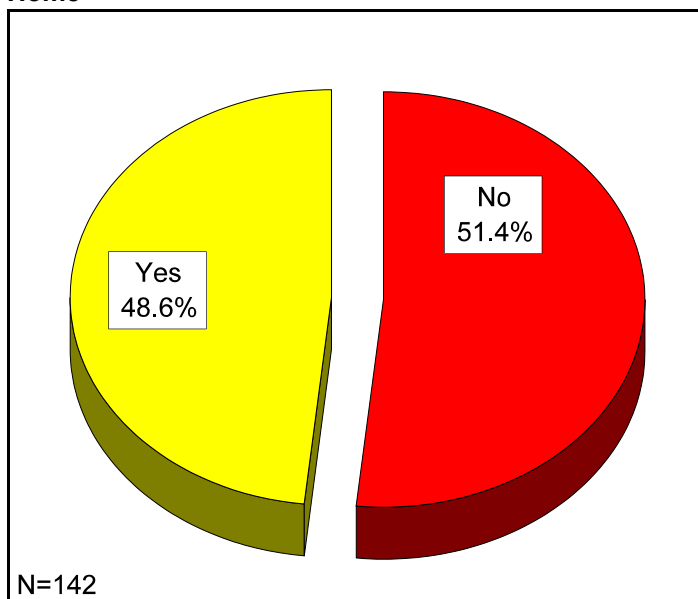
- ▶ Approximately 78 percent of caregivers indicated they do not receive monetary compensation for their caregiving services (Figure 3, Appendix Table 3).

Figure 3. Whether Caregiver Receives Monetary Compensation For Caregiving Services



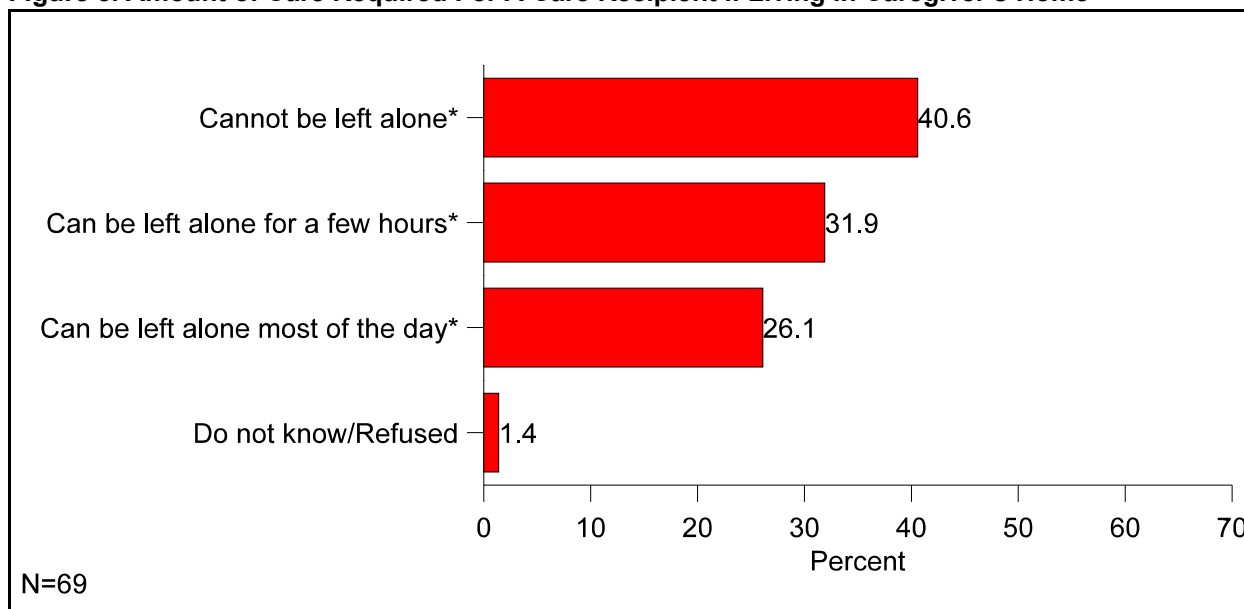
- ▶ Slightly more than half (51.4 percent) of caregivers said they do not provide caregiving services in their home (Figure 4, Appendix Table 4).

Figure 4. Whether Caregiving is Done in Caregiver's Home



- ▶ Although care is generally seen to occur “around the clock,” more than 40 percent of caregivers who do the caregiving in their home said the care recipient cannot be left alone (Figure 5, Appendix Table 5).

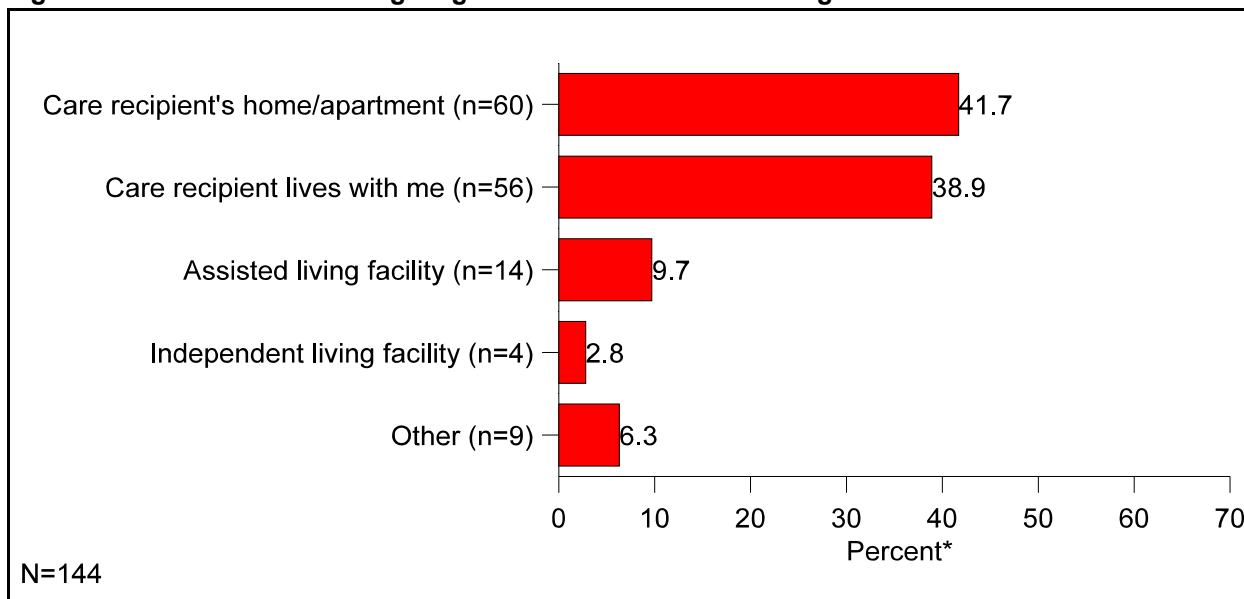
Figure 5. Amount of Care Required For A Care Recipient if Living in Caregiver's Home



*Full response begins with: “Around the clock care, care recipient...”

- ▶ Nearly 42 percent of caregivers indicated the care they provide takes place in the care recipient's home. Approximately 39 percent of the caregivers indicated the care recipient lives with them (Figure 6, Appendix Table 6).

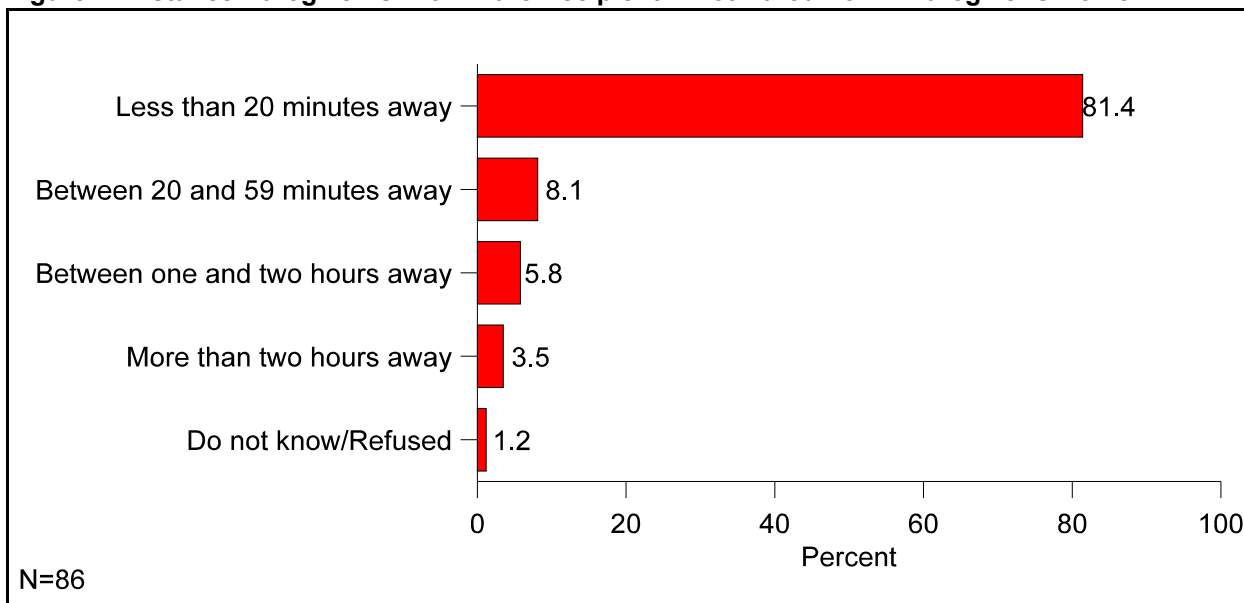
Figure 6. Location Where Caregiving is Done if Not Done in Caregiver's Home



*Percents do not always add to 100.0 due to multiple responses; n=144

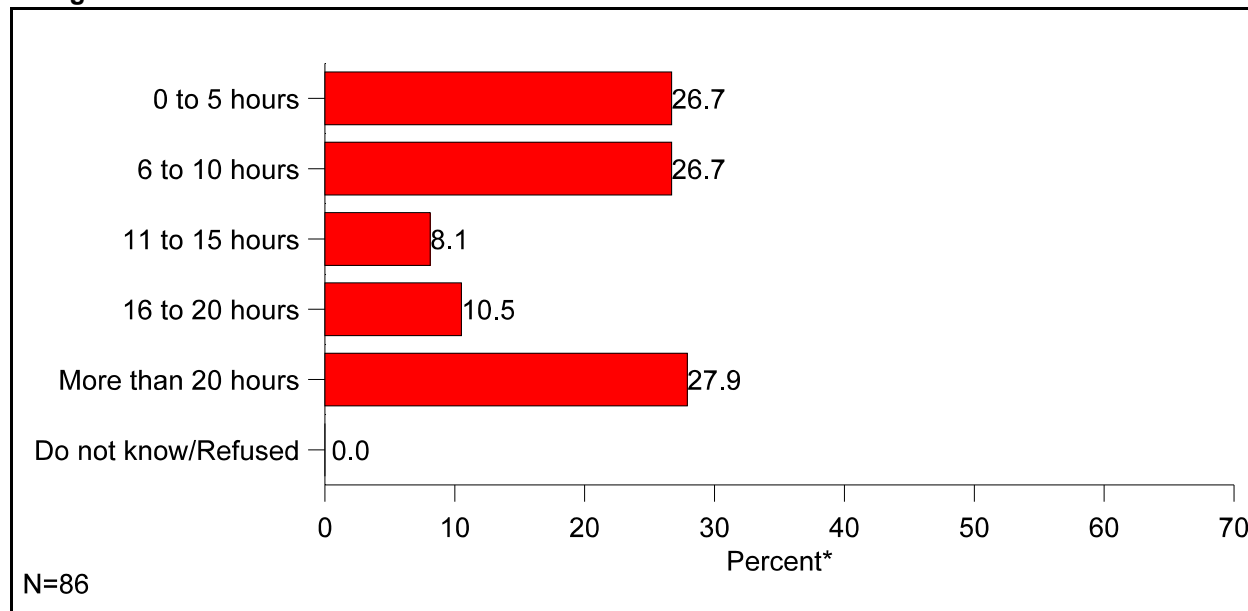
- ▶ Approximately 81 percent of caregivers who do caregiving outside of their home live less than 20 minutes away from the care recipient (Figure 7, Appendix Table 7).

Figure 7. Distance Caregiver is From Care Recipient if Not Cared For in Caregiver's Home



- ▶ Approximately 53 percent of caregivers said they spend up to 10 hours per week on average providing care. However, nearly 28 percent of caregivers said they spend more than 20 hours per week on average providing care (Figure 8, Appendix Table 8).

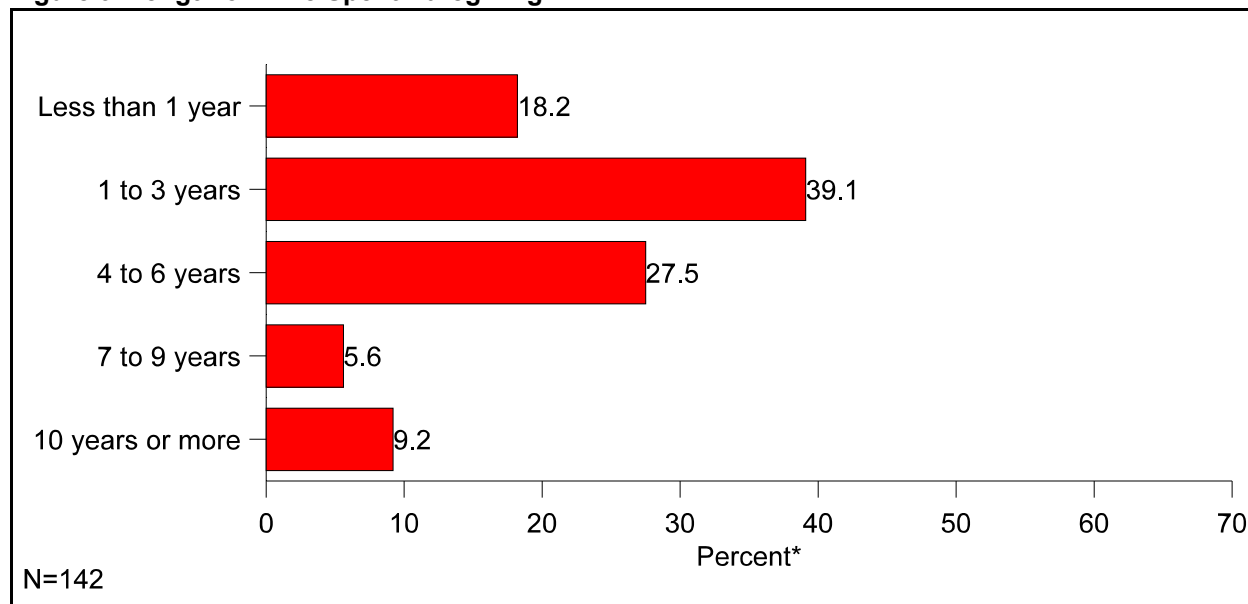
Figure 8. Average Hours Spent Caregiving Per Week if Care Recipient is Not Cared For in Caregiver's Home



*Percents do not always add to 100.0 due to rounding.

- ▶ Approximately 18 percent of caregivers said they have spent less than one year caregiving. More than 42 percent have spent four or more years caregiving (Figure 9, Appendix Table 9).

Figure 9. Length of Time Spent Caregiving



*Percents do not always add to 100.0 due to rounding.

Informal Caregiving Difficulties/Concerns

- ▶ More than 40 percent of caregivers indicated that having no consistent help from other family members (44.7 percent), emotional aspects (44.6 percent), and having the responsibility for making major life decisions for their care recipient (44.0 percent) are serious difficulties which they experience when providing care. (Table 1, Figure 10).
- ▶ More than 30 percent of caregivers indicated lifestyle changes (35.4 percent), less time for themselves (34.7 percent), conflicts with their social lives (33.3 percent), and less time for their families (28.4 percent) are also serious difficulties they experience when providing care (Table 1, Figure 10).

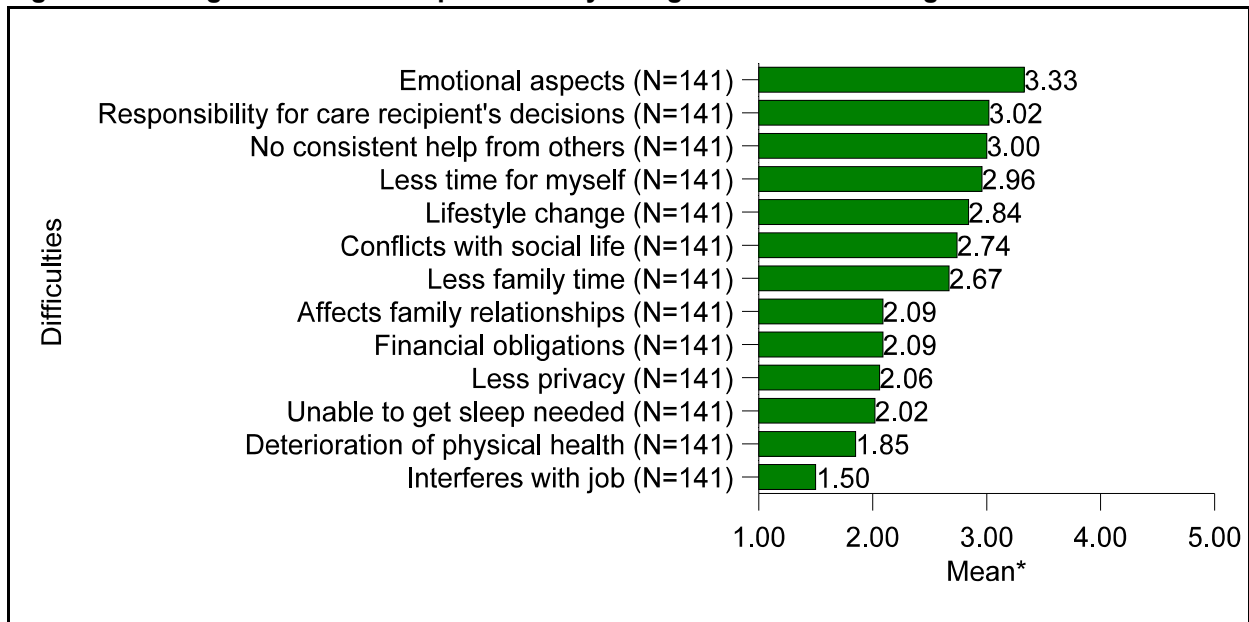
Table 1. Rating of Difficulties Experienced by Caregiver When Providing Care

Difficulties Experienced	Mean*	Responses											
		Not at all serious 1		2		3		4		Very serious 5		Do not know/ Refused 6	
		#	%	#	%	#	%	#	%	#	%	#	%
Emotional aspects (frustration, stress, sadness, anxiety, etc.) (n=141)	3.33	19	13.5	16	11.3	43	30.5	26	18.4	37	26.2	0	0.0
Having the responsibility for making major life decisions for care recipient (n=141)	3.02	34	24.1	25	17.7	20	14.2	28	19.9	34	24.1	0	0.0
No consistent help from other family members (n=141)	3.00	47	33.3	15	10.6	15	10.6	20	14.2	43	30.5	1	0.7
Less time for myself (shopping, hobbies, etc.) (n=141)	2.96	31	22.0	16	11.3	45	31.9	25	17.7	24	17.0	0	0.0
Lifestyle change (n=141)	2.84	37	26.2	22	15.6	32	22.7	27	19.1	23	16.3	0	0.0
Conflicts with my social life (eating out, movies, visiting friends, etc.) (n=141)	2.74	42	29.8	26	18.4	26	18.4	21	14.9	26	18.4	0	0.0
Less time for my family (shorter vacations, missed events, etc.) (n=141)	2.67	46	32.6	18	12.8	36	25.5	19	13.5	21	14.9	1	0.7
Affects my family relationships (n=141)	2.09	74	52.5	22	15.6	19	13.5	10	7.1	16	11.3	0	0.0
Financial obligations (n=141)	2.09	77	54.6	19	13.5	16	11.3	14	9.9	15	10.6	0	0.0
Less privacy (n=141)	2.06	74	52.5	22	15.6	20	14.2	12	8.5	13	9.2	0	0.0
I am unable to get the sleep I need due to caregiving (n=141)	2.02	76	53.9	21	14.9	19	13.5	15	10.6	10	7.1	0	0.0
My physical health is deteriorating due to caregiving (n=141)	1.85	86	61.0	16	11.3	19	13.5	14	9.9	6	4.3	0	0.0
Interferes with my job (n=141)	1.50	101	71.6	21	14.9	11	7.8	5	3.5	3	2.1	0	0.0

*"Do not know/Refused" was excluded from the means.

- ▶ The mean scores of difficulties experienced by caregivers when providing care can be found below (Figure 10).

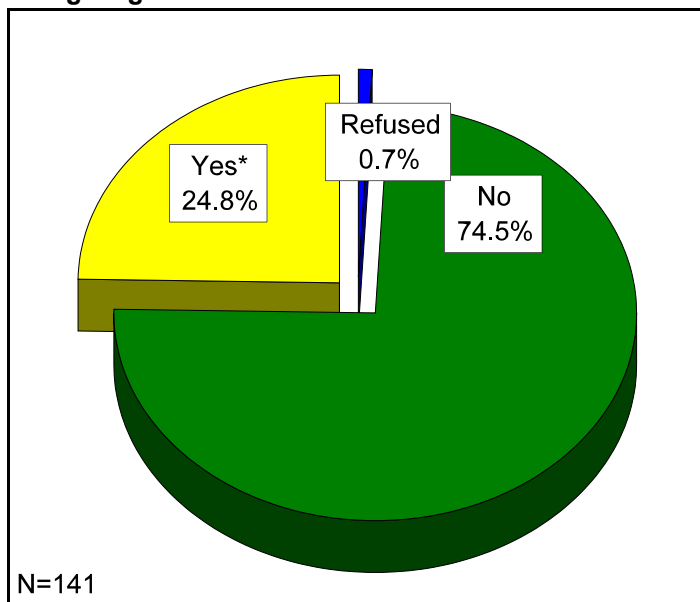
Figure 10. Rating of Difficulties Experienced by Caregiver When Providing Care



*Means were based on a one to five scale, with one being "not at all serious" and five being "very serious." "Do not know/refused" was excluded from the means.

- ▶ Nearly a fourth of caregivers experience caregiving difficulties other than those listed in Figure 10 (Figure 11, Appendix Table 10a).
- ▶ The responses of caregivers who experience other caregiving difficulties are listed in Appendix Table 10b.

Figure 11. Whether Caregiver Experiences Other Caregiving Difficulties



*See Appendix Table 10b for other caregiving difficulties.

- Caregivers were asked to rate the extent to which they agreed or disagreed with various concerns associated with being a caregiver. Nearly a quarter of caregivers agreed that it is difficult for them to find support or assistance when caregiving (24.7 percent) and it is difficult for them to accept support or assistance when caregiving because it is their duty to provide care (23.4 percent) (Table 2, Figure 12).

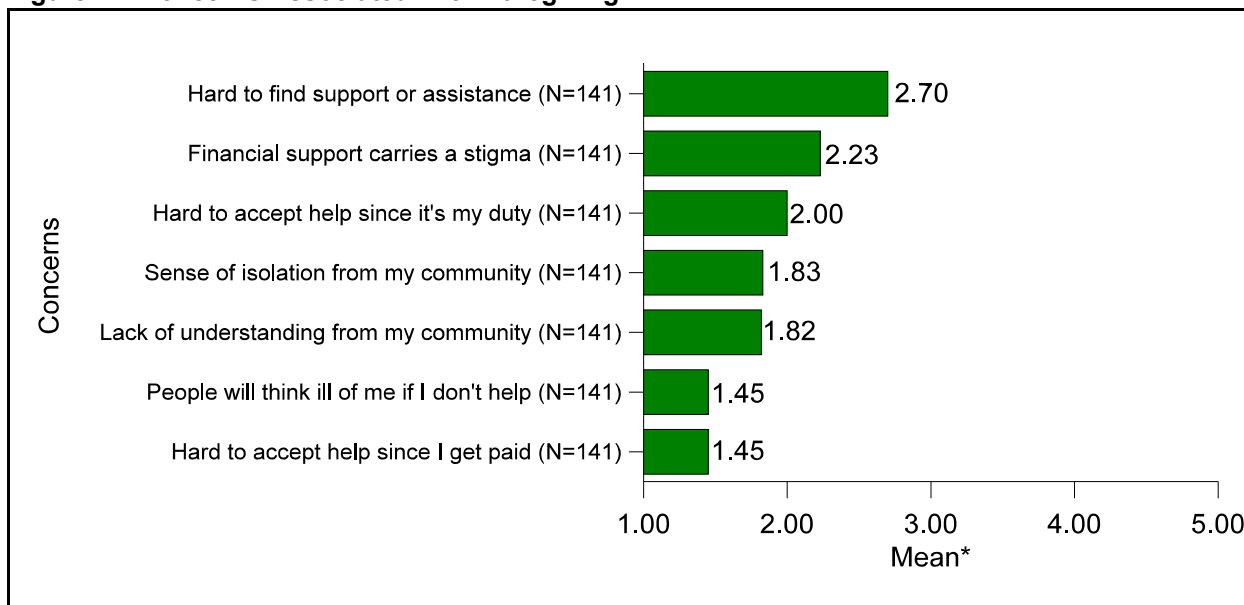
Table 2. Concerns Associated With Caregiving

Concerns	Mean*	Responses											
		Strongly disagree 1		2		3		4		Strongly agree 5		Do not know/ Refused* 6	
		#	%	#	%	#	%	#	%	#	%	#	%
It is difficult for me to find support or assistance when caregiving (I feel like I don't have help) (n=141)	2.70	41	29.1	31	22.0	20	14.2	27	19.1	22	15.6	0	0.0
It is difficult for me to accept financial support or assistance when caregiving because it sometimes carries a negative stigma (n=141)	2.23	67	47.5	28	19.9	19	13.5	8	5.7	11	7.8	8	5.7
It is difficult for me to accept support or assistance when caregiving because it is my duty to provide care (n=141)	2.00	52	36.9	29	20.6	27	19.1	14	9.9	19	13.5	0	0.0
Since I have started caregiving services I've experienced a lack of understanding from others in my community (n=141)	1.82	81	57.4	27	19.1	19	13.5	6	4.3	8	5.7	0	0.0
It is difficult for me to accept help from others when caregiving because I'm being paid (e.g. Qualified Service Provider) (n=141)	1.45	109	77.3	17	12.1	5	3.5	5	3.5	3	2.1	2	1.4
I'm providing caregiving services because people in my community will think ill of me if I don't (n=141)	1.45	109	77.3	16	11.3	4	2.8	9	6.4	3	2.1	0	0.0

*"Do not know/Refused" was excluded from the means.

- ▶ The mean scores of concerns associated with caregiving can be found below (Figure 12).

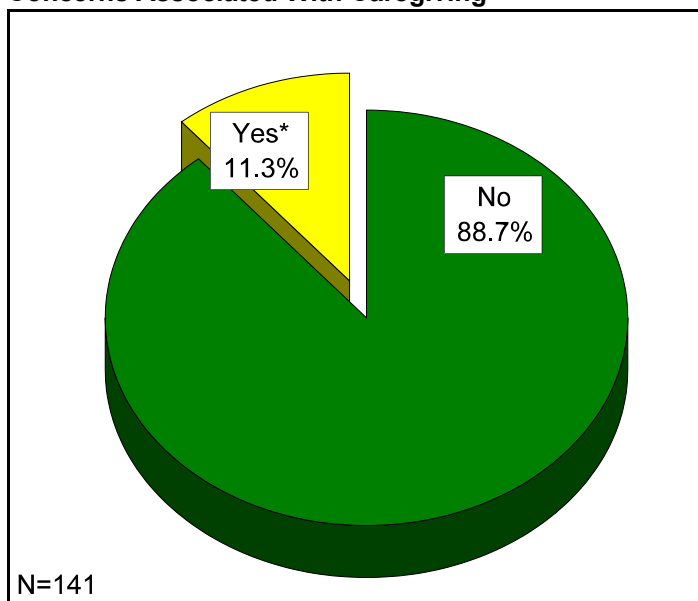
Figure 12. Concerns Associated With Caregiving



*Means were based on a one to five scale, with one being "not at all serious" and five being "very serious"; "Do not know/refused" was excluded from the means.

- ▶ Nearly 89 percent of caregivers do not have concerns associated with caregiving other than those mentioned in Figure 12 (Figure 13, Appendix Table 11a).
- ▶ The responses of caregivers who have other concerns are listed in Appendix Table 11b.

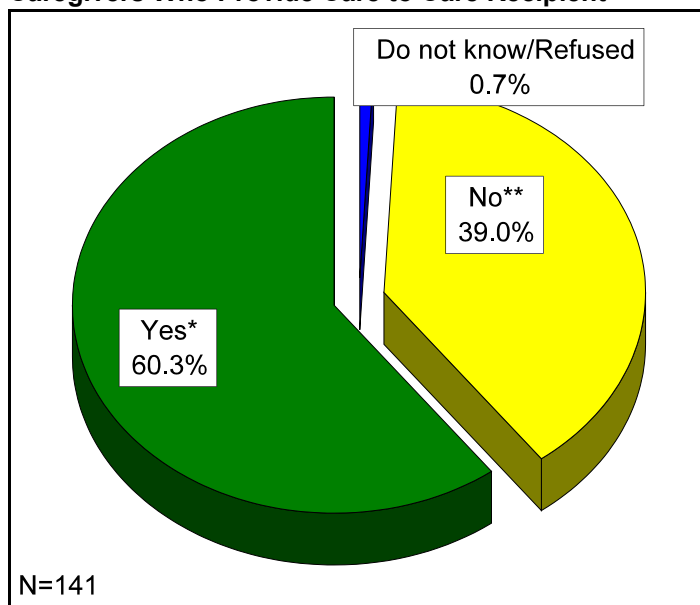
Figure 13. Whether Caregiver Experiences Other Concerns Associated With Caregiving



*See Appendix Table 11b for other concerns associated with caregiving.

- ▶ The majority of caregivers said there are other informal caregivers who provide care to the care recipient (Figure 14, Appendix Table 12a). The highest proportion of other informal caregivers are a sister, followed by a son (Appendix Table 12b).
- ▶ For 39 percent of caregivers, however, no other informal caregivers provide care. The two most common reasons why others are not providing care are because they live farther away (59.7 percent) and/or have full-time jobs (53.5 percent) (Appendix Table 12c).
- ▶ See Appendix Table 12c for reasons why others don't provide care; see Appendix Table 12b for a list of other caregivers.

Figure 14. Whether There Are Other Informal Caregivers Who Provide Care to Care Recipient

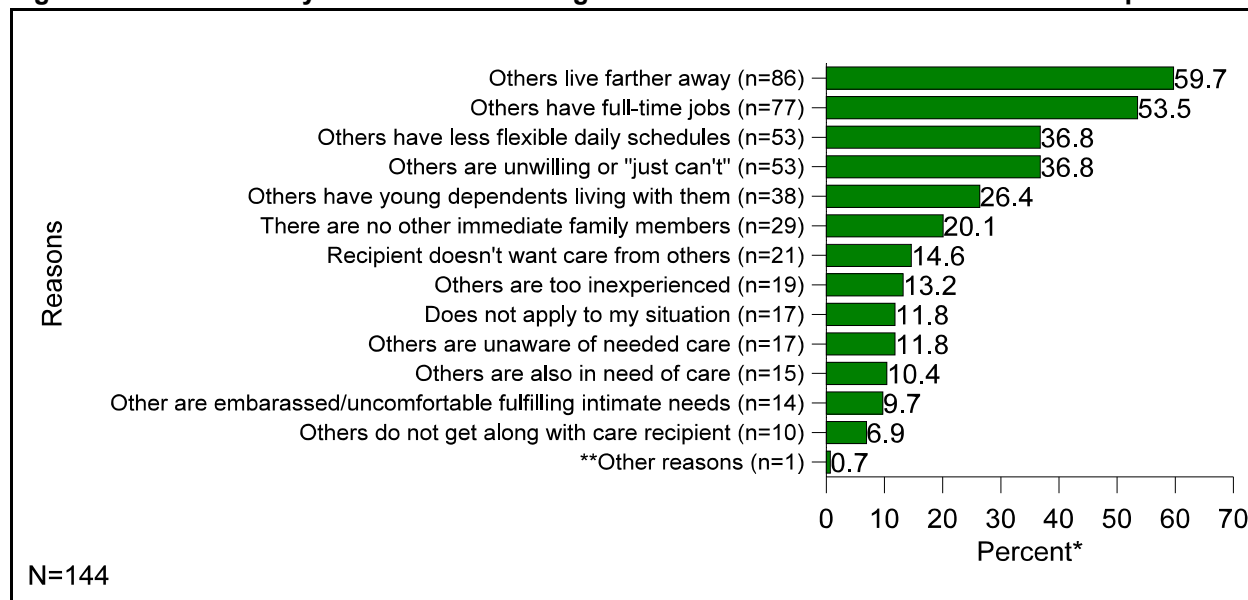


*See Appendix Table 12b for other informal caregivers.

**See Appendix Table 12c for reasons why others do not provide care.

- ▶ The top three reasons why other informal caregivers do not provide care were: others live farther away (44.9 percent), others have full-time jobs (35.2 percent), and there are no other immediate family members (26.8 percent) (Figure 14, Appendix Table 12c).
- ▶ See Appendix Table 12b for a list of other reasons why other informal caregivers do not provide care to the care recipient.

Figure 15. Reasons Why Other Informal Caregivers Do Not Provide Care to the Care Recipient



*Percents do not add to 100.0 due to multiple responses; N=144.

**See Appendix Table 12c for other reasons why other informal caregivers do not provide care.

Services Available to the Informal Care Recipient

- ▶ More than three-fourths of caregivers indicated that homemaker services/home health aides (77.9 percent) and congregate meal settings (76.4 percent) are available to their care recipient. More than half of caregivers indicated the care recipient had a visiting nurse (72.1 percent), home delivered meals (70.0 percent), dietician services (59.3 percent), and escort/transportation services (55.0 percent) available to them (Table 3).
- ▶ For more than half of caregivers, the following services are not available to care recipients: pet service (70.7 percent), parish nurse (67.9 percent), adult day centers (56.4 percent), outreach programs (51.4 percent), and shopping assistance (54.3 percent) (Table 3).

Table 3. Whether Services Are Available to Care Recipient

Care Recipient Services	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
Homemaker services/home health aides	109	77.9	24	17.1	7	5.0	140	100.0
Congregate meal settings (e.g., Senior centers, restaurants, etc.)	107	76.4	32	22.9	1	0.7	140	100.0
Visiting nurse	101	72.1	36	25.7	3	2.1	140	99.9
Home delivered meals (e.g., Meals on Wheels, community volunteering, or church)	98	70.0	38	27.1	4	2.9	140	100.0
Dietician services	83	59.3	53	37.9	4	2.9	140	100.1
Escort/transportation services	77	55.0	60	42.9	3	2.1	140	100.0
Shopping assistance	55	39.3	76	54.3	9	6.4	140	100.0
Outreach programs (e.g., senior companions)	47	33.6	72	51.4	21	15.0	140	100.0
Adult day centers	46	32.9	79	56.4	15	10.7	140	100.0
Parish nurse	30	21.4	95	67.9	15	10.7	140	100.0
Pet service (e.g., grooming, vet needs, etc.)	26	18.6	99	70.7	15	10.7	140	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ More than half of caregivers who do not have these services available to the care recipient already indicated they would like outreach programs (53.8 percent) and homemaker services (51.6 percent) to be available to the care recipient (Table 4).
- ▶ More than 40 percent of caregivers indicated they would like home delivered meals (42.9 percent), a parish nurse (42.7 percent), shopping assistance (42.4 percent), and adult day centers (40.4 percent) to be available to the care recipient (Table 4).

Table 4. If Services Are Not Available to Care Recipient, Whether Caregiver Would Like Them to be Available

Unavailable Care Recipient Services	Respondents by Desire for services							
	Yes		No		Do not know/ Refused		Total	
	#	%	#	%	#	%	#	%*
Outreach programs (i.e., senior companions)	50	53.8	40	43.0	3	3.2	93	100.0
Homemaker services/home health aides	16	51.6	14	45.2	1	3.2	31	100.0
Escort/transportation services	31	49.2	31	49.2	1	1.6	63	100.0
Visiting nurse	19	48.7	19	48.7	1	2.6	39	100.0
Home delivered meals (i.e., Meals on Wheels, community volunteering, or church)	18	42.9	21	50.0	3	7.1	42	100.0
Parish nurse	47	42.7	56	50.9	7	6.4	110	100.0
Shopping assistance	36	42.4	48	56.5	1	1.2	85	100.1
Adult day centers	38	40.4	51	54.3	5	5.3	94	100.0
Dietician services	18	31.6	38	66.7	1	1.8	57	100.1
Congregate meal settings (e.g., at Senior centers, restaurants, etc.)	9	27.3	22	66.7	2	6.1	33	100.1
Pet service (grooming, vet needs, etc.)	11	9.6	98	86.0	5	4.4	114	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ When services are available, more than half of caregivers indicated the care recipient has used a visiting nurse (59.4 percent) and dietician services (51.8 percent). Approximately one-third had used home delivered meals (42.9 percent), pet service (42.3 percent), and homemaker services/home health aides (40.4 percent) (Table 5).

Table 5. Whether Services Are Being Used if Services Are Available to Care Recipient

Available Care Recipient Services	Respondents by Use of Services					
	Yes		No		Total	
	#	%	#	%	#	%
Visiting nurse	60	59.4	41	40.6	101	100.0
Dietician services	43	51.8	40	48.2	83	100.0
Home delivered meals (e.g., Meals on Wheels, community volunteering, or church)	42	42.9	56	57.1	98	100.0
Pet service (e.g., grooming, vet needs, etc.)	11	42.3	15	57.7	26	100.0
Homemaker services/home health aides	44	40.4	65	59.6	109	100.0
Escort/transportation services	27	35.1	50	64.9	77	100.0
Congregate meal settings (e.g., Senior centers, restaurants, etc.)	36	33.6	71	66.4	107	100.0
Parish nurse	10	33.3	20	66.7	30	100.0
Shopping assistance	18	32.7	37	67.3	55	100.0
Outreach programs (e.g., senior companions)	10	21.3	37	78.7	47	100.0
Adult day centers	9	19.6	37	80.4	46	100.0

- ▶ Regardless of the type of service, the most common reason the care recipient does not use the service (if it is available to them) is because they do not need it. (Table 6).
- ▶ In the instances where the service is available, adult day centers (37.8 percent) and escort/transportation services (20.0 percent) are the top two services that care recipients would not use (Table 6).
- ▶ For services available that are not being used by the care recipient, other reasons why care recipients does not use the services available to them are listed in Appendix Table 13 by type of service.

Table 6. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient

Care Recipient Services	Respondents by Reason of Non-Use of Service									
	Do not need it		Care recipient won't use		Other reasons**		Do not know/Refused		Total	
	#	%	#	%	#	#	#	%	#	%
Pet service (grooming, vet needs, etc.)	13	86.7	1	6.7	1	6.7	0	0.0	15	100.1
Dietician services	32	80.0	3	7.5	5	12.5	0	0.0	40	100.0
Shopping assistance	29	78.4	3	8.1	5	13.5	0	0.0	37	100.0
Parish nurse	15	75.0	2	10.0	2	10.0	1	5.0	20	100.0
Home delivered meals (Meals on Wheels, community volunteering, or church)	40	71.4	8	14.3	7	12.5	1	1.8	56	100.0
Homemaker services/home health aides	46	70.8	5	7.7	14	21.5	0	0.0	65	100.0
Outreach programs (i.e. senior companions)	26	70.3	9	24.3	1	2.7	1	2.7	37	100.0
Visiting nurse	28	68.3	5	12.2	8	19.5	0	0.0	41	100.0
Escort/transportation services	29	58.0	10	20.0	11	22.0	0	0.0	50	100.0
Adult day centers	20	54.1	14	37.8	2	5.4	1	2.7	37	100.0
Congregate meal settings (as Senior centers, restaurants, etc.)	36	50.7	12	16.9	22	31.0	1	1.4	71	100.0

*Percents do not add to 100.0 due to rounding.

**See Appendix Table 13 for other reasons services were not being used.

- ▶ For care recipient services they have used, caregivers rated adult day centers, escort/transportation services, and shopping assistance highest. The ratings of care recipient services they have used are low in the areas of congregate meal settings, parish nurse, and dietician services, though still above average (Table 7, Figure 16).

Table 7. Ratings of Services Available to Care Recipient

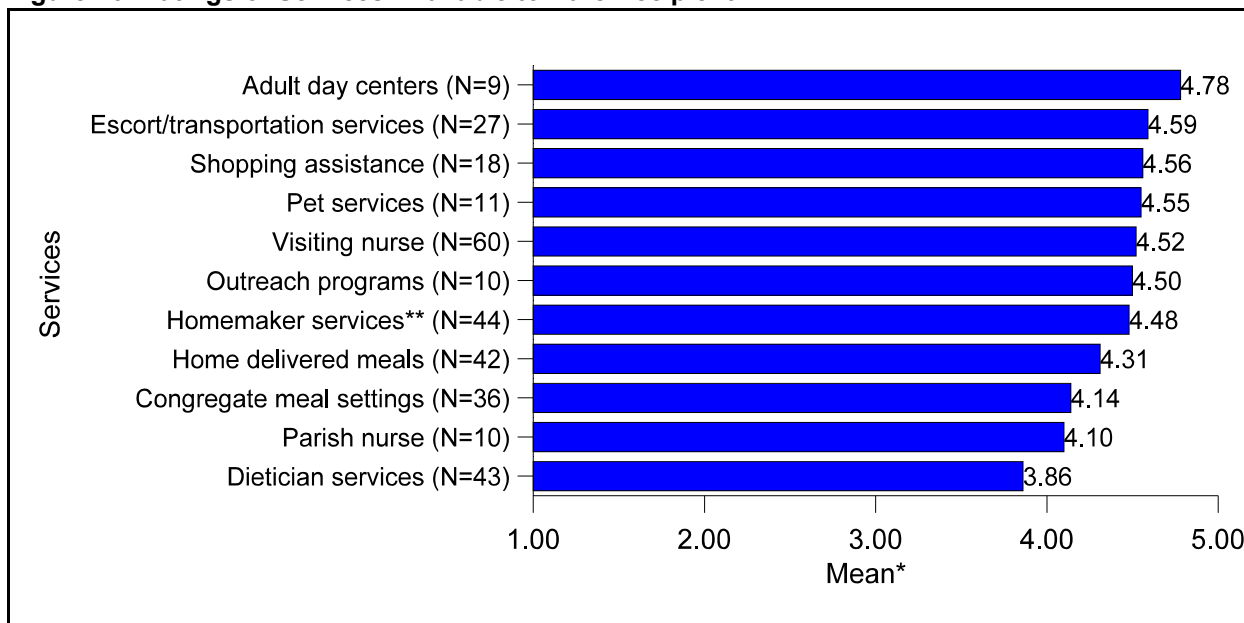
Care Recipient Services	Mean*	Responses											
		Not good at all 1**		2**		3		4		Very good 5		Do not know/ Refused 6	
		#	%	#	%	#	%	#	%	#	%	#	%
Adult day centers (n=9)	4.78	0	0.0	0	0.0	0	0.0	2	22.2	7	77.8	0	0.0
Escort or transportation services (n=27)	4.59	0	0.0	1	3.7	4	14.8	1	3.7	20	74.1	1	3.7
Shopping assistance (n=18)	4.56	0	0.0	0	0.0	2	11.1	4	22.2	12	66.7	0	0.0
Pet service (grooming, vet needs, etc.) (n=11)	4.55	0	0.0	0	0.0	3	27.3	1	9.1	5	45.5	2	18.2
Visiting nurse (n=60)	4.52	2	3.3	1	1.7	5	8.3	8	13.3	44	73.3	0	0.0
Outreach programs (i.e. senior companions) (n=10)	4.50	0	0.0	0	0.0	2	20.0	1	10.0	7	70.0	0	0.0
Homemaker services/home health aides (n=44)	4.48	0	0.0	1	2.3	5	11.4	10	22.7	28	63.6	0	0.0
Home delivered meals (Meals on wheels, community volunteering, or church) (n=42)	4.31	0	0.0	3	7.1	9	21.4	3	7.1	26	61.9	1	2.4
Congregate meal settings (senior centers, restaurants, etc.) (n=36)	4.14	2	5.6	2	5.6	5	13.9	7	19.4	20	55.6	0	0.0
Parish nurse (n=10)	4.10	0	0.0	0	0.0	3	30.0	3	30.0	4	40.0	0	0.0
Dietician services (n=43)	3.86	3	7.0	4	9.3	10	23.3	5	11.6	21	48.8	0	0.0

** "Do not know/Refused" was excluded from the means.

*Reasons why services were not good are listed in Appendix Table 14.

- Reasons why caregivers rated certain services lower (a score of one or two on the scale) can be found in Appendix Table 14.

Figure 16. Ratings of Services Available to Care Recipient

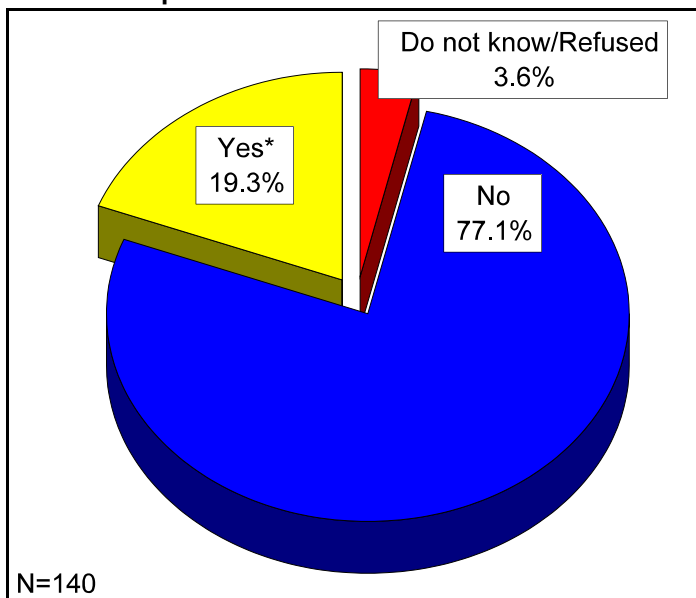


*Means were based on a one to five scale, with one being "not good at all" and five being "very good;" "Do not know/Refused" was excluded from the means.

**Full response category states: "Homemaker services/home health aides."

- Approximately 77 percent of caregivers said there are no other services not mentioned in Figure 16 that they would like to have available to their care recipient (Figure 17, Appendix Table 15a).
- The responses of caregivers who would like other services to be available to the care recipient can be found in Appendix Table 15b.

Figure 17. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Care Recipient



*See Appendix Table 15b for other services.

Services Available to the Informal Caregiver

- ▶ More than 62 percent of caregivers indicated information about available services is available to them (Table 8).
- ▶ At least half of caregivers indicated that respite care (50.0 percent), caregiver training or education (51.4 percent), individual caregiver counseling services (55.0 percent), and caregiver support groups (62.9 percent) are not available to them (Table 8).

Table 8. Whether Services Are Available to Caregiver

Caregiver Services	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
Information about available services	87	62.1	43	30.7	10	7.1	140	99.9
Assistance with accessing available services	65	46.4	58	41.4	17	12.1	140	99.9
Respite care (someone else provides short-term relief for you)	56	40.0	70	50.0	14	10.0	140	100.0
Caregiver training or education	46	32.9	72	51.4	22	15.7	140	100.0
Individual caregiver counseling services	40	28.6	77	55.0	23	16.4	140	100.0
Caregiver support groups	30	21.4	88	62.9	22	15.7	140	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ Regarding services that are not available, the top three services that caregivers would like available to them are information about available services (81.1 percent), respite care (63.1 percent), and assistance with accessing available services (57.3 percent) (Table 6).

Table 9. If Services Are Not Available to Caregiver, Whether Caregiver Would Like Them to be Available

Unavailable Caregiver Services	Respondents by Desire for Services							
	Yes		No		Do not know/ Refused		Total	
	#	%	#	%	#	%	#	%
Information about available services	43	81.1	9	17.0	1	1.9	53	100.0
Respite care (i.e., someone else provides short-term relief for you)	53	63.1	27	32.1	4	4.8	84	100.0
Assistance with accessing available services	43	57.3	27	36.0	5	6.7	75	100.0
Caregiver support groups	57	51.8	47	42.7	6	5.5	110	100.0
Individual caregiver counseling services	51	51.0	47	47.0	2	2.0	100	100.0
Caregiver training or education	46	48.9	44	46.8	4	4.3	94	100.0

- ▶ When the services are available, more than half of caregivers indicate that they are using assistance with accessing available services (72.3 percent) and information about available services (71.3 percent) (Table 10).
- ▶ Regardless of the available services, more than half of caregivers reported that they do not use caregiver training or education (58.7 percent), individual caregiver counseling services (62.5 percent), respite care (69.6 percent), and caregiver support groups (80.0 percent) (Table 10).

Table 10. Whether Services Are Being Used if Services Are Available to Caregiver

Available Caregiver Services	Respondents by Use of Services					
	Yes		No		Total	
	#	%	#	%	#	%
Assistance with accessing available services	47	72.3	18	27.7	65	100.0
Information about available services	62	71.3	25	28.7	87	100.0
Caregiver training or education	19	41.3	27	58.7	46	100.0
Individual caregiver counseling services	15	37.5	25	62.5	40	100.0
Respite care (i.e., someone else provides short-term relief for you)	17	30.4	39	69.6	56	100.0
Caregiver support groups	6	20.0	24	80.0	30	100.0

- ▶ Regardless of the type of service, the most common reason that the caregiver does not use the service (if it is available to them) is because they do not need it. (Table 11).
- ▶ Other reasons why caregivers do not use the services available to them are listed in Appendix Table 16 by type of service.

Table 11. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver

Available Caregiver Services	Respondents by Reason of Non-Use of Service									
	Do not need it		Care recipient won't use it		Other reasons**		Do not know/Refused		Total	
	#	%	#	%	#	%	#	%	#	%*
Information about available services	16	64.0	0	0.0	9	36.0	0	0.0	25	100.0
Assistance with accessing available services	11	61.1	0	0.0	7	38.9	0	0.0	18	100.0
Individual caregiver counseling services	20	80.0	0	0.0	5	20.0	0	0.0	25	100.0
Caregiving training or education	23	85.2	0	0.0	3	11.1	1	3.7	27	100.0
Respite care (i.e., someone else provides short-term relief for you)	27	69.2	2	5.1	10	25.6	0	0.0	39	99.9
Caregiver support programs	22	91.7	0	0.0	2	8.3	0	0.0	24	100.0

*Percents do not always add to 100.0 due to rounding.

**See Appendix Table 16 for other reasons services are not being used.

- ▶ Caregivers rated services available to them highest in the area of caregiver support groups, however, only 6 caregivers reported that they are using support groups that are available to them (Table 12, Figure 18).
- ▶ The most utilized service is assistance with accessing available services. Approximately 72 percent of caregiver utilize this service (Table 12, Figure 18).
- ▶ The service that caregivers rated the lowest is information about available services. It is interesting to note that it is one of the services utilized most by caregivers. More than 71 percent of caregivers who have access to this service utilize it (Table 12, Figure 18).

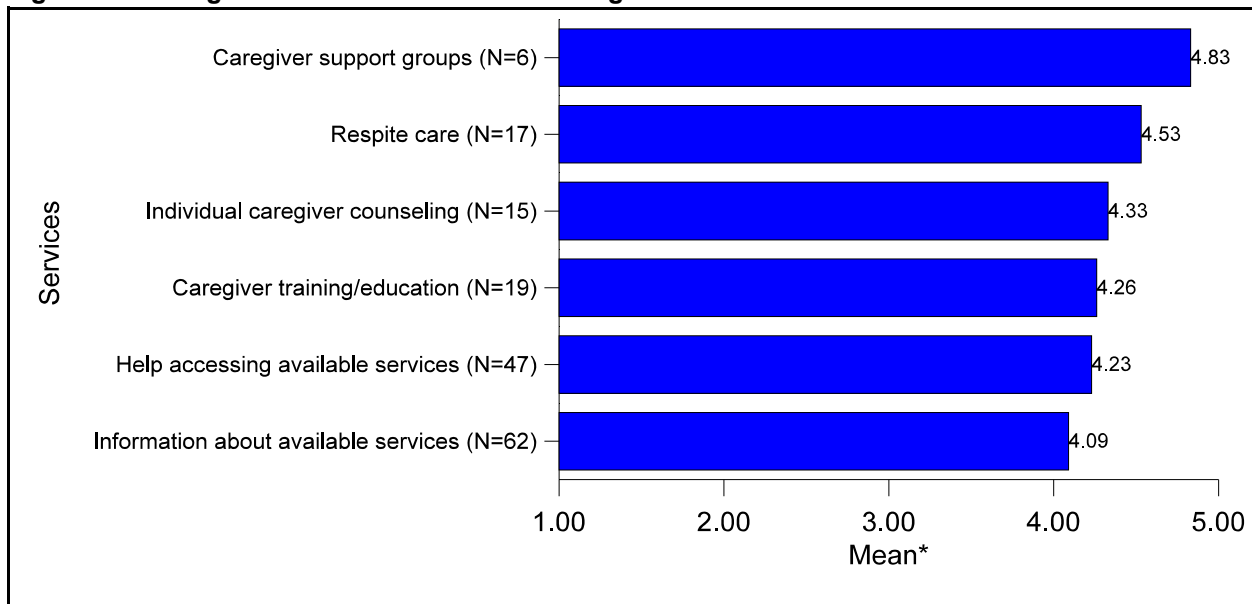
Table 12. Ratings of Services Available to Caregiver

Caregiver Services	Mean*	Responses											
		Not at all good 1*		2*		3		4		Very Good 5		Do not Know/ Refused 6	
		#	%	#	%	#	%	#	%	#	%	#	%
Caregiver support groups (n=6)	4.83	0	0.0	0	0.0	0	0.0	1	16.7	5	83.3	0	0.0
Respite care (someone else provides short-term relief for you) (n=17)	4.53	0	0.0	0	0.0	3	17.6	2	11.8	12	70.6	0	0.0
Individual caregiver counseling services (n=15)	4.33	0	0.0	1	6.7	2	13.3	4	26.7	7	46.7	1	6.7
Caregiver training or education (n=19)	4.26	0	0.0	1	5.3	4	21.1	3	15.8	11	57.9	0	0.0
Assistance with accessing available services (n=47)	4.23	2	4.3	1	2.1	7	14.9	12	25.5	24	51.1	1	2.1
Information about available services (n=62)	4.10	1	1.6	3	4.8	14	22.6	17	27.4	25	40.3	2	3.2

*Reasons why service was not good are listed in Appendix Table 17.

- ▶ Comments regarding why caregivers rated certain services lower (by giving the service a score of 1 or 2) can be found in Appendix Table 17.

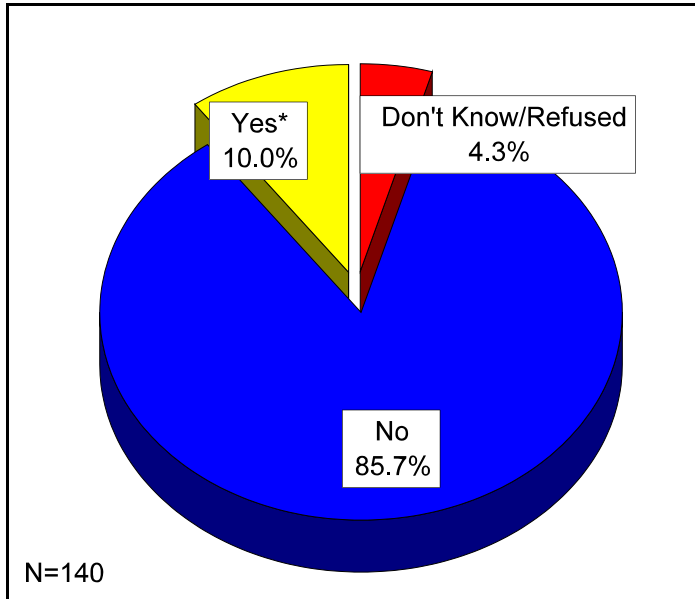
Figure 18. Ratings of Services Available to Caregiver



*Means were based on a one to five scale, with one being “not good at all” and five being “very good”; “Do not know/refused” was excluded from the means.

- ▶ Approximately 86 percent of caregivers said there are no services, other than those mentioned in Figure 17, that they would like to have had available to them (Figure 19, Appendix Table 18a).
- ▶ The other services that caregivers would like to have had available to them are listed in Appendix Table 18b.

Figure 19. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver



*See Appendix Table 18b for other services.

- More than half of caregivers indicated that information or services that would be valuable to caregivers, now or in the future, are information about the care recipient's condition or disability (61.1 percent), an info-line (56.3 percent), and someone to help them arrange for services or assess the care recipient's situation (52.8 percent) (Table 13).

Table 13. Information or Services That Would be Valuable to Caregiver

Information or Services	Respondents (N=144)	
	#	%*
Information about the care recipient's condition or disability	88	61.1
Info-line (central place to call and find out what kind of help is available)	81	56.3
Someone to help you arrange for services, assess your situation	76	52.8
Information on end of life issues	69	47.9
Help in understanding how to pay for nursing homes/adult day care, etc.	67	46.5
Information about developments/changes in laws affecting your situation	64	44.4
Respite care or adult day care	61	42.4
Financial Support	58	40.3
Tax break, stipend, government subsidy	57	39.6
Help in dealing with agencies (bureaucracies) to get services	57	39.6
Help in assessing the timing of placement in formal caregiving institutions	55	38.2
Help in understanding how to select a nursing home/other care facility	55	38.2
Someone to talk to/counseling services/support group	53	36.8
Aftercare/grief counseling	40	27.8
Hotline (for dealing with immediate emotional needs while preserving dignity)	29	20.1
None of the above	12	8.3
Other:	3	2.1
<i>Counseling in my home</i>	1	
<i>Help paying for medications-they keep trying meds</i>	1	
<i>Put services on website online to make it easier to get help</i>	1	

*Percents do not add to 100.0 due to multiple responses; N=144.

Services Provided by the Informal Caregiver

- ▶ At least half of all caregivers reported they have provided one or all of the services listed below (Table 14).
- ▶ At least 90 percent of caregivers reported they have provided companionship (97.1 percent), listened to the care recipient and/or been someone for them to talk to (96.4 percent), and assisted with errands/shopping (90.7 percent).
- ▶ Although contributing financially was the service provided least by caregivers, more than half (50.7 percent) of them had done so (Table 14).

Table 14. Whether Caregiver Provides Any of the Following Services

Services	Respondents by Provision of Services							
	Yes		No		Do not know/ Refused		Total	
	#	%	#	%	#	%	#	%*
Provide companionship	136	97.1	4	2.9	0	0.0	140	100.0
Listen to them-someone for them to talk to	135	96.4	4	2.9	1	0.7	140	100.0
Assist with errands/shopping	127	90.7	13	9.3	0	0.0	140	100.0
Provide transportation, getting places	125	89.3	15	10.7	0	0.0	140	100.0
Assist with meals/nutritional needs	117	83.6	23	16.4	0	0.0	140	100.0
Help with worries, anxiety, and emotional needs (i.e. loss of independence, leaving home behind, fear of death, crying, anger, etc.)	117	83.6	23	16.4	0	0.0	140	100.0
Assist with household tasks (including pet care)	116	82.9	24	17.1	0	0.0	140	100.0
Communicate with medical providers	115	82.1	24	17.1	1	0.7	140	99.9
Get other family members involved in caregiving	100	71.4	40	28.6	0	0.0	140	100.0
Manage finances	100	71.4	40	28.6	0	0.0	140	100.0
Provide phone contact	95	67.9	45	32.1	0	0.0	140	100.0
Assist with maintenance/repair (indoor/outdoor)	90	64.3	50	35.7	0	0.0	140	100.0
Assist with medicines (administering, side effects, etc.)	90	64.3	50	35.7	0	0.0	140	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	88	62.9	52	37.1	0	0.0	140	100.0
Help with legal assistance	77	55.0	61	43.6	2	1.4	140	100.0
Contribute financially	71	50.7	69	49.3	0	0.0	140	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ The services caregivers provided on a daily basis most often are assisting with medicines (85.6 percent), assisting with meals/nutritional needs (81.2 percent), providing companionship (80.9 percent), and listening to the care recipient and/or being someone for them to talk to (79.3 percent) (Table 15).
- ▶ The services the highest proportion of caregivers provided weekly are assisting with errands/shopping (55.1 percent), providing transportation/getting places (44.0 percent), managing finances (25.0 percent), and providing phone contact (20.0 percent) (Table 15).
- ▶ The highest proportion of services caregivers provided monthly are communicating with medical providers (26.1 percent) and managing finances (17.0 percent) (Table 15).
- ▶ It is more common for caregivers to communicate with medical providers on occasion (44.3 percent). They also reported managing finances on an occasional basis as much as they did on a weekly basis (17.0 percent). The service that the highest proportion of caregivers reported providing on an occasional basis is help with legal assistance (75.3 percent) (Table 15).

Table 15. Frequency of Service Delivery if Caregiver Provides Service

Services	Respondents by Frequency of Service Delivery											
	Daily		Weekly		Monthly		On occasion		Do not know/Refused		Total	
	#	%	#	%	#	%	#	%	#	%	#	%*
Assist with medicines (administering, side effects, etc.)	77	85.6	7	7.8	1	1.1	4	4.4	1	1.1	90	100.0
Assist with meals/nutritional needs	95	81.2	9	7.7	0	0.0	13	11.1	0	0.0	117	100.0
Provide companionship	110	80.9	22	16.2	0	0.0	4	2.9	0	0.0	136	100.0
Listen to them-someone for them to talk to	107	79.3	18	13.3	1	0.7	9	6.7	0	0.0	135	100.0
Assist with household tasks (including pet care)	74	63.8	23	19.8	2	1.7	15	12.9	2	1.7	116	99.9
Provide phone contact	58	61.1	19	20.0	1	1.1	17	17.9	0	0.0	95	100.1
Administer personal care (bathing, bandaging, nail care, etc.)	52	59.1	16	18.2	3	3.4	17	19.3	0	0.0	88	100.0
Help with worries, anxiety, and emotional needs (e.g., loss of independence, leaving home behind, fear of death, crying, anger)	60	51.3	19	16.2	4	3.4	34	29.1	0	0.0	117	100.0
Contribute financially	35	49.3	7	9.9	9	12.7	20	28.2	0	0.0	71	100.1
Manage finances	40	40.0	25	25.0	17	17.0	17	17.0	1	1.0	100	100.0
Provide transportation, getting places	39	31.2	55	44.0	11	8.8	20	16.0	0	0.0	125	100.0
Assist with errands/shopping	39	30.7	70	55.1	3	2.4	15	11.8	0	0.0	127	100.0

*Percents do not always add to 100.0 due to rounding.

Table 15. Frequency of Service Delivery if Caregiver Provides Services (continued)

Services	Respondents by Frequency of Service Delivery											
	Daily		Weekly		Monthly		On occasion		Do not know/ Refused		Total	
	#	%	#	%	#	%	#	%	#	%	#	%*
Assist with maintenance/repair (indoor/outdoor)	26	28.9	15	16.7	5	5.6	44	48.9	0	0.0	90	100.1
Get other family members involved in caregiving	27	27.0	19	19.0	8	8.0	45	45.0	1	1.0	100	100.0
Help with legal assistance	11	14.3	0	0.0	8	10.4	58	75.3	0	0.0	77	100.0
Communicate with medical providers	16	13.9	18	15.7	30	26.1	51	44.3	0	0.0	115	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ At least half of caregivers indicated they would like help assisting with household tasks (60.7 percent), assisting with maintenance/repair (52.1 percent), and administering personal care (50.7 percent) (Table 16).
- ▶ Interestingly, for all other services, more than half of caregivers indicated they would like help providing the service (Table 16).

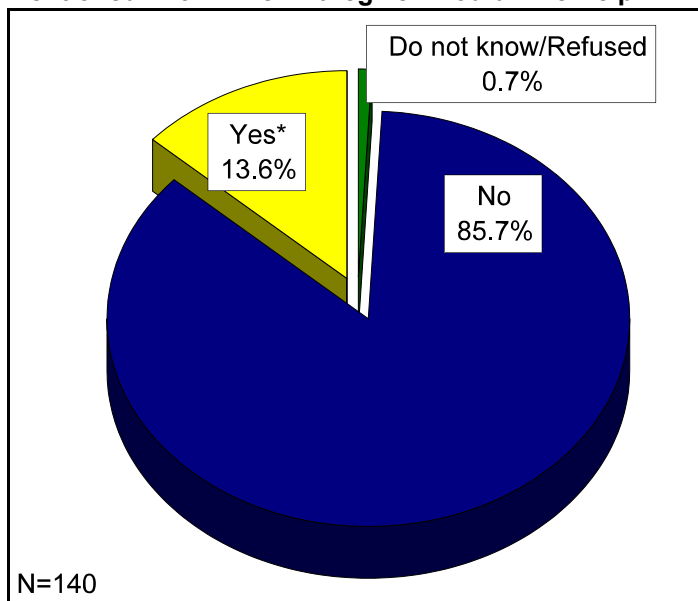
Table 16. Whether Caregiver Would Like Help Providing the Service

Services	Responses							
	Yes		No		Do not know/ Refused		Total	
	N	%	#	%	#	%	#	%*
Assist with household tasks (including pet care)	85	60.7	55	39.3	0	0.0	140	100.0
Assist with maintenance/repair (indoor/outdoor)	73	52.1	65	46.4	2	1.4	140	99.9
Administer personal care (bathing, bandaging, nail care, etc.)	71	50.7	68	48.6	1	0.7	140	100.0
Provide transportation, getting places	67	47.9	73	52.1	0	0.0	140	100.0
Provide companionship	65	46.4	74	52.9	1	0.7	140	100.0
Assist with meals/nutritional needs	59	42.1	80	57.1	1	0.7	140	99.9
Listen to them-someone for them to talk to	54	38.8	83	59.7	2	1.4	139	99.9
Help with worries, anxiety, and emotional needs (i.e. loss of independence, leaving home behind, fear of death, crying, anger, etc.)	53	37.9	85	60.7	2	1.4	140	100.0
Assist with errands/shopping	51	36.4	89	63.6	0	0.0	140	100.0
Contribute financially	50	35.7	88	62.9	2	1.4	140	100.0
Help with legal assistance	45	32.6	93	67.4	0	0.0	138	100.0
Get other family members involved in caregiving	40	28.6	98	70.0	2	1.4	140	100.0
Assist with medicines (administering, side effects, etc.)	37	26.4	103	73.6	0	0.0	140	100.0
Provide phone contact	33	23.6	106	75.7	1	0.7	140	100.0
Communicate with medical providers	30	21.6	109	78.4	0	0.0	139	100.0
Manage finances	24	17.1	116	82.9	0	0.0	140	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ Nearly 86 percent of caregivers said there are not other services not mentioned in Tables 11 and 12 with which they would like help (Figure 20, Appendix Table 19a).
- ▶ Comments from caregivers regarding other services with which they would like help can be found in Appendix Table 19b.

Figure 20. Whether There Are Other Services Not Mentioned With Which Caregiver Would Like Help



*See Appendix Table 19b for other services.

- ▶ Nearly 39 percent of caregivers indicated they have not experienced any of the financial difficulties listed in Table 17 as a result of caregiving. However, 30 percent of caregivers reported they have had time conflicts between working and caregiving (31.3 percent) and taken off work early or arrived to work late because of caregiving (30.6 percent) (Table 17).

Table 17. Financial Difficulties Caregiver Experiences Because of Caregiving

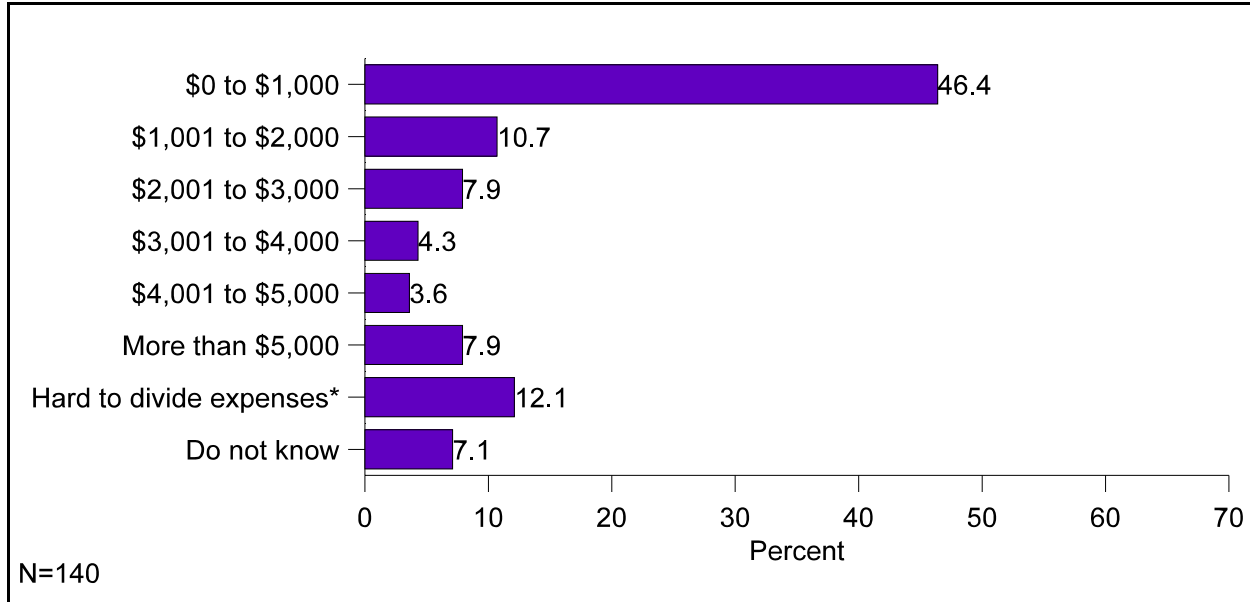
Financial Difficulties	Respondents (N=144)	
	#	%*
Had time conflicts between working and caregiving	45	31.3
Taken off work early or arrived to work late because you provided care	44	30.6
Used your vacation time to provide care	34	23.6
Reduced your official working hours	18	12.5
Changed locations to accommodate care recipients needs (handicap access)	16	11.1
Retired early	16	11.1
Lost some of your employment fringe benefits	14	9.7
Stopped working	12	8.3
Taken a leave of absence to provide care	11	7.6
Taken a less demanding job	7	4.9
Changed from full-time to part-time work	7	4.9
Sold a home to move in with care recipient	6	4.2
Lost a promotion	2	1.4
None of the above	56	38.9
Other:	6	4.2
<i>I got sick so I quit and stayed home took care of him</i>	1	
<i>Had to rent out farm land</i>	1	
<i>Had to sell farm as care recipient is not able to farm</i>	1	
<i>Was a farmer's wife so never worked outside the home</i>	1	
<i>I have arranged work sch to help neighbor</i>	1	
<i>No response</i>	1	

*Percents do not add to 100.0 due to multiple responses; N=144.

Demographics

- ▶ Approximately 46 percent of caregivers reported they have spent an average of \$1,000 or less within the last year caring for the care recipient (Figure 21, Appendix Table 20).

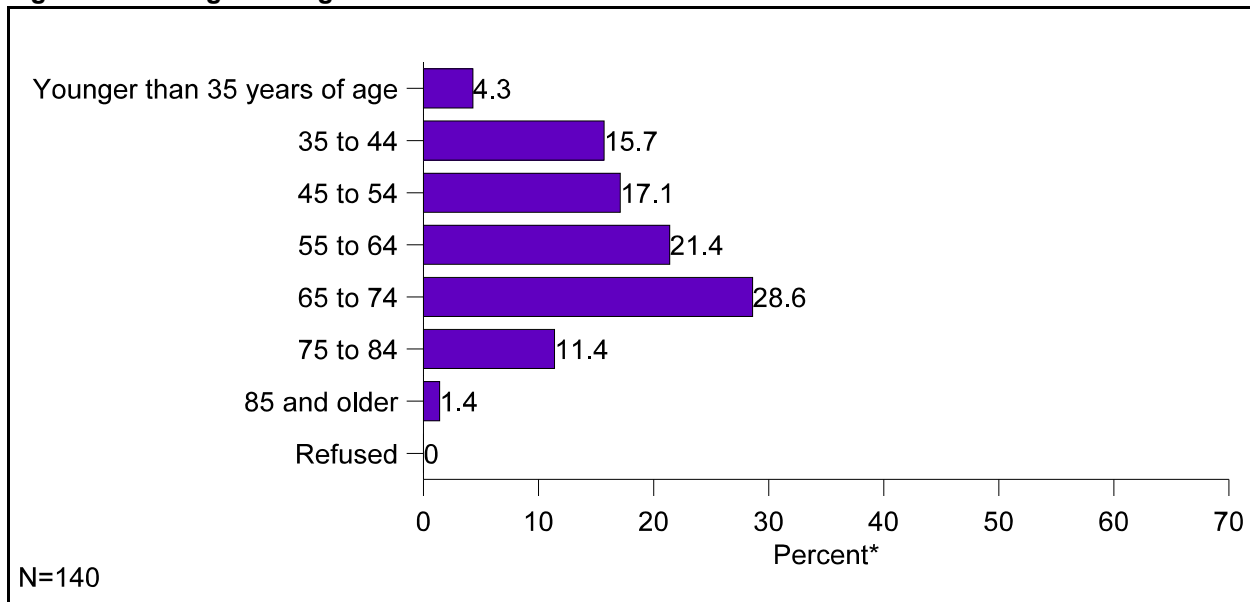
Figure 21. Average Money Spent Within the Last Year Caring For Care Recipient



*Full response category states: "The care recipient lives with me - it's difficult to separate expenses."

- ▶ More than 40 percent of caregivers are age 65 or older. Twenty percent of caregivers are under the age of 45 (Figure 22, Appendix Table 21).

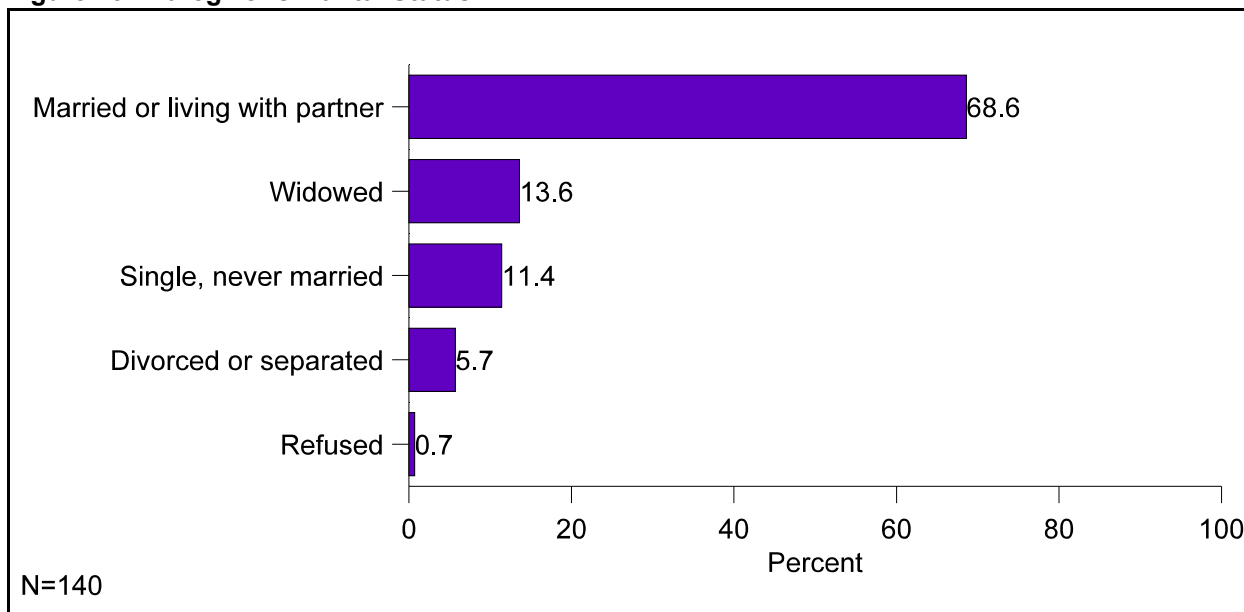
Figure 22. Caregiver's Age



*Percents do not always add to 100.0 due to rounding.

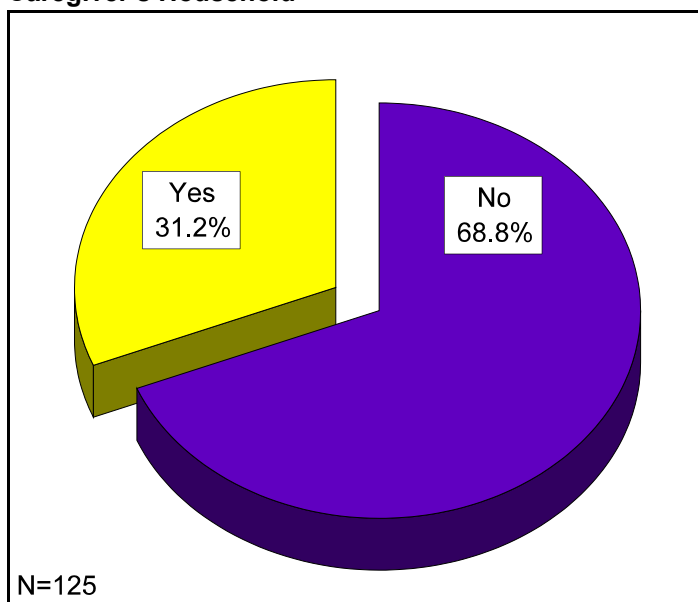
- ▶ Nearly 69 percent of caregivers are married or living with a partner (Figure 23, Appendix Table 22).

Figure 23. Caregiver's Marital Status



- ▶ Almost one-third of caregivers have children residing in their household (Figure 24, Appendix Table 23).

Figure 24. Whether There Are Children That Reside in Caregiver's Household



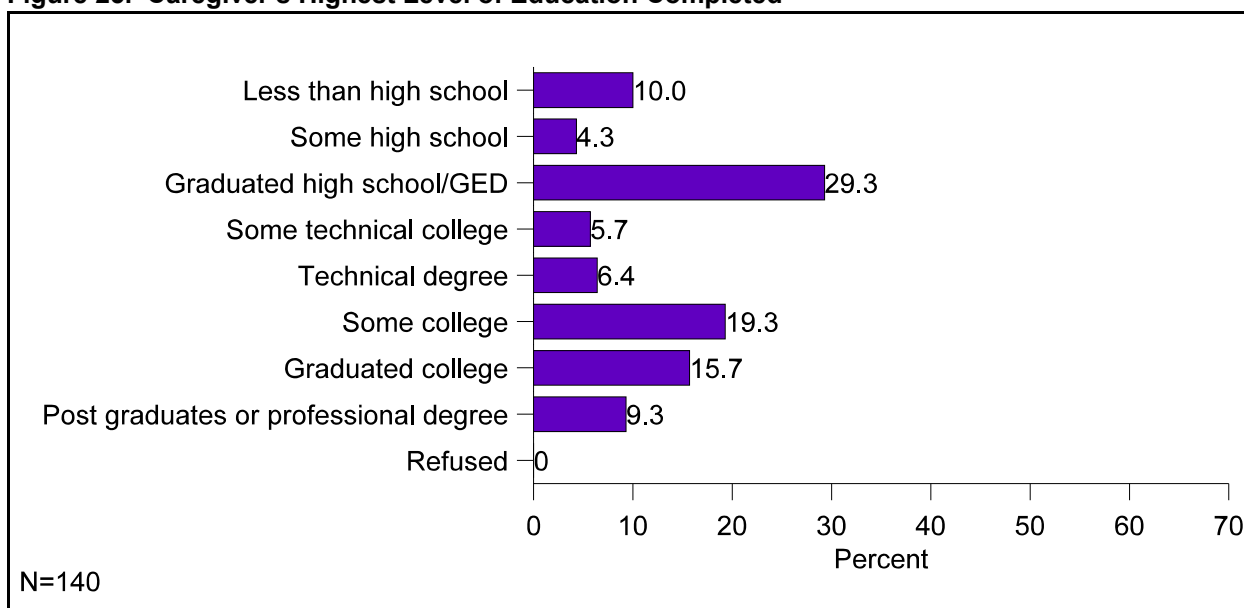
- Of those caregiver's who do have children residing within their household, the number of children they have by age can be found in Table 18 (below).

Table 18. Age of Children That Reside in Caregiver's Household

Age of Children	Number of Respondents with Children by Number of Children									
	Total Number of Respondents with Children		No children		1 child		2 children		3 children	
	#	%	#	%	#	%	#	%	#	%
0 to 4 years old	125	100.0	118	94.4	5	4.0	2	1.6	0	0.0
5 to 9 years old	125	100.0	118	94.4	5	4.0	1	0.8	1	0.8
10 to 14 years old	125	100.0	107	85.6	13	10.4	4	3.2	1	0.8
15 to 18 years old	125	100.0	114	91.2	10	8.0	1	0.8	0	0.0
18 years or older	125	100.0	110	88.0	10	8.0	5	4.0	0	0.0

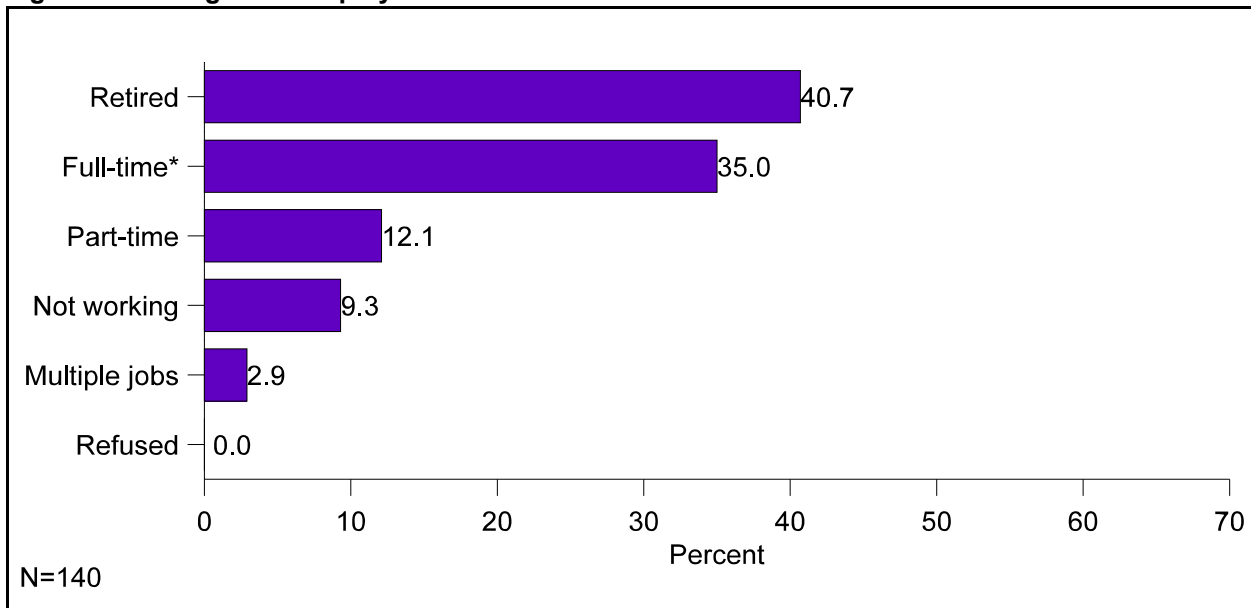
- Approximately 29 percent of caregivers indicated the highest level of education they have reached is at least a high school diploma or GED. Thirty-five percent of caregivers have had some college or had graduated college (Figure 25, Appendix Table 24).

Figure 25. Caregiver's Highest Level of Education Completed



- ▶ Nearly 41 percent of caregivers are retired. Thirty-five percent of caregivers work full-time (Figure 26, Appendix Table 25).

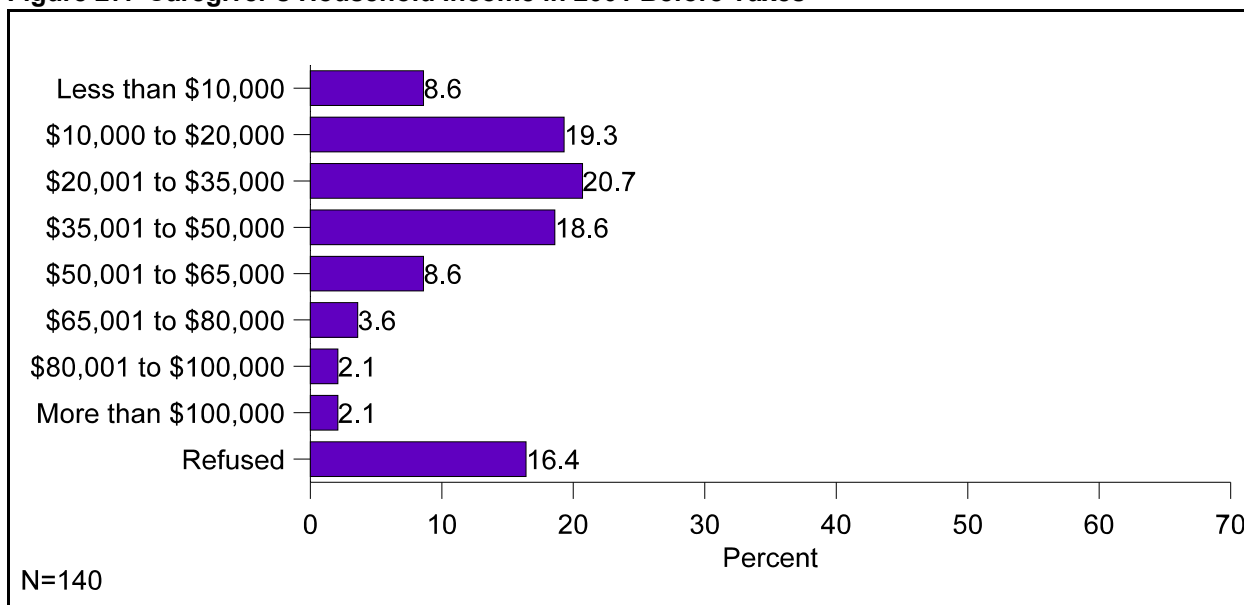
Figure 26. Caregiver's Employment Status



*Full response category states: "Full-time employment (35 hours/week or more)."

- ▶ More than 20 percent of caregivers had a household income in 2001 before taxes of \$20,001 to \$35,000. Nearly 28 percent of caregivers had a household income in 2001 before taxes of \$20,000 or less (Figure 27, Appendix Table 26).
- ▶ According to the 2000 Census, the median household income in North Dakota was \$34,604 (Source: US Census Bureau, 2000 Census, SF3 Table P53).

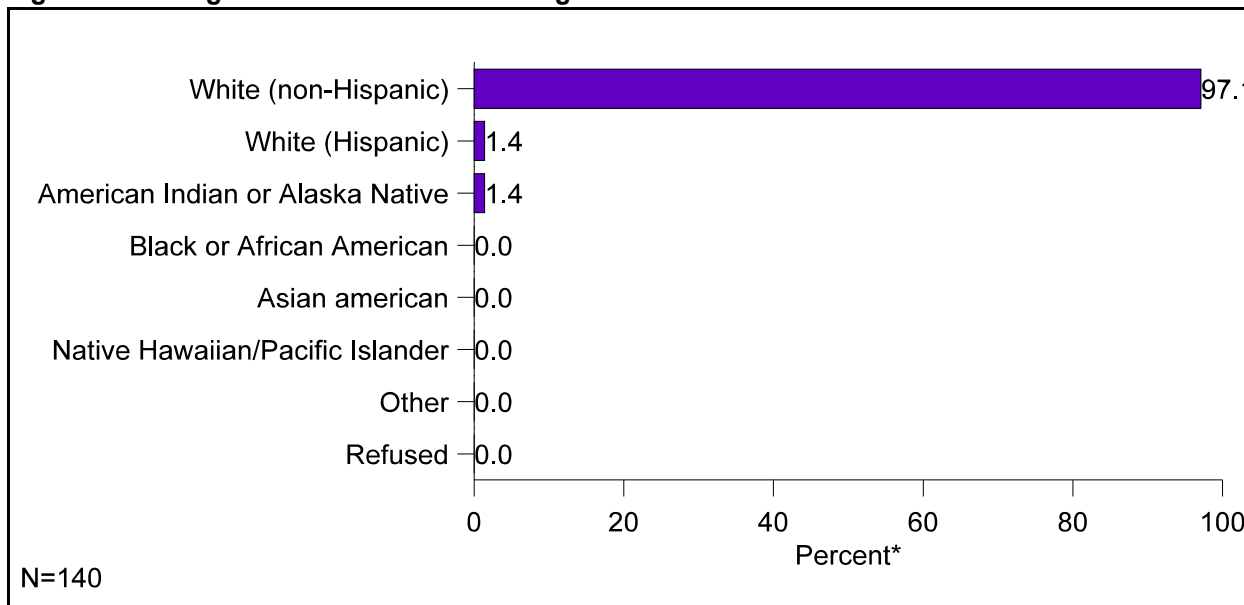
Figure 27. Caregiver's Household Income in 2001 Before Taxes*



*Including money from jobs, social security, retirement income, public assistance, etc.

- ▶ The majority of caregivers are white (non-Hispanic) (97.1 percent) (Figure 28, Appendix Table 27).

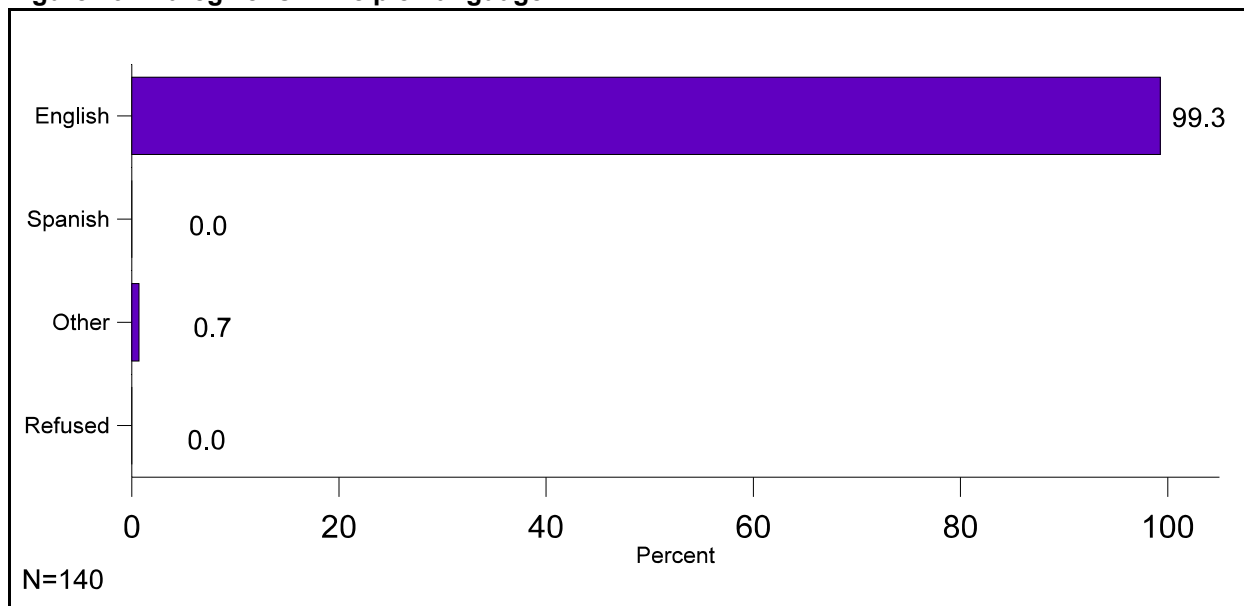
Figure 28. Caregiver's Race or Ethnic Background



*Percents do not always add to 100.0 due to rounding.

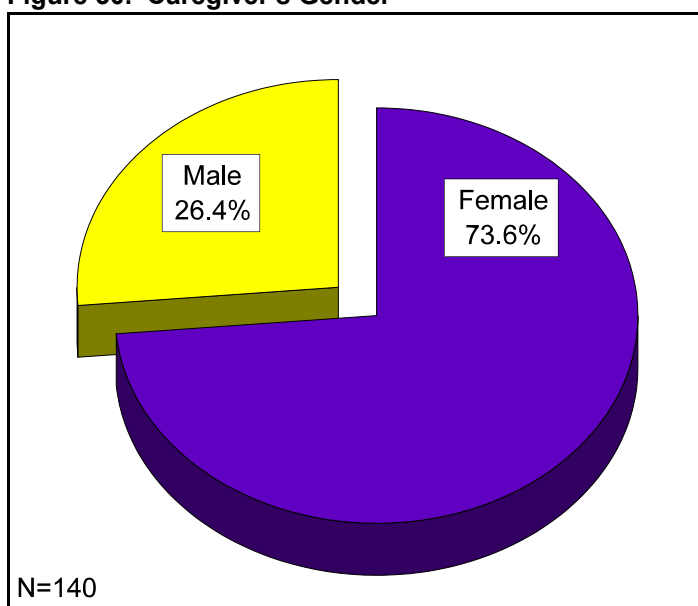
- ▶ The majority of caregivers indicated their principle language is English (99.3 percent) (Figure 29, Appendix Table 28).

Figure 29. Caregiver's Principle Language



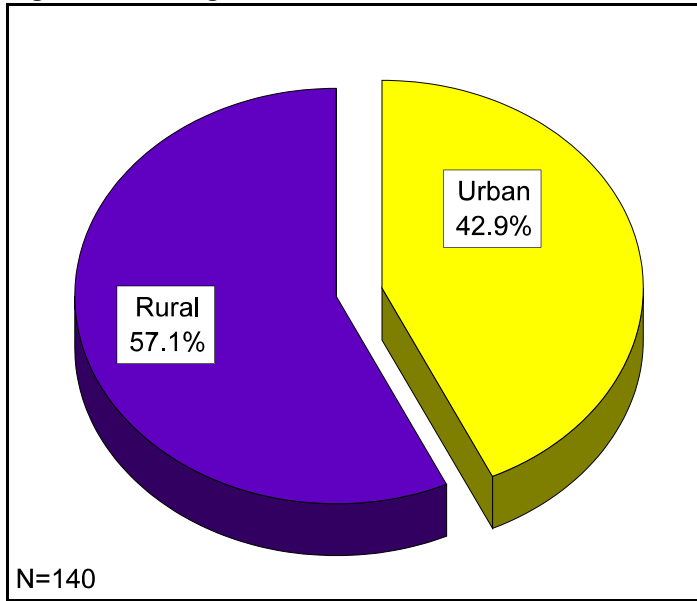
- ▶ Nearly three-fourths of caregivers are female (Figure 30, Appendix Table 29).

Figure 30. Caregiver's Gender



- ▶ Approximately 57 percent of caregivers indicated their place of residence is rural (Figure 31, Appendix Table 30).

Figure 31. Caregiver's Place of Residence



APPENDIX TABLES

Appendix Table 1. Relationship of Care Recipient to Caregiver

Care Recipient	Respondents (N=144)	
	#	%*
Mother/Mother-in-law	66	45.8
Spouse	36	25.0
Father/Father-in-law	21	14.6
Friend	14	9.7
Relative	14	9.7
Currently does not provide care, but has done so within the last year	2	1.4
Adult child (60 or older)	0	0.0
Sibling/Sibling-in-law	0	0.0
<i>Other</i>	3	2.1
<i>Son age 51 who is developmentally disabled</i>	1	
<i>North Dakota Disabled Association</i>	1	
<i>No</i>	1	

*Percents do not add to 100 due to multiple responses; N=144.

Appendix Table 2. Reasons Care Recipient Needs Services

Reasons	Respondents (N=144)	
	#	%*
The aging process	92	63.9
Physical disabilities (arthritis, stroke, etc.)	77	53.5
Cognitive impairment (e.g., Alzheimer's/dementia)	31	21.5
Mental illness (depression, panic/anxiety disorder, schizophrenia)	8	5.6
End of life issues (e.g., Hospice)	8	5.6
Head injury	3	2.1
Developmental disabilities/mental retardation	3	2.1
Substance abuse issues	0	0.0
Other:	19	13.2
<i>Blind</i>	3	
<i>Dialysis</i>	2	
<i>Parkinson</i>	1	
<i>Aging difficulties after an accident</i>	1	
<i>Has seizures/learning disabilities</i>	1	
<i>No</i>	1	
<i>Bad eyesight and poor hearing, loss of balance</i>	1	
<i>Diabetic, heart problems</i>	1	
<i>COPD</i>	1	
<i>Was in hospital for five months and needs much care</i>	1	
<i>Emphysema</i>	1	
<i>Lung problems, has oxygen tank</i>	1	
<i>Bad arm because it was broken</i>	1	
<i>Stroke and open heart surgery</i>	1	
<i>Had lung cancer surgery</i>	1	
<i>Congestive heart failure, diabetes, kidney failure, rheumatoid arthritis and glaucoma</i>	1	

*Percents do not add to 100.0 due to multiple responses; N=144.

Appendix Table 3. Whether Caregiver Receives Monetary Compensation For Caregiving Services

Response	Respondents	
	#	%
Yes	31	21.8
No	111	78.2
Do not know/Refused	0	0.0
Total	142	100.0

Appendix Table 4. Whether Caregiving is Done in Caregiver's Home

Response	Respondents	
	#	%
Yes	69	48.6
No	73	51.4
Do not know/Refused	0	0.0
Total	142	100.0

Appendix Table 5. Amount of Care Required For a Care Recipient Living in Caregiver's Home

Amount of Care Required	Respondents	
	#	%
Around the clock-care recipient cannot be left alone	28	40.6
Around the clock-care recipient can be left alone for a few hours	22	31.9
Around the clock-care recipient can be left alone for most of the day	18	26.1
Do not know/Refused	1	1.4
Total	69	100.0

Appendix Table 6. Location Where Caregiving is Done if Not Done in Caregiver's Home

Response	Respondents (N=144)	
	#	%*
Care recipient's home/apartment	60	41.7
An assisted living facility	14	9.7
An Independent living facility	4	2.8
No-care recipient lives with me	56	38.9
Other	9	6.3
<i>Nursing home</i>	2	
<i>Day care center</i>	1	
<i>Nursing care day care only</i>	1	
<i>Lived in assisted living from April 2001-December 2001, since has been in nursing home</i>	1	
<i>Regular nursing home for the past 18 months, in my home for 1 year before that</i>	1	
<i>In an Alzheimer's unit in a nursing home</i>	1	
<i>Nursing</i>	1	
<i>One parent is in nursing home</i>	1	

*Percents do not add to 100.0 due to multiple responses; N=144.

Appendix Table 7. Distance Caregiver is From Care Recipient if Not Cared For in Caregiver's Home

Distance	Respondents	
	#	%
Less than 20 minutes away	70	81.4
20 and 59 minutes away	7	8.1
One to two hours away	5	5.8
More than two hours away	3	3.5
Do not know/Refused	1	1.2
Total	86	100.0

Appendix Table 8. Average Hours Spent Caregiving Per Week if Care Recipient is Not Cared For in Caregiver's Home

Average Hours	Respondents	
	#	%*
0 to 5 hours/week	23	26.7
6 to 10 hours/week	23	26.7
11 to 15 hours/week	7	8.1
16 to 20 hours/week	9	10.5
More than 20 hours/week	24	27.9
Do not know/Refused	0	0.0
Total	86	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 9. Length of Time Spent Caregiving

Length of Time	Respondents	
	#	%
Less than 1 year	26	18.3
1 year to 3 years	56	39.4
4 years to 6 years	39	27.5
7 years to 9 years	8	5.6
10 years or more	13	9.2
Total	142	100.0

Note: Lengths of time past 1 year provided by respondent in terms of half years have been rounded up to the nearest whole year; lengths of time provided as a range have been coded as the upper value of the range.

Appendix Table 10a. Whether Caregiver Experiences Other Caregiving Difficulties

Response	Respondents	
	#	%
Yes*	35	24.8
No	105	74.5
Refused	1	0.7
Total	141	100.0

*Other caregiving difficulties listed in Appendix Table 10b.

Appendix Table 10b. Other Caregiving Difficulties Experienced by Caregiver

Response	#
A lot of emotions-because of seeing the changes and how it effects emotionally her losing abilities and zest for life	1
Adult day services or short term care	1
Dealing with someone with mental illness was difficult because of not knowing how to deal with it. Too much money for assistance	1
Effects on other family members-young children. Prostate trouble-bleeding makes it difficult to answer their questions	1
Forgetfulness, repeating things	1
Getting him to his doctor appointments and convincing him that he needs to go	1
Getting in touch with health care professionals..indicate to patient but not family members...call to track down	1
Hard to parent one's own parents	1
Her biggest complaint was that she couldn't do things for herself	1
Hospice did some of the caregiving. She would come over in the evenings if we wanted to go out and eat	1
How do you handle phone calls at work because of relative's needs	1
I couldn't help to clear him up with allergy to soap used for dialysis	1
I need help with aging process, when parent won't cooperate	1
I was caring for a grandchild at the same time-the last 3 years	1
I wish there would of been programs so my mom could of lived in her house longer, such as live ins	1
I would of liked someone to come in and do adult daycare services; also improvement on home health regulations	1
Isolation-can't take recipient to things	1

Appendix Table 10b. Other Caregiving Difficulties Experienced by Caregiver (continued)

Response	#
Just trying to do this and that and then things not working-stress	1
Lack of help	1
Lack of our own families time	1
Lining up household care and someone to stay with her at night	1
Medical concerns are harder for us	1
Patient was difficult to please for meals	1
People criticize my efforts	1
Personal care for him	1
Reliable help is difficult to find and keep	1
Sometimes the care is so [total] inconsistent to feeding, tremendous clothes washing, bathing care, time consuming	1
The biggest was that the homes didn't take good care of them	1
The forgetfulness gets frustrating sometimes for both of us	1
Transportation is difficult for her	1
Worried about her falling when getting into the car when she became frail	1
Worry would be one....the large amount of doctors appointments, drug stores, drug needs, frustration without assistive tech items	1
Mental health is affected	1

Appendix Table 11a. Whether Caregiver Experiences Other Concerns Associated With Caregiving

Response	Respondents	
	#	%
Yes*	16	11.3
No	125	88.7
Total	141	100.0

*Other concerns listed in Appendix Table 11b.

Appendix Table 11b. Other Concerns Associated With Caregiving

Response	#
Financial aide frustrating	1
How do I get other family members involved, and they do not really care	1
I am concerned due to income I am unable to receive help	1
I am concerned with the burial for my son, that we be buried together	1
I can't always identify the problem, when I am not with her all the time	1
If the care is long term I am concerned as to how to get a break	1
It is important to have long term nursing home insurance for the future	1
It was a 24 hour job, you couldn't get any rest because even when he was sleeping you never knew when he might get up	1
Lack of sleep, I feel sorry for them	1
My main concern was at night when I slept with one eye open with concern for if she would need help	1
No one to ask for help while going on vacation for 2 weeks, is an only child	1
So many elderly in our community and wish they could connect, do something fun, activity of some kind	1
The difficulties between my husband and myself-he couldn't understand it taking 14 hour care some days and some people thought you could get help whenever but not true	1
The families expect more that I am allowed to do as a caregiver	1
The government program, the idea is good but make it so complicated that the older person cannot understand what's needed. Put program's in clearer language, not so many gray areas	1

Appendix Table 12a. Whether There Are Other Informal Caregivers Who Provide Care to Care Recipient

Response	Respondents	
	#	%
Yes*	85	60.3
No**	55	39.0
Don't know/refused	1	0.7
Total	141	100.0

*Other informal caregivers listed in Appendix Table 12b.

**Reasons why other informal caregivers did not provide care listed in Appendix Table 12c.

Appendix Table 12b. Other Informal Caregivers Who Provide Care to Care Recipient

Response	#
Sister	9
Son	5
Brothers	3
Daughter	3
Husband	3
Children	3
Family and neighbors help out some	1
CNA's	1
Other siblings help out	1
A friend will come in when I go shopping and sometimes my son comes	1
A girl comes in about once a week...if something comes up I try to get her	1
A neighbor checks on her everyday	1
A nurse, and one friend occasionally	1
A renter, and various other neighbors visit and ask if they can get groceries or take him for a ride. One neighbor gives him haircuts, etc.	1
A stepson	1
Adult day care	1
All the family and other good friends	1
Another relative also assisted with care	1
At present, the whole family is helping out as she has assisted living at present	1

Appendix Table 12b. Other Informal Caregivers Who Provide Care to Care Recipient (continued)

Response	#
Brother in law	1
[name omitted to protect privacy], neighbor and brothers and sisters	1
Children are able to take rec out at times	1
From family when I need to get out	1
Grandchildren, sister	1
Granddaughter, and friend [name omitted to protect privacy]	1
His son and grandson	1
Home health and my sister and some of my brothers	1
Home health occasionally and a daughter helps	1
Husband and daughter	1
Husband, sister in law	1
Husband and kids help	1
I work caring for him for 2 weeks at a time and someone else works the other 2 weeks	1
Is temporarily in a home	1
It was a distant cousin who was a good friend and neighbor	1
Ladies to watch her when are out of town	1
Meals on wheels after surgery home health nurse	1
Most have another caregiver during part of the day	1
Mother came and gave respite care	1
Moved to a nursing home in January	1
My husband and two children help out	1
My mother who has him 24 hrs. a day	1
Neighbor comes over to assist sometimes. It really helps.	1
Only in times of illness	1
Other townspeople all pitch in to help this woman remain a part of our community	1
Our daughter and our son	1
Physical therapy and home health care aide bathes her	1
Relatives help out	1

Appendix Table 12b. Other Informal Caregivers Who Provide Care to Care Recipient (continued)

Response	#
Relatives of recipient	1
Sister and sister-in-law and brothers	1
The nursing home after his stroke	1
We have had a home health nurse	1
Two other siblings help out	1
Was in and out of hospital	1
Wife helps sometimes	1
She is in a nursing home now, son from Rapid City comes so we can leave town	1
Senior companion program	1
Also my step-father	1
Daughter and grandsons help out	1
Daughter has hired someone to clean our house	1
Entire family-mother, grandmother, brothers and sisters, aunts and uncles	1
Friend, has no family members	1

Appendix Table 12c. Reasons Why Other Informal Caregivers Do Not Provide Care to Care Recipient

Response	Respondents (N=144)	
	#	%*
Others live farther away	86	59.7
Others have full-time jobs	77	53.5
Others have less flexible daily schedules	53	36.8
Others are unwilling or "just can't"	53	36.8
Others have young dependents living with them	38	26.4
There are no other immediate family members	29	20.1
Recipient doesn't want care from others	21	14.6
Others are too inexperienced	19	13.2
Others are unaware of needed care (have not been informed-have not been asked to help)	17	11.8
Does not apply to my situation	17	11.8
Others are also in need of care	15	10.4
Others are embarrassed/uncomfortable fulfilling intimate needs (bathing, toileting, etc.)	14	9.7
Others do not get along with care recipient	10	6.9
Other reasons	1	0.7
<i>I'm the only girl, I have brothers and it is harder for them to face the issues of mother needing the help</i>	1	

*Percents do not add to 100.0 due to multiple responses; N=144.

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient

Other Reasons by Type of Service	#
Dietician Services	
Didn't feel we needed it anymore	1
Foods suggested were not available in our small community and cost was prohibitive	1
For now she's in assisted living	1
Mother provides meals at home	1
Not interested	1
Home delivered meals (Meals on wheels, community volunteering, or church)	
Because it's not available on a one day a week basis, you have to have it five days a week	1
Can't afford it-voluntary contributions solicited	1
Friend is in assisted living	1
I have not had the opportunity to have this service	1
It is a long drive 22 miles away	1
She was deaf, couldn't hear them when they came, so it was just more convenient to do it themselves	1
Tried it and didn't like it	1
Congregate meal settings (senior centers, restaurants, etc.)	
Difficult to get her around	2
Could not go because of no transportation	1
Difficult to get there	1
Difficult to get to and she didn't care for that	1
Due to blindness in recent years, it's harder to get to places	1
Due to diabetic diet	1
Feels uncomfortable being she's a widow	1
Hard for her to get around	1
Haven't checked into it	1
In nursing home	1
It's difficult to get her there physically. Also, because of lack transportation	1
It's more difficult for us to get there now	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
Located too far away	1
Never been informed as to how to use this service	1
Physically impaired	1
They do not have transportation available	1
Too hard to get to town for a meals	1
Too uncomfortable around other people	1
Was unable to leave home to use it	1
Wasn't able to get there	1
With bladder and bowel problems, it was difficult to plan	1
Adult day centers	
Recipient is too weak	1
Worked night shift so wasn't needed	1
Outreach programs (i.e. senior companions)	
Because no woman is providing this service only a man	1
Visiting nurse	
Cost is too expensive for me	1
Does not qualify for now	1
In nursing home right now, but hoping to return	1
It would have to be under a doctor's orders	1
Limited reimbursement of insurance carriers	1
Not necessary	1
She is actually a little better right now with her bi-polar and is in a stage where it isn't needed	1
Wouldn't admit to needing the service	1
Parish nurse	
Wasn't available at the time I needed this	1
Wouldn't admit needing help	1
Homemaker services/home health aides	
Too expensive for me	2

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
Because they're expensive	2
Because of insurance sets limits	1
Don't know enough about it to know if we qualify	1
Doctor needs to order one for care recipient	1
Family took care of it	1
Respondent was an aide	1
There is a limited time with medicare. 150 miles round trip and that costs money	1
They took us off of it because we went out to church and to get her hair fixed and bingo a few times. We were told she was not to be out in order to get services.	1
We just do it ourselves	1
Escort/transportation services	
Too expensive	2
Care recipient can't get out, arthritis is too bad	1
Care recipient can't walk, too far to use the transportation	1
Caregiver wished to do this service	1
Daughter is providing this service	1
Hard for her to use it	1
She has to pay to use it	1
The senior bus is difficult to get on and off	1
Because we are still able to drive	1
Shopping assistance	
Can't use because 20 miles from town	1
Have to get recipient to Edgeley	1
This would be delivery from stores-they don't know enough about this service	1
Unable to afford services	1
We have just been doing this service ourselves	1
Pet service (grooming, vet needs, etc.)	
We have traveling vet but our dogs are too big to use this service	1

Appendix Table 14. Reasons Why Services Are Not Good if Services Available to Care Recipient Are Rated “One” or “Two”

Reasons by Type of Service	#
Dietician Services	
I already knew been diabetic for 20 years	1
Just basic stuff	1
Mom liked foods that they wouldn't provide	1
She didn't like the foods	1
The food isn't good, but the service is o.k.	1
The food needs to be tasteful, colorful, and interesting and there is a lack	1
We just couldn't get together	1
Home delivered meals (Meals on wheels, community volunteering, or church)	
Food was bad	1
She didn't care for it	1
She didn't like it	1
Congregate meal settings (senior centers, restaurants, etc.)	
No comment	1
She didn't care for it	1
Tried once and did not care for this	1
Wasn't much of a program	1
Visiting nurse	
Delta service-charge [is] too much...[there] has been disputes	1
Mom feels she doesn't need their assistance	1
The individual itself-the nurse wouldn't show up half the time....breezed in and breezed out	1
Homemaker services/home health aides	
They did not do what they were asked to do, didn't understand her illness	1
Escort or transportation services	
Because we had to wait a long time and once it was for 2 hours behind Penny's	1

Appendix Table 15a. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Care Recipient

Response	Respondents	
	#	%
Yes*	27	19.3
No	108	77.1
Don't know/refused	5	3.6
Total	140	100.0

*Other services listed in Appendix Table 15b.

Appendix Table 15b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Care Recipient

Response	#
Day care services for elderly	1
A transportation system, where they would help the person get into the vehicle	1
Ombudsman (representative for seniors)	1
Cell phone service (Her father is rural and no signal towers are located nearby)	1
Companionship program	1
Home health care should be available, but this woman is too crippled up to get to a doctor	1
I would like a big brother program to take my son to movies, if trustworthy	1
I would like short term care for a weekend	1
I would like to see a traveling eye doctor, eyeglass wear, and hearing specialist	1
I would like to see more activities during the day for the elderly	1
I would like meals on wheels on weekends and holidays	1
If there could be home foot care so she wouldn't have to be taken out somewhere...that would be great...someone from community to help with housework	1
It would be nice to have a beautician do hair, then they would feel good about themselves	1
Laundry service would be nice	1
Lawn mowing service, snow shoveling, house repair and maintenance	1
Limited financial help, hard to budget with that to be helpful with anything additional; respite care would be wonderful, too much to hope	1
Meals, home health aide, visiting nurse, senior companion program	1
More activities such as a movie night, the library or social time to get together, to a beautician	1
More frequent home health aide services	1

Appendix Table 15b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Care Recipient (Continued)

Response	#
More organizations where people come to visit	1
Mr. Repairmen available	1
Respite care	1
Taking away drivers license when it should be taken—it's hard for the family to do that; the doctors should report this	1
They owned a little too much land for services yet the services were unaffordable such as a van and the sp. foods	1
I would need someone to coordinate appointments	1
I would like to find someone who could daily check in with mother, so we can go on vacation. We would qualify.	1
People just to come and take her out for coffee	1

Appendix Table 16. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver

Reasons by Type of Service	#
Information about available services	
As a family, we just got along with everything the way we were	1
Don't know what else she needs	1
Haven't needed this service yet	1
I didn't research this so I don't know	1
I work in this area and am very familiar with this	1
Lack of trained personnel to go around for all the people needing it	1
Not apply right now	1
Too expensive	1
We're independent	1
Assistance with accessing available services	
Can't find any information	1
Didn't qualify	1
Does not apply to situation now	1
Don't know where to get them	1
I didn't know about it originally and had to find out about it on my own. There should be more publicity.	1
I don't know if this service is available	1
Not available to us	1
Individual caregiver counseling services	
Do not know if this was available	1
Long distance, miles	1
Not apply now	1
Not sure if it's available	1
The distance is too far for me	1
Caregiver training or education	
Just don't know if it's available	1

Appendix Table 16. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver (Continued)

Reason by Type of Service	#
Our daughter is a home health care taker and could help us and son helped whenever needed	1
Unable to go	1
Respite care (someone else provides short-term relief for you)	
As stated before, someone has to order this service and the care recipient needs constant care	1
Budget	1
Counted on other relatives and a parish group of teenagers earning their way on a group tour of Rome-earning money	1
Don't qualify for this service	1
Helped by taking care of minor son	1
I do not use this due to the distance	1
I don't think this is available yet	1
Not apply	1
Not available out in the country	1
We had family help	1
Caregiver support groups	
I would like to go, but it's difficult to get out and go	1
The hours are bad	1

Appendix Table 17. Reasons Why Services Are Not Good if Services Available to Caregiver Are Rated “One” or “Two”

Reasons Why Services Were Not Good	#
Information about available services	
Because I had to hunt for it, not easily accessible	1
It's hard to find information that's available, the right sources	1
Lack of knowing what was available and where to find it	1
Too rural	1
Assistance with accessing available services	
Not available out in the area 15 miles from a town	1
Staff was not in touch with patient's needs. Not able to help work out a solution	1
Individual caregiver counseling services	
Couldn't find it easily	1
Caregiver training or education	
I found out informally on my own	1
Respite care (someone else provides short-term relief for you)	0
Caregiver support groups	0

Appendix Table 18a. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver

Response	Respondents	
	#	%
Yes*	14	10.0
No	120	85.7
Don't know/refused	6	4.3
Total	140	100.0

*Other services listed in Appendix Table 18b.

Appendix Table 18b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver

Services	#
A general number or office for help for her eligibility, needed an easier process	1
A nutritionist and cooking would be nice sometimes	1
I would be interested in more services, but don't qualify for anything and it's all too expensive	1
I would like help for bathing and laundry	1
It would be helpful	1
List of names for respite care	1
Money	1
Needed more volunteers so he could get away	1
Needs someone to mow lawn	1
Nutritional service	1
Services that would include yard work, helping heavy duty stuff	1
Someone to come in every once in awhile so that I could have gone away-respite care	1
Telephone help line	1
Traveling doctor	1

Appendix Table 19a. Whether There Are Other Services Not Mentioned With Which Caregiver Would Like Help With

Response	Respondents	
	#	%
Yes*	19	13.6
No	120	85.7
Don't know/refused	1	0.7
Total	140	100.0

*Other services are listed in Appendix Table 19b.

Appendix Table 19b. Other Services Not Already Mentioned With Which Caregiver Would Like Help

Other Services	#
Daily services	1
Financial advisor help down the road	1
How to get on insurance until medicare kicks in	1
I would like a mentor person to assist with the process of what is needed and when it is needed. Cancer center should have there own transportation.	1
I would like help with yard work	1
I would like to see attorney's volunteer to give free legal advice	1
Income tax	1
Laundry services and someone to take her shopping (department store) once in awhile, wish I had access to a wheelchair	1
Make employers more aware that there are younger children and older people employees need to help	1
More information on any services	1
Should not be my responsibility to stop her from driving	1
Some one to mow the lawn and shovel snow, son is busy with the farm in the summer	1
Setting up home to become handicapped accessible. If he couldn't afford set up-how could it get done? He has lost both legs.	1
With the rent when he was in a nursing home for two months	1

Appendix Table 20. Average Money Spent Within the Last Year Caring For Care Recipient

Response	Respondents	
	#	%
0 to \$1,000	65	46.4
\$1,001 to \$2000	15	10.7
\$2,001 to \$3,000	11	7.9
\$3,001 to \$4,000	6	4.3
\$4,001 to \$5,000	5	3.6
More than \$5,000	11	7.9
The care recipient lives with me-it's difficult to separate expenses	17	12.1
I do not know	10	7.1
Total	140	100.0

Appendix Table 21. Caregiver's Age

Age	Respondents	
	#	%*
Younger than 35 years of age	6	4.3
35 to 44	22	15.7
45 to 54	24	17.1
55 to 64	30	21.4
65 to 74	40	28.6
75 to 84	16	11.4
85 and older	2	1.4
Refused	0	0.0
Total	140	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 22. Caregiver's Marital Status

Marital Status	Respondents	
	#	%
Married or living with partner	96	68.6
Widowed	19	13.6
Single, never married	16	11.4
Divorced or separated	8	5.7
Refused	1	0.7
Total	140	100.0

Appendix Table 23. Whether There Are Children That Reside in Caregiver's Household

Response	Respondents	
	#	%
Yes	39	31.2
No	86	68.8
Refused	0	0.0
Total	125	100.0

Appendix Table 24. Caregiver's Highest Level of Education Completed

Level of Education	Respondents	
	#	%
Less than high school	14	10.0
Some high school	6	4.3
Graduated high school/GED	41	29.3
Some technical college	8	5.7
Technical degree	9	6.4
Some college	27	19.3
Graduated college	22	15.7
Post graduates or professional degree	13	9.3
Refused	0	0.0
Total	140	100.0

Appendix Table 25. Caregiver's Employment Status

Employment Status	Respondents	
	#	%
Retired	57	40.7
Full-time employment (35 hours/week or more)	49	35.0
Part-time	17	12.1
Not working	13	9.3
Multiple jobs	4	2.9
Refused	0	0.0
Total	140	100.0

Appendix Table 26. Caregiver's Household Income in 2001 Before Taxes*

Household Income	Respondents	
	#	%
Less than \$10,000	12	8.6
\$10,000 to \$20,000	27	19.3
\$20,001 to \$35,000	29	20.7
\$35,001 to \$50,000	26	18.6
\$50,001 to \$65,000	12	8.6
\$65,001 to \$80,000	5	3.6
\$80,001 to \$100,000	3	2.1
More than \$100,000	3	2.1
Refused	23	16.4
Total	140	100.0

*Includes money from jobs, social security, retirement income, public assistance, etc.

Appendix Table 27. Caregiver's Race or Ethnic Background

Race or Ethnic Background	Respondents	
	#	%*
White (non-Hispanic)	136	97.1
White (Hispanic)	2	1.4
American Indian or Alaska Native	2	1.4
Black or African American	0	0.0
Asian American	0	0.0
Native Hawaiian or other Pacific Islander	0	0.0
Other	0	0.0
Refused	0	0.0
Total	140	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 28. Caregiver's Principle Language

Language	Respondents	
	#	%
English	139	99.3
Spanish	0	0.0
Other	1	0.7
Refused*	0	0.0
Total	140	100.0

*Respondent wrote "German" as other language.

Appendix Table 29. Caregiver's Gender

Gender	Respondents	
	#	%
Male	37	26.4
Female	103	73.6
Total	140	100.0

Appendix Table 30. Caregiver's Place of Residence

Residence	Respondents	
	#	%
Rural	80	57.1
Urban	60	42.9
Total	140	100.0

SURVEY INSTRUMENT

Script for Telephone Interviewers (Informal and Senior Caregiver's Study)

Hello, my name is _____ and I'm calling from the Center for Social Research at North Dakota State University. We are conducting a study, sponsored by the North Dakota Department of Human Services Aging Services Division, on caregivers in North Dakota. Do you have a few moments to answer some questions?

The purpose of the study is to develop a service delivery system that responds to the needs of North Dakota's caregivers. The survey is voluntary and you are free to quit at any time. The information you provide will be recorded without your name or any other identifying information.

If you have any questions about the study you may call Aging Services at (701) 328-8910. If you have any questions about the rights of human research subjects please contact the North Dakota State University IRB office at (701) 231-8908.

Let's begin with a discussion of relative caregivers.

*A **relative caregiver** is a grandparent who lives with a child and is the primary caregiver for that child, because of either a legal or informal relationship with the child.*

- A. Are you at least 60 years of age and caring for a child 18 years of age or younger?
__Yes (continue with Senior Caregiver Tool)
__No
- B. If no, do you know a relative, friend, or neighbor who is a senior caregiver?
__Yes (if yes, please list name, address, and phone number on sheet)
__No----If no, go on to ask about informal caregivers

Next let's talk about informal caregivers.

*An **informal caregiver** provides needed care on a long term basis to a someone who is most often a relative, friend, or neighbor. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group), or those who provide care as a career. Long-term care often involves assisting the person with personal hygiene, getting dressed, using the bathroom, or household tasks such as preparing meals. It does not include recovery from an injury after which the person no longer needs care.*

- B. Are you an informal caregiver (as defined above) of someone who is least 60 years of age?
__Yes (continue with Informal Caregiver Tool)
__No
- C. If you are not an informal caregiver, are you *receiving* informal care (as we defined) and at least 60 years of age?
__Yes (if yes, could you please tell me the name and phone number of your **primary caregiver** and skip to QD)
__No
- D. Do you know a relative, friend, or neighbor in your community who either gives or receives informal care?
__Yes (if yes, could you please tell me their name and phone number/address so we may contact them to add them to the registry)
__No

END: Thank you for taking the time to help us with this important survey. Goodnight.

Informal Caregiver Phone Tool
April, 2002

The purpose of the study is to develop a service delivery system that responds to the needs of North Dakota's caregivers. The survey will take about 25 minutes [can restart]. The survey is voluntary and you are free to quit at any time. The information you provide will be recorded without your name or any other identifying information.

If you have questions about the study, you may call Aging Services at 701-328-8910. If you have questions about the rights of human research subjects, you may call the NDSU Institutional Review Board at 701-231-8908.

An informal caregiver provides needed care on a long term basis to a care recipient, who is most often a relative, friend, or neighbor. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group), or those who provide care as a career. Long-term care often involves assisting the care receiver with personal hygiene, getting dressed, using the bathroom, or household tasks such as preparing meals. It does not include recovery from an injury after which the recipient no longer needs care. Currently we are interested only in those recipients of care who are at least 60 years of age.

Q1

What is your caregiver status? (read list - check all that apply)

- I provide care to my spouse
- I provide care to my mother/mother-in-law
- I provide care to my father/father-in-law
- I provide care to a friend
- I provide care to a relative
- I provide care to a sibling/sibling-in-law
- I provide care to my adult child (60 or older)
- I currently do not provide care, but have done so within the last year
- Other

Q2

Why does the care receiver need services? Is it because of...
(read list - check all that apply)

- The aging process
- Cognitive impairment (e.g., Alzheimer's/dementia)
- Developmental disabilities/mental retardation
- Mental illness (depression, panic/anxiety disorder, schizophrenia)
- Physical disabilities (arthritis, stroke, etc.)
- Head injury
- Substance abuse issues
- End of life issues (e.g., Hospice)
- Other

Q3

Do you receive monetary compensation for any of the caregiving services you provide?
(such as Qualified Service Providers or Guardian Services, where you are compensated because it would cost the state more for formal care)

- 1 Yes
- 2 No
- 3 [DNK/refused]

Q4

Is the caregiving done in your home because the care recipient lives with you?

- 1 Yes
- 2 No
- 3 [DNK/refused]

Q4a

How much care is required?

- 1 Around the clock, care recipient cannot be left alone
- 2 Around the clock, care recipient can be left alone for a few hours
- 3 Around the clock, care recipient can be left alone for most of the day
- 4 [DNK/refused]

If (Q4 > 1) Skp

Q4b

Is there caregiving done at another place, such as...

- the care recipient's home/apartment
- an assisted living facility
- an independent living facility
- other (where?)
- No - care recipient lives with me

If (ans = 5) skipto Q6

Q5

How far does the care recipient live from you?

- 1 Less than 20 minutes away
- 2 Between 20 and 59 minutes away
- 3 Between one and two hours away
- 4 More than two hours away
- 5 [DNK/refused]

Q5a

How many hours per week, on average, are you caregiving?

- 1 0 to 5 hours/week
- 2 6 to 10 hours/week
- 3 11 to 15 hours/week
- 4 16 to 20 hours/week
- 5 More than 20 hours/week
- 6 [DNK/refused]

Q6

How long have you been providing caregiving service to your care recipient?

(enter number, then months, or years)

Q7

Next, I will read you a list of caregiving difficulties you may have experienced when providing care. On a one to five scale, with one being "not at all serious" and five being "very serious", please tell me how serious the difficulty was.

- 1 Not at all serious
- 2
- 3
- 4
- 5 Very serious
- 6 [DNK/refused]

Q7a

Are there other caregiving difficulties you may have experienced when providing care that I haven't already mentioned?

- 1 Yes
- 2 No
- 3 [Refused]

Now I will read you a list of concerns that may have applied to you at some time during your caregiving. On a one to five scale, with one being "strongly disagree" and five being "strongly agree", please tell me how much you disagree or agree with each statement.

Q8a

It is difficult for me to accept support or assistance when caregiving because it is my duty to provide care. Do you...

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8b

It is difficult for me to find support or assistance when caregiving.
(I feel like I don't have help)

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8c

It is difficult for me to accept financial support or assistance when caregiving because it sometimes carries a negative stigma.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8d

It is difficult for me to accept help from others when caregiving because I'm being paid (e.g., Qualified Service Provider)

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8e

I'm providing caregiving services because people in my community will think ill of me if I don't.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8f

Since I have started caregiving services I've experienced a sense of isolation from others in my community.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8g

Since I have started caregiving services I've experienced a lack of understanding from others in my community.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q8h

Are there other concerns for you as a caregiver that I have not mentioned?

- 1 Yes
- 2 No

Q9

Are there other informal caregivers who are providing care to the recipient?

- 1 Yes
- 2 No
- 3 [DNK/refused]

Q10

If there are other people who are not providing care, why not?
(Check all that apply)

- There are no other immediate family members
- Others are also in need of care
- Others are embarrassed/uncomfortable fulfilling intimate needs (bathing)
- Others are too inexperienced
- Others live farther away
- Others have full-time jobs
- Others have less flexible daily schedules
- Others have young dependents living with them
- Others do not get along with care recipient
- Others are unaware of needed care (haven't been informed or asked to help)
- Others are unwilling or "just can't"
- Recipient doesn't want care from others
- Does not apply to my situation
- Other reason

Next I will read you a list of services. (Please answer Q11 through Q11f for each of the services listed below).

- Dietician services
- Home delivered meals (Meals on Wheels, community volunteering or church)
- Congregate meal settings (as Senior centers, restaurants, etc.)
- Adult day centers
- Outreach programs (i.e. senior companions)
- Visiting nurse
- Parish nurse
- Homemaker services/home health aides
- Escort/transportation services
- Shopping assistance
- Pet service (grooming, vet needs, etc.)

Q11

Is this service available to your care recipient?

- 1 Yes
- 2 No
- 3 [DNK]

If (ans > 1) skipto Q11e

Q11a

Are you using this service?

- 1 Yes
- 2 No

If (ans = 2) skipto q11d

Q11b

On a one to five scale, please rate the service.

- 1 Not good at all
- 2
- 3
- 4
- 5 Very good
- 6 [DNK/Refused]

Q11c

Why wasn't the service good?

If (Q11b > 2) Skp

Q11d

Why aren't you using the service?

- 1 Do not need it
- 2 Care recipient won't use it
- 3 Other
- 4 [DNK/refused]

If (Q11a = 1) skp

Q11e

Would you like it to be available to your care recipient?

- 1 Yes
- 2 No
- 3 [DNK/refused]

If (Q11 = 1) skp

Q11f

Are there other services I haven't already mentioned that you would like to have available to your care recipient?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Now I will read you another list of services. (Please answer Q12 through Q12f for each of the services listed below).

Information about available services

Assistance with accessing available services

Individual caregiver counseling services

Caregiver training or education

Respite care (someone else provides short-term relief for you)

Caregiver support groups

Q12

Is this service available to you as a care giver?

- 1 Yes
- 2 No
- 3 [DNK]

If (ans > 1) skipto Q12e

Q12a

Are you using this service?

- 1 Yes
- 2 No

If (ans = 2) skipto q12d

Q12b

On a one to five scale, please rate the service.

- 1 Not good at all
- 2
- 3
- 4
- 5 Very good
- 6 [DNK/Refused]

Q12c

Why wasn't the service good?

If (Q12b > 2) Skp

Q12d

Why aren't you using the service?

- 1 Do not need it
- 2 Care recipient won't use it
- 3 Other
- 4 [DNK/refused]

If (Q12a = 1) skp

Q12e

Would you like it to be available to you as a care giver?

- 1 Yes
 - 2 No
 - 3 [DNK/refused]
- If (Q12 = 1) skip

Q12f

Are there other services I haven't already mentioned that you would like to have available to you as a care giver?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Think about the services that you have provided or are now providing to your care recipient. (Please answer Q13 through Q13c for each of the services listed below).

Manage finances

Contribute financially

Administer personal care (bathing, bandaging, nail care, etc.)

Assist with household tasks (including pet care)

Assist with maintenance and repair (indoor and outdoor)

Assist with meals or nutritional needs

Assist with errands and shopping

Provide companionship

Provide phone contact

Help with worries/anxiety/emotional needs (loss of home/fear of death, crying)

Listen to them - someone for them to talk to

Provide transportation - getting places

Assist with medicines (administering/side effects, etc.)

Communicate with medical providers

Get other family members involved in caregiving

Help with legal assistance

Q13

Have you in the past or do you now...

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Q13a

How often have you provided this service?

- 1 Daily
- 2 Weekly
- 3 Monthly
- 4 On occasion
- 5 [Do not know/refused]

If (Q13 > 1) skip to Q13b

Q13b

Regardless of whether or not you have provided this service, would you have liked, or would you now like help providing the service?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

If (Q13 = 3) skip

Q13c

Are there other services I haven't already mentioned that you would have liked help with?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Q14

Please tell me what kinds of information/services would be valuable to you as a caregiver, now or in the future. [read list - check all that apply]

- Information about the care recipient's condition or disability
- Information on end of life issues
- Information about developments/changes in laws affecting your situation
- Info-line (central place to call & find out what kind of help is available)
- Someone to help you arrange for services, assess your situation
- Someone to talk to/counseling services/support group
- Respite care or adult day care
- Aftercare/grief counseling
- Hotline (for dealing with immediate emotional needs while preserving dignity)
- Help in understanding how to select a nursing home/other care facility
- Help in assessing the timing of placement in formal caregiving institutions
- Help in understanding how to pay for nursing homes/adult day care etc.
- Help in dealing with agencies (bureaucracies) to get services
- Financial support
- Tax break, stipend, government subsidy
- Other

Q15

Because of caregiving have you...
[read list - check all that apply]

- Changed locations to accommodate care recipients needs (handicap access)
- Sold a home to move in with care recipient
- Stopped working
- Retired early
- Taken a less demanding job
- Changed from full-time to part-time work
- Reduced your official working hours
- Lost some of your employment fringe benefits
- Had time conflicts between working and caregiving
- Used your vacation time to provide care
- Taken a leave of absence to provide care
- Lost a promotion
- Taken off work early or arrived to work late because you provided care
- Other
- None of the above

Q16

Within the last year, on average, how much money have you spent caring for your care recipient?

- 1 0 to \$1,000
- 2 \$1,001 to \$2,000
- 3 \$2,001 to \$3,000
- 4 \$3,001 to \$4,000
- 5 \$4,001 to \$5,000
- 6 More than \$5,000
- 7 [The care recipient lives with me - it's difficult to separate expenses]
- 8 [I do not know]

Q17

Would you mind telling me your age?

- 1 Younger than 35 years of age
- 2 35 to 44
- 3 45 to 54
- 4 55 to 64
- 5 65 to 74
- 6 75 to 84
- 7 85 or older
- 8 [Refused]

Q18

What is your marital status?

- 1 Married or living with partner
- 2 Single, never married
- 3 Divorced or separated
- 4 Widowed
- 5 [Refused]

Q19

Are there children that reside within your household?

- 1 Yes
- 2 No
- 3 [Refused]

If (ans > 1) skip to Q20

Q19a

How many children are between 0 and 4 years of age?

Q19b

How many children are between 5 and 9 years of age?

Q19c

How many children are between 10 and 14 years of age?

Q19d

How many children are between 15 and 18 years of age?

Q19e

How many children are 18 or older?

Q20

What is the highest level of education you have completed?

- 1 Less than high school
- 2 Some high school
- 3 Graduated high school/GED
- 4 Some technical college
- 5 Technical degree
- 6 Some college
- 7 Graduated college
- 8 Post graduate or professional degree
- 9 [Refused]

Q21

What is your employment status?

- 1 Full-time employment (35 hours/week or more)
- 2 Part-time
- 3 Multiple jobs
- 4 Retired
- 5 Not working
- 6 [Refused]

Q22

What was your annual household income in 2001 before taxes (including money from jobs, social security, retirement income, public assistance, etc.)

- 1 Less than \$10,000
- 2 \$10,000 to \$20,000
- 3 \$20,001 to \$35,000
- 4 \$35,001 to \$50,000
- 5 \$50,001 to \$65,000
- 6 \$65,001 to \$80,000
- 7 \$80,001 to \$100,000
- 8 More than \$100,000
- 9 [Refused]

Q23

What is your race or ethnic background?

- 1 White (non-Hispanic)
- 2 White (Hispanic)
- 3 Black or African American
- 4 Asian American
- 5 American Indian or Alaska Native
- 6 Native Hawaiian or other Pacific Islander
- 7 Other
- 8 [Refused]

Q24

What is your principle language?

- 1 English
- 2 Spanish
- 3 Other
- 4 [Refused]

Q25

The North Dakota Department of Human Services Aging Services Division is interested in establishing a registry of caregivers in North Dakota. Information gathered from the survey will assist policymakers in developing programs and educational materials to help meet the needs of caregivers such as yourself. If you are willing, please give us your name, address, and phone number so we may add you to the registry. That concludes our survey. Thank you for taking the time to help us with this important study. Good night.

Q26

Record gender based on voice.

- 1 Male
- 2 Female

Q27

Record county code from calling sheet.

- 1 Rural
- 2 Urban