

Caregiving: A National Profile and Assessment of Caregiver Services and Needs

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INTRODUCTION

The Project

During the summer and fall of 2005, Dr. Elena Andresen and her research team at the University of Florida (UF) undertook a project with the Rosalynn Carter Institute to analyze and understand better the role of caregivers in United States society. As part of a broad attempt by the National Quality Caregiving Coalition (NQCC) to understand better caregiving, the aforementioned project aimed to: 1) investigate the services that exist and those that are needed by caregivers at national and state levels; and 2) analyze caregiving prevalence nationally among target populations (populations targeted by age, race, or gender). From June through November 2005, the UF team worked with data from the Behavioral Risk Factor Surveillance System (BRFSS) and other sources to complete the aims of the project. The results of the project are presented in this report. For further information, please contact Dr. Elena Andresen at the University of Florida, College of Public Health and Health Professions (eandresen@phhp.ufl.edu).

The BRFSS

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest telephone survey and is used to track ongoing and developing health risks in the United States. The survey generates information about health risk behaviors, clinical preventive practices, and health care access and use. The BRFSS is a cross-sectional telephone survey conducted by state health departments with technical and methodological assistance provided by the Centers for Disease Control and Prevention (CDC). Some states have well-developed internal programs for collecting, cleaning, and analyzing their own BRFSS data, while others contract out the work. States conduct monthly telephone surveillance using a standardized questionnaire to determine the distribution of risk behaviors and health practices among adults 18 and over. The states forward the responses to the CDC, where, annually, the monthly data are aggregated for each state. The data are returned to the states and published on the BRFSS Web site. Information from the survey is publicly held and is used by researchers and practitioners alike in working to improve health nationwide. The core CDC-supported questions used nationally on the BRFSS include universal core questions that repeat annually, and core questions that are asked on a recurring basis or in a single year. In addition to the CDC-supported data, most states choose to add questions of particular relevance to their constituencies on an annual basis.

In 2000, two questions concerning caregiving of older adults (aged 60 and older) were added to the national BRFSS questionnaire. The 2000 caregiving questions attempted to determine a) the prevalence of informal caregiving in the US to adults aged 60 and older, and b) the resources that Americans turn to when arranging for short or long-term in-home care. By analyzing both the prevalence of caregiving (a) and the resources sought by family members arranging for care (b) by age, race and gender, it is possible to create a demographic sketch of a the typical American caregiver and to identify variations across states.

The Context of Caregiving

Informal caregivers in the United States benefit not only the care recipient but society as well. Each year, family caregivers provide an estimated \$257 billion/year in informal care

services (National Family Caregivers Association [NFCA], 2005). A majority of people with chronic and disabling diseases rely on informal caregivers, often family members, for the provision of care. According to the 2000 Behavioral Risk Factor Surveillance System (BRFSS), less than 13% of persons with disability (PWD) who reported needing care assistance were using paid caregivers.

As population trends in the US evolve, caregiving will likely become a more pressing issue. The number of persons 65 years and older is expected to climb from 35 million in 2000 to over 71 million in 2030 (CDC, 2003). This increase in the number of elderly will likely heighten the demand for informal caregivers, since chronic and disabling diseases are more common in the elderly. Other factors will also change the demand for informal caregivers. Persons with disabilities now have a longer lifespan and they often want to remain in their homes (Klingbeil et al., 2000). For the first time since the US military engagement in Vietnam, a significant number of wounded US soldiers are returning home as disabled men and women. Reimbursement issues are also important factors, as the services of paid caregivers are usually not reimbursed. With the expected rise in the number of persons with disability and the number of informal caregivers, the Nation's public health agenda increasingly needs to address the needs of persons with disability and the needs of their informal caregivers.

Part of the national public health objectives set forth in *Healthy People 2010* (CDC, 2002) includes health promotion and disease prevention in persons with disabilities (Focus Area 6: Disability and Secondary Conditions). *Healthy People 2010* calls for a reduction in the number of persons with disability in congregate care and emphasizes the importance of supporting people with disabilities by providing more personal assistance and support to caregivers. Further, *Healthy People 2010* appeals for improved public health surveillance and health promotion programs for people with disabilities and their caregivers.

There is a growing need for population-level surveillance data on caregivers. From a general public health perspective, there is currently very little information available about the impact of caregiving. Most of the focus in past research efforts has been on small non-representative samples of caregivers of persons with specific disorders or impairments, and very little is known about the national phenomena of caregiving in the United States. However, in April 2004, the National Alliance for Caregiving (NAC) and AARP (NAC/AARP) published a report titled *Caregiving in the US* (NAC, 2004). Unlike the vast majority of research previously conducted on caregiving, this report captured national, non-disease specific data on caregivers for adult care recipients (aged 18 or over). Though the sample size was relatively small (6,139), this survey provides geographically representative national-level data. This unique survey can be augmented with the findings of the BRFSS 2000 for a more complete picture of caregiving and gaps in services and data.

2005 North Carolina BRFSS Caregiving Data

In September 2004, the CDC and Association for Teachers of Preventive Medicine (ATPM) funded Dr. Andresen to investigate caregiving at a population level across varying age and disability domains in North Carolina. Through collaborative efforts with key stakeholders nationally, Dr. Andresen and her research team created a 10-question caregiver module that

was implemented as a state added question to the 2005 North Carolina BRFSS during the months of May-August. From the module, respondents were screened for caregivers. A total of 5,859 adults answered the module screener, and 895 completed the module as caregivers. Once identified, caregivers were asked if they would be willing to participate in a follow-back survey in the next few weeks. Those who agreed were called back and 367 participated in a 20-minute, in-depth follow-back survey. Both the BRFSS screening questions and the follow-back survey are provided in the Appendices.

The 2005 NC BRFSS follow-back survey relied heavily upon the findings of the 2004 NAC/AARP *Caregiving in the US* report. However, certain domains included in the follow-back survey, such as environmental factors affecting caregivers, were not included in the NAC/AARP study and were taken from other tested sources. Questions regarding the influence of environmental factors on caregiving were adapted from The Craig Hospital Inventory of Environmental Factors (CHIEF) and are explained in further detail in that section of this report (Whiteneck et al., 2003).

Data from the follow-back interviews provide information on the prevalence of caregiving, characteristics of caregiving (duration, frequency, type and burden), as well as environmental factors, use of services, coping mechanisms, and injury associated with caregiving. Data from the follow-back interviews are linked back to the caregiving module, as well as the entire BRFSS questionnaire through a unique identifier. This allows for investigation into other domains, including health related quality of life (HRQoL). HRQoL of caregivers has been assessed in a number of studies. Both positive (Tarlow et al., 2004; Rabkin et al., 2000; Boerner et al., 2004) and negative (Schulz and Beach, 1999; Scott, 2000) aspects of caregiving that influence HRQoL have been reviewed in the literature. We provide a profile of the effect of caregiving on HRQoL as a broad general outcome representing health impacts, below.

NATIONAL CAREGIVER PROFILE

In 2003, over 12% of the U.S. total population was aged 65 and over (He, 2004). It is estimated that the population age 85 and over will grow from 4 million in 2000 to 21 million by 2050, due in part to a declining death rate (Horiuchi, 2000; Oeppen, 2002; Tykhaoyrjarm, 2000). Rapid growth of the population aged 65 and over affects many aspects of the society: it challenges policymakers, families, friends, and care providers (formal and informal), among others, to adapt to the changing and growing needs of the aging population.

Regular informal care plays a pivotal role in the maintenance of independent living among elders and individuals with long-term illness or disability. A large body of research has provided important information on the needs of informal care (Doty, 1986; McKinlay, 1995; Horowitz, 1985; Jett, 1988), characteristics of the caregivers and care recipients (Bullock, 2003; Horowitz, 1985), types of care (Tennstedt, 1996), costs associated with the care, impacts of the care on health outcomes (McKinlay, 1995; Branch, 1983; Skinner, 1994), and implications of care for health policy and practice (Jette, 1995; Morris, 1983; Tennstedt, 1993). Previous studies indicate that family members and friends have been and continue to be the primary and “preferred” informal caregivers (Branch, 1983; Eggert, 1977; Stone, 1987). It is estimated that 21% of the adult U.S. population provided unpaid care to an adult

(≥ 18 years old) family member or friend who needed the care (NAC and AARP, 2005). Nationally, family members and friends are the sole source of informal care for nearly three-quarters of older adults with varying types and degrees of impairment (Doty, 1986).

Caregiver age has been found to be a major factor associated with informal care. According to a recent nationwide telephone survey to identify and profile the experience of caregivers conducted between September and December 2003 (NAC and AARP, 2005), the average age of caregivers in the U.S. is 46, and 58% of the caregivers are between the ages of 18-49 years.

Findings on the relationship between caregiving and caregivers' gender have been inconsistent. The results from the NAC/AARP survey of a representative sample of U.S. adults indicate that caregivers are much more likely to be women (73%) (NAC and AARP, 2005), reflecting traditional female family roles. Tennstedt et al. (Tennstedt, 1993 and 1989) reported that spousal caregivers were as likely to be men as women, and men were more likely to provide informal care without assistance from others. However, in a recent study, Yee and Schulz (Yee, 2000) found that women tend to maintain the caregiving role longer than men and are less likely than men to request additional informal support.

In recent years there has been an increasing interest in the differences in caregiving across cultural, racial, and ethnic groups. According to the NAC/AARP survey, there were higher prevalences of caregiving among Asian-American (32%), African-American (29%) and Hispanic (27%) households than the general population (NAC and AARP, 2005). Two recent studies also showed that African-American caregivers reported higher level of rewards and were more likely to expect to provide care to their elders than white caregivers (White, 2000); and, compared to whites, Hispanics reported larger social networks to provide personal care (Aranda, 2000).

As previously stated, the aims of the research presented herein are to analyze national caregiving prevalence among the certain demographic populations and to investigate the gaps and current fit of services that are available. In doing so, we hope to contribute to the growing number of individuals and agencies working to meet the *Healthy People 2010* disability population goals.

Analyses for the achievement of these aims have relied heavily on the NAC /AARP report (national data), the BRFSS 2000, and on preliminary findings from the 2005 North Carolina BRFSS Caregiver project (state-specific information on caregivers and their experience). This information is essential to greater public health understanding of the role of caregiving in the U.S. and in informing policy that affects both the caregiving and disability communities.

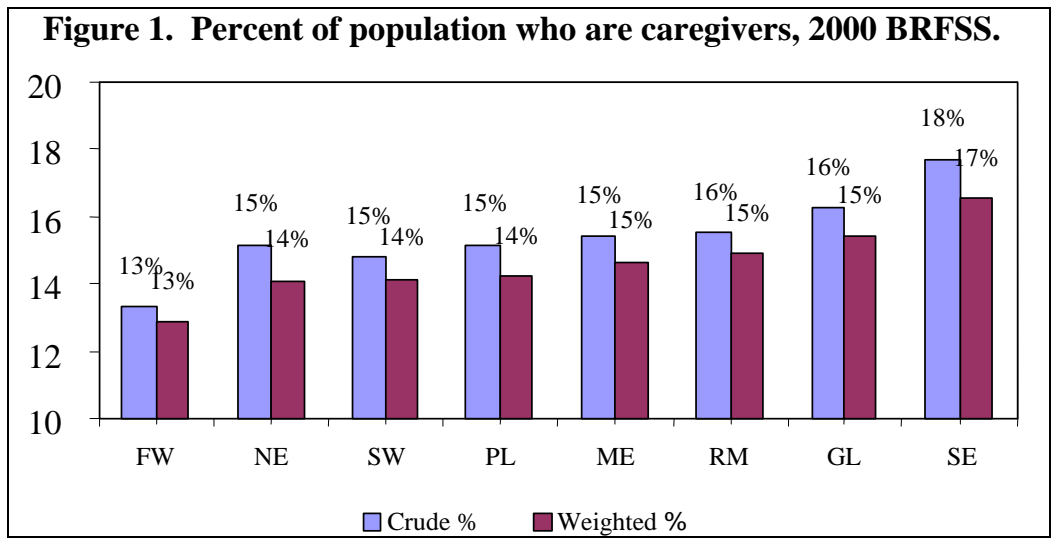
The following data, based on 2000 BRFSS data, presents caregiving prevalence data by geographic region, age, sex, and race. Additionally, data on the Health Related Quality of Life (HRQoL) of caregivers are included in this section. Of note, previous reports have neglected any analysis of caregiving by region, perhaps due to the tendency for reported national surveillance data to be weighted by sampling methods, but not adjusted for

demographic differences. Regional data in the comparisons that follow have been adjusted to account for regional demographic discrepancies, thus allowing for accurate comparison across regions.

Caregiving Prevalence Data

According to 2000 BRFSS data, 16.1% of Americans provide regular care or assistance to a family member or friend aged 60 or older who has a long-term illness or disability. Prevalence varies, however, across states and regions. Based on the classification of the U.S. Bureau of Economic Analysis, we grouped states into the following eight geographic regions for the presentation of data: **1) New England (NE)**: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont; **2) Mideast (ME)**: Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania; **3) Great Lakes (GL)**: Indiana, Michigan, Ohio, Wisconsin; **4) Plains (PL)**: Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota; **5) Southeast (SE)**: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, West Virginia; **6) Southwest (SW)**: Arizona, New Mexico, Oklahoma, Texas; **7) Rocky Mountains (RM)**: Colorado, Idaho, Montana, Utah, Wyoming; **8) Far West (FW)**: Alaska, California, Hawaii, Nevada, Oregon, Washington. It should be noted that Illinois is a part of the Great Lakes. In the 2000 BRFSS survey, however, fewer than 50% of the respondents in Illinois answered the caregiving question. Therefore, data from the state of Illinois were excluded from the Great Lakes region.

Caregiving prevalence by region ranges from 13% in the Far West to 17% in the South East. These data are presented in Figure 1 (below) and in detail in Table 1. State-specific caregiving prevalence is presented in Table 2. Weighted data estimates are the result of accounting for the sampling and demographic differences among regions and states. In the following tables, data are presented about caregiving prevalence and for results from the second caregiving question on “where to call for help...”. The results of the second question are described in more detail below on page 20.



Beyond geographic variability in the prevalence of caregiving, it is equally important to understand what demographic characteristics describe the population of caregivers.

Caregiving Demographic Data

In order to understand best how to target and serve the needs of caregivers, it is important to know who they are. Findings from the 2000 BRFSS support previous research that indicates that men are less likely than women to provide informal care. A significant majority of caregivers identified in the survey are women (60%). The average age of caregivers is 47.6, which is slightly higher than the average age of non-caregivers (average 44.9) and the population in general (45.4). The average age among caregivers is highest in the South East (47.1) and the Plains (47.8) regions, and is lowest in the Far West, Rocky Mountains, and Mid East (45.9, respectively).

Additionally, the typical U.S. adult caregiver is married (64.5%), has education beyond high school (57.7%), and is employed (62.3%). Demographic characteristics of caregivers and non-caregivers are presented in Table 3: Table 4 presents the age distribution of caregivers from the North Carolina BRFSS sample, suggesting a slightly older age range than the national data from BRFSS 2000.

Table 1: Regional/National Assessment of Caregiving Prevalence & Knowledge of Where to Call for Support from the 2000 BRFSS

Region	Sample Size	Caregiving Prevalence		"Who would you call to arrange short or long-term care . . . "							
		Raw %	Final %	Relative or Friend	Self	Medical support	Religious support	Area Agency on Ageing	Other	Don't Know	Missing
New England (NE)	25,797	15.2%	14.1%	19.4%	12.3%	21.1%	0.2%	2.3%	4.8%	39.2%	0.8%
Mid East (ME)	19,746	15.4%	14.6%	23.1%	14.1%	19.2%	0.4%	2.7%	5.1%	34.9%	0.7%
Great Lakes (GL)	11,506	16.2%	15.4%	20.8%	11.0%	19.0%	0.3%	1.7%	5.2%	27.8%	14.3%
Plains (PL)	25,102	15.1%	14.2%	16.4%	13.1%	23.3%	0.4%	2.9%	3.5%	40.1%	0.4%
Southeast (SE)	41,893	17.7%	16.6%	23.9%	19.7%	19.1%	0.3%	1.2%	3.0%	32.2%	0.6%
Southwest (SW)	14,632	14.8%	14.2%	24.1%	15.4%	19.1%	0.5%	1.0%	5.5%	34.1%	0.5%
Rocky Mountains (RM)	16,337	15.6%	14.9%	25.8%	18.5%	24.7%	1.0%	1.6%	4.5%	23.3%	0.6%
Far West (FW)	21,438	13.3%	12.9%	30.2%	18.0%	22.9%	0.9%	2.8%	7.9%	17.1%	0.4%
National Total		16.1%	15.6%	23.7%	16.2%	20.1%	0.5%	1.9%	4.9%	30.0%	2.8%

Table 2: State Assessment of Caregiving Prevalence & Knowledge of Where to Call for Support from the 2000 BRFSS

State	Sample Size	Caregiving Prevalence		"Who would you call to arrange short or long-term care . . . "						
		Raw %	Final %	Relative or Friend	Self	Medical support	Religious support	Area Agency on Ageing	Other	Don't Know
Alabama	2,238	18.6%	16.4%	32.5%	23.0%	26.2%	0.7%	0.7%	2.6%	14.4%
Alaska	2,066	11.8%	9.9%	19.5%	12.0%	15.3%	0.2%	2.2%	7.7%	43.0%
Arizona	2,654	13.5%	12.9%	17.6%	14.4%	12.0%	0.3%	1.7%	15.6%	38.3%
Arkansas	2,993	19.0%	17.9%	20.8%	16.3%	26.7%	0.3%	3.9%	2.9%	29.0%
California	3,896	13.8%	14.0%	29.7%	16.9%	24.9%	0.9%	3.0%	9.8%	14.7%
Colorado	3,031	13.7%	13.3%	26.7%	19.6%	29.7%	1.0%	2.1%	4.9%	16.0%
Connecticut	3,885	15.3%	14.5%	17.5%	13.2%	23.0%	0.2%	2.0%	6.4%	37.7%
Delaware	2,750	15.7%	15.3%	24.8%	22.0%	17.6%	0.2%	1.8%	28.4%	5.3%
District of Columbia	1,688	13.8%	12.1%	30.9%	10.2%	17.2%	0.8%	2.7%	5.8%	32.4%
Florida	5,153	14.4%	13.8%	25.1%	19.7%	18.9%	0.4%	1.5%	2.9%	31.6%
Georgia	4,083	18.0%	17.1%	25.3%	17.0%	19.8%	0.4%	1.1%	3.4%	33.0%
Hawaii	6,004	12.9%	10.5%	27.0%	23.5%	19.8%	0.1%	2.7%	1.2%	25.7%
Idaho	4,946	15.3%	14.6%	22.3%	16.4%	23.6%	0.8%	1.7%	4.7%	30.5%
Illinois	Illinois used the question for 50% of its surveys in 2000 & is not listed here									
Indiana	2,909	16.0%	15.2%	23.0%	17.4%	25.6%	0.6%	2.0%	2.5%	28.9%
Iowa	3,602	14.9%	14.5%	12.4%	7.8%	23.9%	0.3%	1.2%	4.0%	50.4%
Kansas	4,224	14.6%	13.9%	18.9%	16.3%	22.0%	0.4%	1.6%	2.8%	37.9%
Kentucky	6,399	18.0%	16.2%	11.9%	26.9%	18.7%	0.2%	0.2%	1.4%	40.7%
Louisiana	4,995	17.5%	16.8%	24.2%	26.2%	19.5%	0.2%	0.4%	1.7%	27.7%
Maine	4,574	16.0%	15.3%	17.6%	12.8%	25.4%	0.2%	2.9%	4.4%	36.6%

Table 2: State Assessment of Caregiving Prevalence & Knowledge of Where to Call for Support from the 2000 BRFSS

State	Sample Size	Caregiving Prevalence		"Who would you call to arrange short or long-term care . . . "						
		Raw %	Final %	Relative or Friend	Self	Medical support	Religious support	Area Agency on Ageing	Other	Don't Know
Maryland	4,561	14.7%	13.5%	22.3%	13.7%	19.0%	0.4%	2.5%	4.8%	37.3%
Massachusetts	8,089	15.0%	14.2%	20.2%	11.7%	20.1%	0.1%	2.5%	5.2%	40.2%
Michigan	2,592	17.8%	16.5%	24.4%	8.7%	21.5%	0.3%	2.2%	10.1%	32.8%
Minnesota	2,845	16.6%	15.3%	18.6%	8.3%	26.0%	1.0%	6.6%	3.2%	36.3%
Mississippi	2,176	22.2%	21.2%	26.7%	16.5%	23.3%	0.4%	0.5%	2.7%	30.1%
Missouri	4,369	14.9%	13.9%	15.1%	20.6%	24.4%	0.2%	2.1%	3.4%	34.2%
Montana	3,016	17.7%	15.4%	12.4%	15.6%	19.7%	0.1%	0.9%	4.9%	46.3%
Nebraska	3,053	15.0%	14.1%	13.9%	6.5%	22.6%	0.4%	2.3%	3.4%	50.9%
Nevada	2,082	13.3%	13.5%	25.0%	22.5%	28.5%	0.8%	1.5%	5.1%	16.5%
New Hampshire	1,930	14.8%	13.9%	15.4%	11.7%	23.5%	0.4%	2.4%	2.9%	43.7%
New Jersey	3,762	15.5%	15.1%	19.9%	13.3%	18.0%	0.3%	2.5%	4.8%	41.2%
New Mexico	3,238	14.7%	13.6%	20.6%	16.8%	18.5%	0.4%	1.0%	3.1%	39.6%
New York	3,334	15.4%	14.9%	22.9%	12.3%	19.7%	0.5%	2.4%	5.7%	36.6%
North Carolina	2,997	17.7%	15.7%	20.5%	24.7%	22.4%	0.2%	1.9%	3.5%	26.8%
North Dakota	1,901	11.9%	12.1%	19.4%	9.6%	25.5%	0.3%	2.1%	5.1%	38.0%
Ohio	3,231	15.8%	15.4%	21.5%	13.6%	20.8%	0.3%	1.5%	3.8%	38.4%
Oklahoma	3,685	15.3%	14.3%	22.5%	13.4%	20.7%	0.1%	0.6%	1.3%	41.2%
Oregon	3,708	14.7%	14.4%	22.1%	14.9%	19.3%	0.9%	3.4%	6.0%	33.4%
Pennsylvania	3,508	16.7%	15.4%	22.5%	18.3%	23.0%	0.5%	4.3%	3.9%	27.5%
Rhode Island	3,515	16.1%	14.8%	19.6%	14.9%	20.6%	0.3%	2.2%	4.8%	37.6%

Table 2: State Assessment of Caregiving Prevalence & Knowledge of Where to Call for Support from the 2000 BRFSS

State	Sample Size	Caregiving Prevalence		"Who would you call to arrange short or long-term care . . . "						
		Raw %	Final %	Relative or Friend	Self	Medical support	Religious support	Area Agency on Ageing	Other	Don't Know
South Carolina	3,288	17.7%	16.4%	24.6%	14.7%	18.5%	0.4%	1.5%	3.7%	36.7%
South Dakota	4,983	16.5%	15.5%	18.3%	13.4%	28.7%	0.3%	2.7%	3.0%	33.7%
Tennessee	3,022	17.9%	16.4%	20.3%	24.1%	14.6%	0.3%	0.6%	1.2%	39.0%
Texas	4,991	15.1%	14.9%	25.3%	15.5%	22.9%	0.6%	1.1%	3.6%	31.1%
Utah	2,884	16.3%	16.5%	30.1%	16.6%	25.1%	0.8%	1.6%	4.3%	21.5%
Vermont	3,607	13.5%	11.1%	17.0%	11.5%	27.8%	0.1%	3.0%	5.3%	35.4%
Virginia	1,974	16.0%	14.5%	23.5%	9.5%	17.9%	0.4%	1.9%	6.4%	40.5%
Washington	3,565	12.9%	12.5%	25.6%	24.3%	25.1%	1.0%	3.3%	2.1%	18.6%
West Virginia	2,350	19.2%	20.4%	18.2%	23.0%	21.1%	0.2%	2.0%	2.5%	33.1%
Wisconsin	2,698	15.5%	14.4%	23.9%	7.8%	25.2%	0.5%	3.0%	10.9%	28.6%
Wyoming	2,383	14.9%	13.5%	20.5%	16.4%	29.3%	0.3%	1.5%	3.2%	28.7%
Puerto Rico	4,203	34.0%	23.7%	24.7%	53.4%	8.3%		1.0%	0.1%	12.5%
TOTAL	181,479	16.1%	15.6%	21.5%	17.2%	21.6%	0.4%	2.0%	4.5%	32.7%

Table 3: Characteristics of Caregivers and Non-Caregivers Adjusted for Sampling Weight*

	Caregiver (mean)	Non Caregiver	Total (mean)
Age (mean±SD)	47.62±16.24	44.92±17.65	45.35±17.47
- 65 and older (%)	17.71	17.39	17.44
Gender (% women)	59.97	50.37	51.87
Race			
-Non Hispanic White	73.89	72.74	72.92
-Hispanic White	7.81	9.20	8.98
-Non Hispanic African American	10.85	9.28	9.52
-Hispanic African American	1.03	0.75	0.79
-Hispanic other race	2.84	3.50	3.40
-Asian/Pacific Islander	1.64	2.71	2.54
-Native American/Alaskan Native	1.16	0.94	0.97
-other non Hispanic	0.79	0.89	0.88
Marital status			
-Married/Coupled	64.54	61.18	61.71
-Divorced/Separated	13.03	12.13	12.27
-Widowed	5.99	7.47	7.24
-Never been Married	16.43	19.21	18.78
Education			
-No formal/Grades 1-8	3.53	5.53	5.22
-<HS	7.56	8.20	8.10
-HS graduate	31.24	30.96	31.00
->HS	57.67	55.31	55.68
Employment (% employed)			
-Employed for Wages/Self-employed	62.32	64.46	64.12
-Out of Work for > or < 1 year	4.17	3.67	3.74
-Homemaker	7.96	7.40	7.48
-Student	3.35	4.10	3.99
-Retired	18.06	16.35	16.61
-Unable to work	4.14	4.03	4.05

*The sample weight is the number of population members whom the respondent represents as a member of the sample (see Gentry et al., 1985). Due to large sample sizes, there were statistically significant differences at $p < 0.0001$ level between the caregiver and the non-caregiver in all factors listed in Table 1.

Table 3 Cont.: Characteristics of Caregivers and Non-Caregivers

	Caregiver (mean)	Non Caregiver (mean)	Total (mean)
Income			
-<\$25,000	29.32	30.14	30.01
-\$25,000 - \$34,999	15.73	15.51	15.55
-\$35,000 - \$49,999	19.16	18.59	18.68
-\$50,000 - \$74,999	17.96	17.30	17.41
-\$75,000 or more	17.83	18.45	18.35
Healthcare coverage (% with)	86.91	85.63	85.82
Personal Doctor or Health Care Provider(% with)	89.88	85.49	86.16
Seen health profession in last 12 months (% yes)	73.66	70.62	71.10
BMI			
-Underweight	1.81	2.12	2.07
-Normal Weight	36.61	39.23	38.82
-Overweight	35.18	35.51	35.46
-Obese	26.39	23.14	23.65
Ever Had High Blood Pressure (%yes)	27.98	25.05	25.52
Flu shot (% receiving last 12 months)	37.04	31.08	31.99
Smoking frequency (% yes)			
-Everyday	37.51	36.23	36.44
- Sometimes	10.94	11.33	11.26
- Not at all	51.55	52.44	52.30
At Least 1 Alcoholic Beverage Consumed in Past Month (% yes)	50.86	55.37	54.67
Number Times in Past Month Consumed >=5 Alcoholic Beverages	1.36±3.97	1.36±3.67	1.34±3.69
Number of Alcoholic Beverages Consumed	2.62±2.62	2.79±2.87	2.76±2.81
> 5 fruits and vegetables (% yes)	2.80	4.39	4.14
Participate in Physical Activity (% yes)	73.92	71.86	72.18
Healthy days (mean)	22.98±10.29	24.41±9.40	24.2±9.55
-Days Physical Health Not Good (mean)	3.80±8.03	3.27±7.64	3.34±7.70
-Days Mental Health Not Good (mean)	4.16±8.24	3.02±7.04	3.19±7.23
Frequent Mental Distress (% yes)	13.02	8.93	9.56
Provide Care for someone 60+ (%)	100.00	0.00	15.57
HRQoL			
-Excellent/Very Good/Good	83.24	84.51	84.26
-Fair/Poor	16.59	15.27	15.52

Table 4. Age distribution of 895 Caregivers, North Carolina BRFSS 2005

Age Group	Number*	Percent
18-34	128	14.4
35-44	168	18.9
45-54	213	23.8
55-64	202	22.8
65 and over	179	20.1

*Due to missing values (n=5) the number does not sum to 895

Nationally, 73.9% of caregivers are white, 11.7% are Hispanic, and 10.9% are African-American. Data for ethnicity (Hispanic or Non-Hispanic) were collected in a question separate from race, however for data presentation purposes, all Hispanic respondents, independently of their race, have been categorized as Hispanic. Large variations in the racial and ethnic composition of the caregiver population exist by region. These variations are largely representative of the regional population, though the variations must be noted when considering any national level response to the needs of caregivers. Notably, 16.3% of caregivers are African-American in the Mid East and the South East, while in the Rocky Mountain region less than one percent of caregivers are African-American. In the South West, 21.3% of caregivers are Hispanic, compared to less than 3% in both the Plains and Great Lakes regions. Similarly, 12.2% of caregivers are Asian/Pacific Islander in the Far West, yet in no other region do Asian/Pacific Islanders make up more than 2% of the population of caregivers. These data are shown in Table 6.

To demonstrate the relative effect of these demographic characteristics, data on demographics are combined with an analysis of race, ethnicity and gender. Adjusted Odds Ratios (OR) are shown – these are interpretable as relative effects, where 1.0 means “equal outcomes or likelihood of being a caregiver”, 0.50 means a 50% relative reduction of likelihood, and 1.5 means a 50% relative increase in the likelihood of being a caregiver. These results indicate that, compared to white women, only African-American men in the Far West, African-American women in the Plains, South West and Rocky Mountain regions women, and Asian/Island Pacificers in the Far West, are more likely to be caregivers. See Tables 6 and 7 for more information. There were no care recipient data collected in the national BRFSS 2000. However, preliminary data from the North Carolina 2005 BRFSS provide details for that state. Major categories of medical reasons why the recipient needs care, age, gender, and time spent in caregiving are listed below in Table 5. Similarly to mortality data in the U.S., the top two diagnoses of care recipients are heart disease and cancer.

Table 5: Characteristics of Care Recipients, North Carolina BRFSS 2005 (n=895)

Characteristic	Percent	Characteristic	Percent
Leading Diagnoses:		Age groups:	
Heart disease	11%	0-5	2%
Cancer	10%	6-17	6%
Dementia	8%	18-29	3%
Stroke	8%	30-49	10%
Diabetes	8%	50-64	15%
Arthritis	5%	65-74	19%
Female	67%	75 and older	45%
Mean hours per week spent in caregiving = 22.8 (standard deviation 35.8; median = 10 hours)			

Table 6. Behavioral Risk Factor 2000 respondent demographic characteristics by region

Characteristics	Region								p value
	New England	Mid East	Great Lakes	Plains	South East	South West	Rock Mts	Far West	
	(N=25,797)	(N=19,746)	(N=11,506)	(N=25,102)	(N=41,893)	(N=14,632)	(N=16,337)	(N=21,438)	
Age (mean ± SD +)	46.6±17.2	45.9±17.1	46.6±17.3	47.8±18.3	47.1±17.4	46.6±17.7	45.9±17.2	45.9±16.8	<.0001
Race/Ethnicity (%)									<.0001
White	86.8	71.9	85.6	91.9	77.5	67.5	89.1	65.6	
African American	3.3	16.3	8.8	2.6	16.3	5.0	0.6	2.6	
Hispanic	6.6	7.0	2.2	2.5	3.9	21.3	5.8	10.9	
Asian/P Islander	1.3	2.0	0.9	0.7	0.8	1.3	0.7	12.2	
Am Ind/AK Native	0.5	0.5	0.9	1.6	0.6	3.3	2.7	6.4	
All others	1.5	2.2	1.7	0.8	1.0	1.7	1.1	2.3	
Gender (%)									<.0001
Men	40.0	39.6	42.0	39.9	38.7	42.0	42.7	43.6	
Women	60.0	60.4	58.0	60.1	61.3	58.0	57.3	56.4	

P = Pacific; Am = American; Ind = Indian; AK = Alaska. SD = standard deviation.

The p values for testing between region differences are based on Chi-squared tests on discrete variables and F test on continuous variables.

+ SD = standard deviation

Table 7. Adjusted odds ratios (OR: relative likelihood) of being a caregiver, 2000 BRFSS

Variable	Region							
	New England	Mid East	Great Lakes	Plains	South East	South West	Rock Mts	Far West
	Adjusted OR (95% Confidence Interval)							
Age	1.1 (1.1-1.1) [†]	1.1 (1.0-1.1) [†]	1.1 (1.1-1.1) [†]	1.1 (1.1-1.1) [†]	1.1 (1.1-1.1) [†]	1.1 (1.1-1.1) [†]	1.1 (1.1-1.1) [†]	1.1 (1.1-1.1) [†]
Age ²	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]	1.0 (1.0-1.0) [†]
Race/Ethnicity (Reference group = white women):								
White Men	0.7 (0.6-0.7) [†]	0.7 (0.6-0.8) [†]	0.6 (0.5-0.6) [†]	0.7 (0.6-0.7) [†]	0.7 (0.7-0.7) [†]	0.7 (0.6-0.8) [†]	0.6 (0.6-0.7) [†]	0.7 (0.7-0.8) [†]
African Am Men	0.5 (0.3-0.7) [†]	0.7(0.5-0.8) [†]	0.7 (0.5-0.9) [†]	0.6 (0.4-0.9) [‡]	0.8 (0.7-0.9) [†]	0.7 (0.5-1.0) [‡]	0.3 (0.1-1.1)	1.2 (0.9-1.8)
African Am Women	1.0 (0.8-1.2)	1.0 (0.9-1.1)	1.0 (0.8-1.2)	1.1 (0.8-1.4)	1.0 (0.9-1.1)	1.3 (1.0-1.7) [‡]	1.4 (0.8-2.7)	1.0 (0.8-1.5)
Hispanic Med	0.5 (0.4-0.6) [†]	0.4 (0.3-0.6) [†]	0.6 (0.3-1.0)	0.6 (0.4-0.9) [†]	0.5 (0.4-0.7) [†]	0.6 (0.5-0.8) [†]	0.6 (0.4-0.8) [†]	0.7 (0.6-0.9) [†]
Hispanic Women	0.7 (0.5-0.8) [†]	0.8 (0.7-1.0) [‡]	0.8 (0.5-1.3)	0.7 (0.5-1.0) [‡]	0.7 (0.6-0.9) [†]	1.0 (0.9-1.2)	0.9 (0.7-1.1)	1.0 (0.9-1.2)
Asian/P Islander Men	0.5 (0.3-0.8) [†]	0.3 (0.1-0.5) [†]	0.8 (0.4-1.6)	0.6 (0.3-1.2)	0.4 (0.2-0.7) [†]	0.2 (0.1-0.6) [†]	0.4 (0.2-1.2)	0.7 (0.6-0.9) [†]
Asian/P Islander Women	0.5 (0.3-0.9) [‡]	0.5 (0.3-0.8) [†]	0.7 (0.3-1.7)	0.7 (0.4-1.4)	0.5 (0.3-0.8) [†]	0.6 (0.3-1.1)	0.5 (0.2-1.1)	1.1 (0.9-1.3)
Am Ind/AK Native Men	0.5 (0.2-1.1)	1.0 (0.4-2.3)	0.4 (0.1-1.2)	1.3 (0.8-1.9)	1.0 (0.6-1.7)	1.1 (0.7-1.6)	1.1 (0.8-1.6)	1.2 (0.9-1.5)
Am Ind/AK Native Women	0.9 (0.4-1.7)	1.3 (0.7-2.3)	0.9 (0.4-1.8)	1.6 (1.2-2.1) [†]	1.3 (0.9-1.9)	1.8 (1.3-2.3) [†]	1.1 (0.8-1.5)	1.2 (1.0-1.5) [‡]
All other Men	0.7 (0.4-1.1)	0.9 (0.6-1.3)	0.7 (0.4-1.2)	0.8 (0.4-1.5)	0.7 (0.5-1.1)	1.1 (0.7-1.8)	1.1 (0.7-1.9)	0.8 (0.5-1.2)
All other women	1.4 (1.0-1.9)	0.9 (0.7-1.3)	1.5 (0.9-2.4)	1.1 (0.6-1.8)	0.9 (0.7-1.3)	1.1 (0.7-1.7)	1.1 (0.6-2.0)	1.3 (0.9-1.8)
Gender:								
Men versus Women	0.6 (0.5-0.8) [†]	0.7 (0.5-0.9) [†]	0.6 (0.4-0.9) [†]	0.7 (0.6-1.0) [‡]	0.7 (0.6-0.9) [†]	0.6 (0.5-0.8) [†]	0.7 (0.5-1.0) [‡]	0.8 (0.7-0.9) [†]

[†] $p < 0.01$; [‡] $p < 0.05$.

P = Pacific; Am = American; Ind = Indian; AK = Alaska.

Dependent variable = caregiving status (0 = no, 1 = yes).

For all the racial/ethnic and gender categories, reference group = white women

Health Related Quality of Life (HRQoL)

HRQoL can be defined as the “physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person’s experiences, beliefs, expectations, and perceptions” (Testa and Simonson, 1996). Included in the HRQoL core (asked in all states since 1993) are four questions measuring HRQoL:

- “Would you say that in general your health is excellent, very good, good, fair or poor?”
- “Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?”
- “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?”
- “During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work or recreation?”

The “unhealthy days” index is calculated by adding a person’s physical and mental unhealthy days, with a maximum of 30 days per person (Moriarty, Zack and Kobau, 2003). The “healthy days” index then is created by subtracting the number of unhealthy days from 30. This metric for HRQoL has been used extensively to describe population health outcomes across different conditions and among states and population groups (CDC, 2000).

In order to assess the HRQoL in a very simple manner and for consistency in comparing to published reports (e.g., Andresen, Catlin, Wyrwich and Jackson-Thompson, 2003; CDC, 2001), we created a dichotomous variable for poor health. BRFSS respondents reporting “fair” or “poor” health were coded as “1”, and respondents reporting “excellent”, “very good”, or “good” were coded as “0”. We also assessed “healthy days” as a continuous variable, as outlined above.

In the adjusted logistic regression model, caregivers were found to have a 14% higher odds ratio (OR chance or likelihood) of rating their health as fair or poor than non-caregivers (OR = 1.14, 95% CI). After adjusting for the effects of age, gender, race, marital status, education level, and income, caregivers had an adjusted odds ratio of 1.16 (95% CI), suggesting a modest but significant increase in reduced HRQoL. In addition, statistically significant differences in healthy days were found between caregivers and non-caregivers ($p < .001$). More non-caregivers reported 30 healthy days compared to the caregivers (51% vs. 44%, respectively), and more caregivers reported having 0 healthy days compared to the non-caregivers (13% vs. 10%, respectively). We will return to a discussion of HRQoL of caregivers in the *Discussion* section of this report. See Table 8 for more information.

Table 8: Adjusted Odds Ratio (OR: relative likelihood) of Poor or Fair Health

Variable	Odds ratio & 95% CI *
Caregiver vs. non caregiver	1.16 (1.11-1.20)
Gender	
Women vs. men	0.98 (0.95-1.02)
Age (per increasing year of age)	1.03 (1.03-1.03)
Race/ethnicity	
White, non-Hispanic	1.00 (referent)
Other	1.20 (1.12-1.29)
Hispanic	1.66 (1.58-1.74)
Black, non-Hispanic	1.31 (1.24-1.38)
Marital Status	
Married/Coupled	1.00 (referent)
Never been Married	0.97 (0.92-1.02)
Widowed	0.82 (0.78-0.86)
Divorced/Separated	1.19 (1.15-1.24)
Education	
No formal Education	1.00 (referent)
< High School	3.39 (3.19-3.62)
High School	2.75 (2.61-2.89)
> High School	1.55 (1.50-1.605)
Annual household income	
More than \$25,000/year vs. less	0.35 (0.33-0.36)

* Odds ratios (95% confidence intervals) adjusted for all variables in the table.

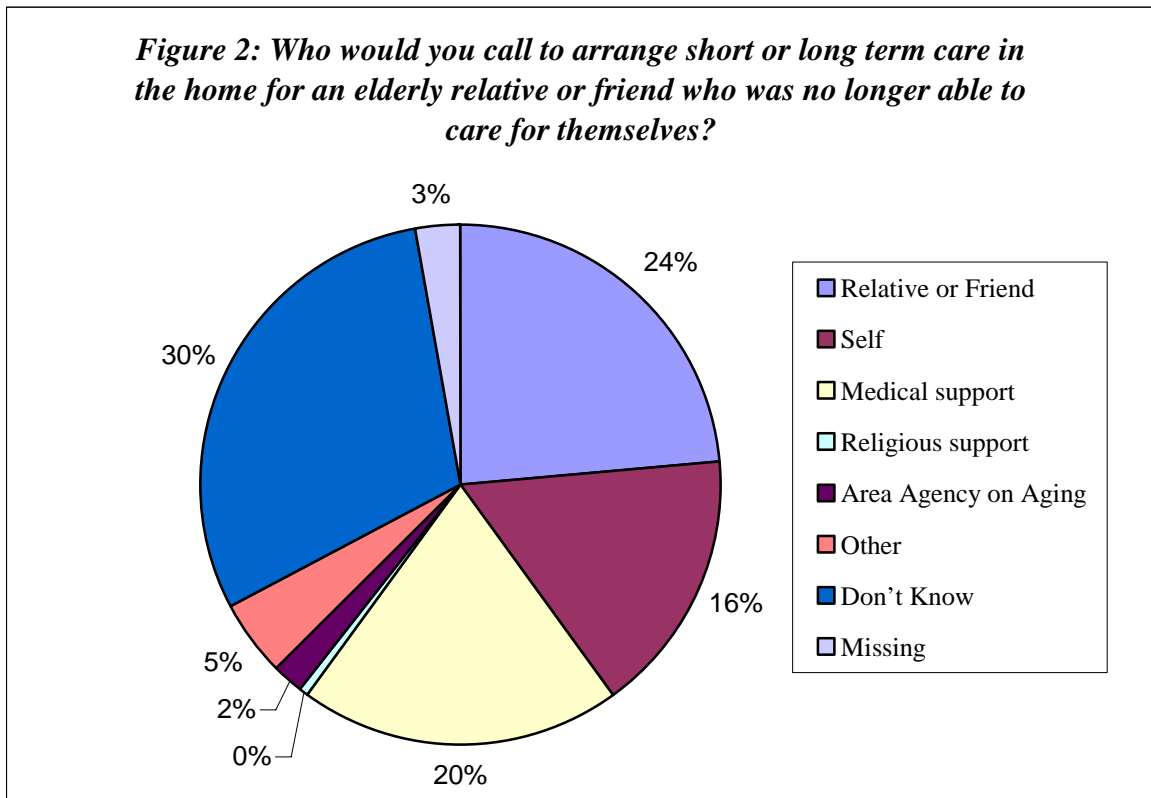
SERVICES AND NEEDS PROFILE

This section aims to identify the services and the gaps in services for caregivers that exist in the USA today. We begin by exploring the second caregiving question from the 2000 BRFSS and then compare the available in-depth national level data with newly collected and analyzed in-depth state-level data from North Carolina. These data include information on environmental factors, medication, additional support, and coping mechanisms. These data provide examples of critical information in understanding the needs of caregivers today, and suggest the need for similar data for other states.

Where to Call for Support

The second caregiving question included as part of the national 2000 BRFSS survey, “Who would you call to arrange short or long-term care in the home for an elderly relative or friend who was no longer able to care for themselves?” has not proved as useful as prevalence. This is due, in large part, to a very high portion of respondents indicating that they do not know where they would call to arrange for such services. However, there is still information to be gleaned from the data. Figure 2, below, presents national data on the response to this question.

First, by function of 30% of adults saying, “I don’t know,” there is clear evidence that information about where to seek care is limited among the general population.



Second, it is worthwhile to look at variations in where people call to arrange care by region. These data are presented in Table 1, on page 10.

The number of “I don’t know” responses varies regionally from 17.1 to 41.0%. In six of the eight US regions, “I don’t know” was the most common response. In the Far West and Rocky Mountain regions, however, more respondents indicated that they would call a friend or relative than any other option (30.2% and 25.8% respectively). In the Far West and Rocky Mountain regions, a greater percentage of respondents indicated that they would call some type of medical support compared to the percentage that indicated “I don’t know.”

Additionally, the Plains region had the highest percent of respondents reporting “I don’t know” (40.1%) and the lowest percent of respondents reporting that they would call a friend or relative (16.4%). The New England region was just behind, with 39.2% reporting “I don’t know,” and 19.4% reporting that they would call a friend or relative.

State-specific data on where to call to arrange care are presented above in Table 2. This varied substantially by state, from a low of 5.3% in Delaware to a high of 50.1% in Nebraska. In addition, a large proportion of individuals said they or their family/friends would be a resource, suggesting that informal caregivers are the most likely source of assistance. Specific state programs or initiatives, disability prevalence, or demographic and cultural differences in some areas may explain these large differences. More detailed

questioning will be needed to understand why there are gaps in population knowledge or program availability.

These summary statistics can also be examined more closely for possible differences in knowledge by if a person actually provides care. Below in Table 9, the prevalence is provided based on caregiving status for all BRFSS 2000 respondents (n=181,419). Most categories are similar. However, more noncaregivers (33%) than caregivers (16%) responded they didn't know where to call for support. A greater number of caregivers relied on (or called on) themselves for support (27%) than noncaregivers (15%). This suggests that current caregivers are less likely to report they do not know because they would not call on others or agencies, and instead count themselves as the sole or primary source of care.

Table 9: National Assessment of Knowledge of Where to Call for Support from the 2000 BRFSS

"Who would you call to arrange short or long-term care . . . "	Caregivers (n = 29,206)	Non Caregivers (n = 152,209)
Relative or friend	23%	24%
Self	27%	15%
Nursing home	5%	5%
Home health service	12%	8%
Personal physician	4%	4%
Area Agency on Aging	3%	2%
Hospice	2%	2%
Hospital nurse	1%	1%
Minister/Priest/Rabbi	1%	1%
Other	6%	5%
Don't know	16%	33%

There are substantial economic implications of identifying those individuals with care needs and leading them to appropriate services. Inappropriately cared for, these individuals create a large economic burden on state health care systems. At least in the general population, a substantial proportion of people are not aware of community resources should they be faced with a caregiving situation.

In-depth Understanding of CG Needs

As noted in the introduction, Dr. Andresen and her research team at the University of Florida developed a 10-question caregiving module that was implemented as part of the BRFSS survey in North Carolina during the summer of 2005. The module includes important details about caregivers and the person they care for that was not available in the simple prevalence data acquired in the BRFSS 2000. A total of 895 adults reported they were caregivers and completed this module. In addition, when caregivers were identified, they were asked to participate in an in-depth follow-back interview, built in large part on the measures used in the NAC/AARP report. The follow-back interview, a 114-question, 20-minute survey, included additional questions not asked on the NAC/AARP survey. A total of 367 adults completed this follow-back interview.

The purpose of the research presented below is to augment national data from the NAC/AARP report and state-level data from North Carolina's BRFSS and to begin to understand the services, and gaps in services that currently exist for caregivers. Undoubtedly, the situation and needs of caregivers will vary across geographic areas; however, we use the North Carolina data as a case study to better understand how, with more detailed and comprehensive data, we can better understand and meet the needs of caregivers in any given area.

Environmental Factors

The Craig Hospital Inventory of Environmental Factors (CHIEF) is a survey developed to assess the impact of environmental factors on people with disabilities (Whiteneck et al., 2003). In the North Carolina follow-back survey, we used a number of questions from the CHIEF short form to gauge the impact of environmental constraints. It is important to note that the CHIEF short form was the basis for these questions, but that a few significant modifications were made. Modifications include:

- CHIEF questions modified and asked of caregivers, not of the person with disability.
- Because of restrictions on the length of the survey, not all short-form questions were asked. (See Table 8 for a complete list and the format of questions).
- Though subscales were modeled after the short form subscales, changes included generalizing the *Attitude/Support Subscale* so that it was no longer specific to home or work.

Data collected from the modified CHIEF questions indicate that caregivers perceive the natural environment as an obstacle for care recipients to do what they want (46% indicate that this is a problem that occurs at least monthly, while 11.9% indicate that it is a daily problem). Additionally, data indicate that a substantial portion of caregivers believe that the person they care for continues to need help at home, school or work and cannot get it (41.3% indicate that this is a problem at least monthly, while 10.8% indicate that this is a daily problem). The responses (in percent) are presented for each question in Table 10.

Questions that make up three CHIEF subscales (Physical/Structural, Service/Assistance, and Attitude/Support) were modified and included in the follow-back survey. Analysis included frequencies (percentages shown below in Table 10) and a more complex analysis outlined in the CHIEF Manual (Version 3.1, see Table 11). This methodology is based on the calculation of three scores:

- A frequency score on a scale of 0-4 indicating the frequency with which barriers were encountered (0= never, 1=less than monthly, 2=monthly, 3=weekly, and 4=daily).
- Magnitude score on a scale of 0-2 indicating the size of a problem that a barrier typically presented (0=no problem since the barrier was never encountered, 1=small problem, 2=big problem).
- A frequency-magnitude product score on a scale of 0-8, calculated as the product of the frequency score and the magnitude score, indicating the overall impact of the barrier.

Based on these calculations, the Physical/Structural Subscale (composed of transportation and natural environment obstacles) had the greatest impact of the subscales assessed (0.92 as opposed to 0.67 and 0.62 for Service/Assistance and Attitude/Support, respectively). Also of particular interest is the frequency that caregivers reported some level of problems with attitudes in their environment.

Table 10. Percent responses to the occurrence of various environmental factors that constrain care recipients. North Carolina BRFSS caregiver sample follow-back, 2005.

	<i>n</i> =	Daily	Weekly	Monthly	Less than Monthly	Never
Transportation	381	4.4%	6.0%	7.5%	6.9%	75.2%
Natural Environment	362	11.9%	9.5%	10.3%	11.4%	54.0%
Surroundings	366	6.7%	5.2%	6.5%	11.0%	70.6%
Information	366	5.5%	4.9%	6.9%	12.6%	70.2%
Health Care Services	370	3.8%	2.7%	6.9%	12.9%	73.6%
Need Someone Else's Help at Home/Work/School	370	10.8%	10.2%	9.7%	10.6%	58.7%
Attitudes	360	5.5%	8.9%	13.1%	12.0%	60.5%
Prejudice	362	1.9%	2.8%	5.5%	5.5%	84.4%

Table 11. Modified Craig Hospital Inventory of Environmental Factors (CHIEF) Subscales: Frequency, Magnitude, and Product Scores #. North Carolina BRFS caregiver sample follow-back, 2005.

	Scales Scores					
	Frequency		Magnitude		Product	
	Mean	SD +	Mean	SD +	Mean	SD +
<i>Physical//Structural Subscale</i>	0.90	1.10	0.51	0.57	0.92	1.66
In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult for your (*) to do what he/she wants or needs to do?	1.11	1.54	0.64	0.81	1.68	2.70
In the past 12 months, how often have other aspects of the surroundings – lighting, noise, crowds, etc – made it difficult to do what your (*) wants or needs to do?	0.66	1.26	0.40	0.67	0.96	2.01
<i>Services/Assistance Subscale</i>	0.69	0.77	0.45	0.49	0.67	1.15
In the past 12 months, how often has the availability of transportation been a problem?	0.58	1.11	0.35	0.63	0.85	1.80
In the past 12 months, how often has the information you or your (*) wanted or needed not been available in a format that your (*) uses or understands?	0.63	1.12	0.43	0.74	0.93	2.01
In the past 12 months, how often has the availability of health care services or medical care been a problem for your (*)?	0.50	1.09	0.41	0.76	0.09	2.08
In the past 12 months, how often did your (*) need someone else’s help at home, school or work & could not get it easily?	1.04	1.39	0.59	0.77	1.49	2.29
<i>Modified Attitude Support Subscale</i>	0.59	0.87	0.38	0.55	0.62	1.32
In the past 12 months, how often have other people’s attitudes been a problem for your (*) at home, school or work?	0.87	1.26	0.56	0.77	1.27	2.17
In the past 12 months, how often did your (*) experience prejudice or discrimination?	0.32	0.86	0.21	0.57	0.05	1.44

* (Care recipient asked, e.g., Mother) + SD = standard deviation

Scores range from 0.05-1.68, see bulleted points on pg. 23 for full explanation

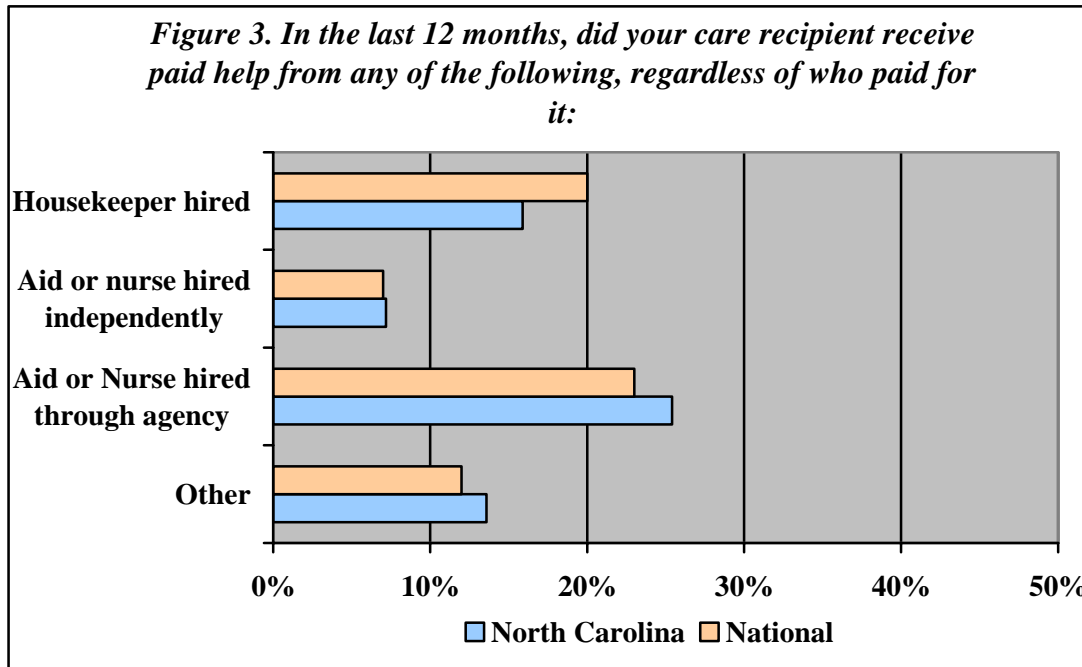
Medications

Based on the NC follow-back survey, 20.9% of caregivers feel that they do not know as much as they need to about the prescription medicine that their care recipient takes. This percentage is slightly lower than the 24% observed nationally by the NAC.

Outside Support

The presence or absence of outside support for the informal caregiver is an important component of the caregiving picture. Paid or unpaid individuals may provide this support.

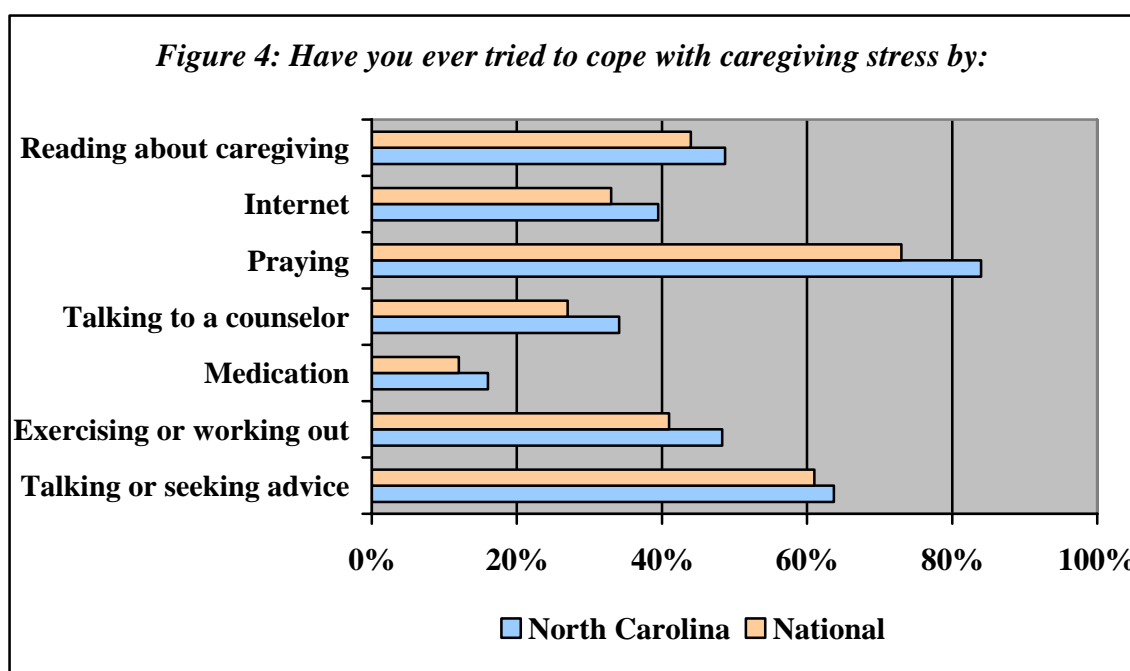
Fully 25.4% of caregivers in North Carolina (and 23% nationally, NAC) report that an aide or nurse hired through an agency provided help to their care recipient. An additional 7.2% and 7% of caregivers in North Carolina and nationally, respectively, report assistance from a paid aid or nurse hired independently. In North Carolina 15.9% of caregivers report paid help from a housekeeper who cleans or cooks, while this percent reaches 20% nationally. It is interesting to note that North Carolinian caregivers are more apt than caregivers nationally to have help from an agency-hired aid or nurse, but are less likely than caregivers nationally to have a housekeeper. In North Carolina, 63.7% of respondents indicated that someone else provided some unpaid help to the care recipient in the past 12 months. This is slightly higher than the national observation of 59%. In North Carolina, 33.1% of caregivers who do have additional support from unpaid sources indicated that they provide most of the unpaid care, while 48.8% indicate that someone else provides most of the unpaid care.



Coping

Caregivers nationally and in North Carolina were asked to respond to a series of questions regarding coping mechanisms. Participants were asked to indicate if they'd ever tried to cope with caregiving stress by completing a list of various coping activities, which were named.

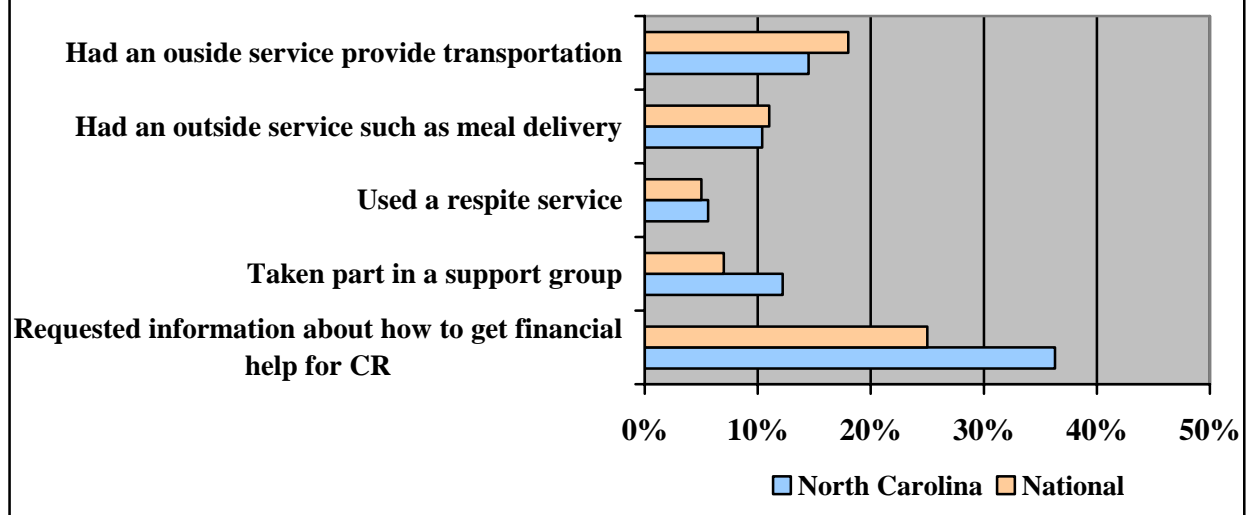
Prayer was the most common caregiver coping mechanism, both nationally and in North Carolina. Respectively, 73% and 84% of caregivers report using prayer to cope with caregiving stress. Talking with or seeking the advice of a friend or relative was the second most common response in both surveys (61% nationally and 63.7% in North Carolina). Of note, North Carolinians reported higher utilization of every coping mechanism named when compared to the national responses (Figure 4). This data will vary by state, thus, where data are available, it will be important to evaluate in which states and in which regions caregivers utilize which coping mechanisms.



Additionally, participants in each survey were asked specifically about a number of services they might have utilized as a caregiver. Of those asked, a higher portion of individuals nationally and in North Carolina indicated having requested information about getting financial help for the care recipient than any other kind of service or assistance listed; 25% of respondents nationally and 36.3% in North Carolina reported making this request.

In North Carolina 12.2% of respondents reported having taken part in a support group for caregivers, compared to only 7% of caregivers nationally. Conversely, a higher portion of caregivers nationally report having an outside service provide transportation and having an outside service such as meal delivery when compared to caregivers in North Carolina. These data are presented below in Figure 5.

Figure 5: In your experience as a caregiver, have you ever:



Unmet Need

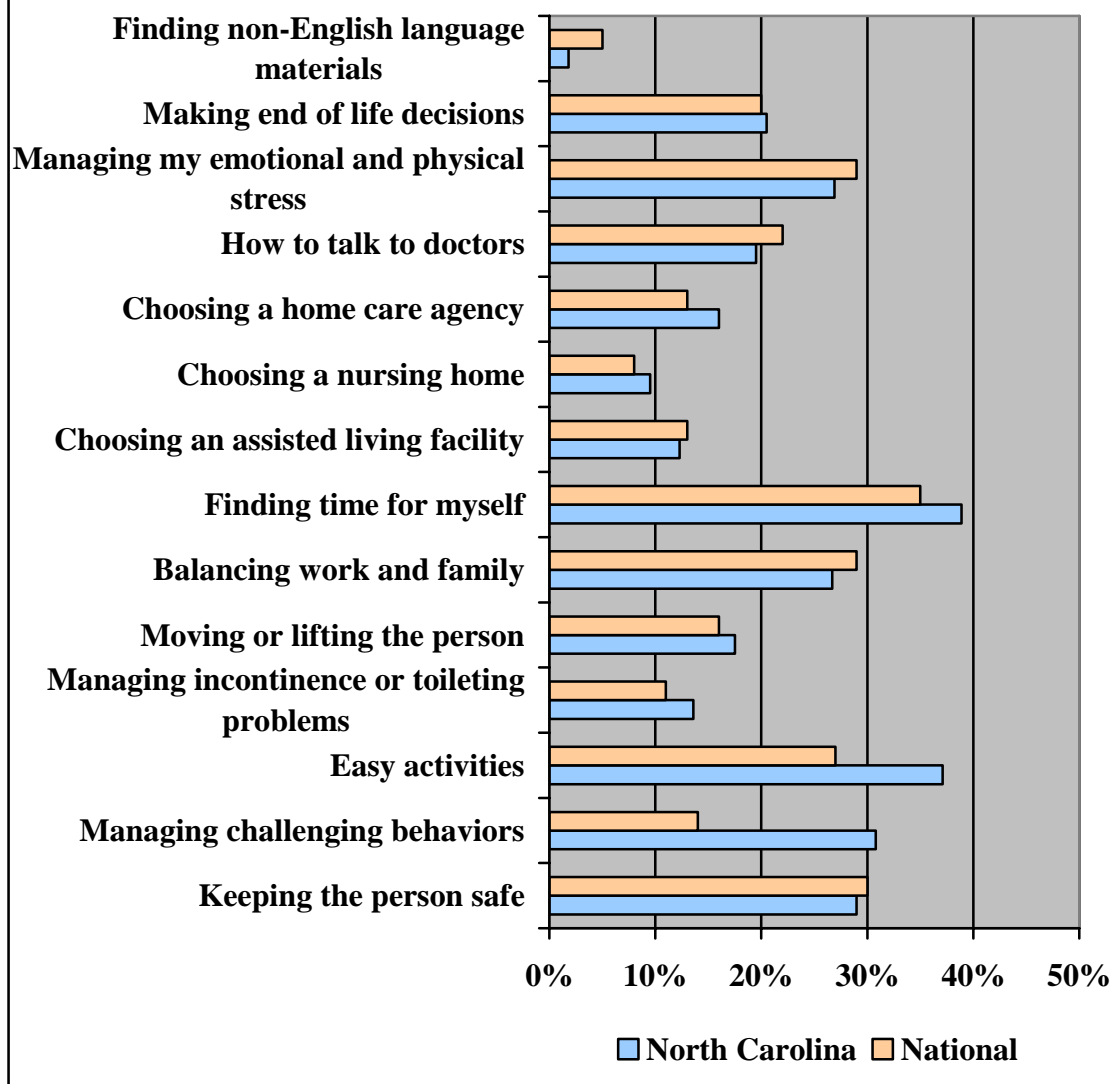
An important component of this project is to assess the gaps that exist in current services for caregivers. In order to better understand what needs may persist for caregivers, participants in NAC/AARP’s national survey and the North Carolina follow-back survey were asked to indicate from a list of 14 activities or issues which they needed more help with or information about.

Results from these questions indicate that caregivers need help most in finding time for themselves (35% nationally and 38.9% in North Carolina). Generally, respondents from NC and the Nation answered in similar fashion. Over 20% of respondents on both surveys indicated needing more help or information in making end of life decisions, managing emotional and physical stress, balancing work and family, and keeping the care recipient safe at home.

Unlike the national response, caregivers in North Carolina demonstrated a substantial need (37.1%) for more information on “easy activities” to do with the care recipient. This ranks as the second greatest unmet need for North Carolinians and is substantially higher than the 27.1% of respondents nationally who indicated a need for help in this area.

These data and other details are presented in Figure 6.

Figure 6: As a caregiver, on which of the following do you feel you need more help or information:



DISCUSSION

By investigating the demographic profile of caregivers in the U.S at national, regional, and state levels, and by analyzing new and existing data on caregiver services that are available and needed, a number of key issues affecting caregivers have been identified. Key findings and their implications for public health are presented in this section.

Key Findings and Implications

Demographics

Caregiver prevalence varies from 13%-17% by region, and from 10%-21% by state or region (not including Illinois or Puerto Rico). Racial and ethnic composition of the caregiver population varies substantially by state and region; most often this composition mirrors that of the general population.

In every region, women are more likely than men to be caregivers (range: 56.4%-61.3% female). This is especially true in the South East where 61.3% of caregivers are women.

Because of vast differences in prevalence and racial/ethnic composition of caregivers, further research is needed at regional and, preferably, the state level in order to effectively target the specific needs of caregivers. While financial resources for caregiver services remain scarce, it is of utmost importance that services, interventions and provisions be targeted and effective when implemented.

HRQoL

A major finding of this research is that caregivers nationally are 14% more likely to rank their HRQoL as “fair” or “poor” than non-caregivers. This finding adds to a growing body of literature that demonstrates the negative outcomes associated with caregiving. This study, however, generalizes the negative effects of caregiving, independent of care recipient age or disease status.

The public health implications of a generalized reduction in HRQoL among caregivers are enormous, especially when 17% of the population falls within this group. It is incumbent upon us to explore further and understand these data - to understand better how and why caregivers are suffering a diminished quality of life and to create appropriate services and policies that better meet the needs of this population. National level data are only indicators of the problem; real and effective interventions to improve the HRQoL of caregivers must rely upon state-level data, so as to respond to the specific, distinct needs of a caregiver population.

Support

Another major finding of this research is that some caregivers are reaching out for additional support. The data indicate that 25.4% of respondents in NC and 23% nationally receive outside help from an agency-hired aid or nurse. Additionally, 7.2% of caregivers in NC and 7% nationally receive outside help from an independently-hired aid or nurse. In North Carolina, 63.7% of caregivers identified have someone else who provides some unpaid care, and 31% of all caregivers are not the primary unpaid caregiver to their care recipient.

This information is important as individual communities think about building and further developing support networks for caregivers. Further analysis of support of caregivers in North Carolina is intended and possible within this dataset. This type of information will be critical in understanding the potential impact external support may have on the experience of being a caregiver.

Unmet Need

Two specific areas of caregiver unmet need surface as a product of this research. The first is a product of the outline of the national, regional and state response to the 2000 BRFSS question regarding where individuals would go to seek information on short or long term care. This question was initially dismissed and is now re-examined based on the very high prevalence of respondents indicating “I don’t know” as a response to the question. A full 30% of respondents nationally chose this response, indicating that they did not know where they would turn for information on this aspect of caregiving. Regional variation in the

portion of respondents who did not know where to seek information ranged from 17.1% in the Far West to 40.1% in the Plains. Over 50% of respondents in Iowa and Nebraska indicated that they did not know where they would go to seek this information.

Public health information, education, and communication (IEC) about where to go for certain services needs to be integrated into any program that aims to better the lives of caregivers or care recipients. This unmet need has the capacity to undermine any service program that is available to the caregiving dyad; if the caregiver is unaware of how to secure information on certain services, the service itself is of little help to the dyad it intends to serve.

Ironically, the second area of unmet need for caregivers might be identified as support. This unmet need is substantiated by a high proportion of respondents in North Carolina, who indicated that their care recipient needed someone else's help at home, school or work and could not easily get it (41.3% experience this at least monthly, 10.8% experience it daily), in conjunction with a high portion of respondents (35% nationally and 38.9% in North Carolina) who indicated that finding time for themselves is something with which they need more help or information.

The implications of these unmet needs are that caregivers need more support – in order to both provide the needed help to care recipients and find the time that they need for themselves. Interestingly, however, of those caregivers who indicated that they need help or information finding time for themselves 9.4% have used respite services. A majority of caregivers who have used respite services (64.6%) are caregivers who also need help finding time for themselves.

Thus, the public health implication of these findings may actually be, again, to stress the importance of information and public health messages and communication. If services are available, a critical piece of service delivery is to make sure that target populations know how to access these services.

Need for Further Research

Clearly there is substantial need for further research on the state-level experience of caregivers and the needs of caregivers. The research team at the University of Florida will continue to analyze the in-depth data from North Carolina, but other states must follow suit if the data are to be meaningful at a national level.

State Variability and Quality as an Outcome

The BRFSS is an incredible asset for investigation into the experience of caregivers. By linking with BRFSS and using the expanded caregiving module, researchers have access to the entire BRFSS database of core questions, as well as the targeted caregiver questions included in the module. However, as more states begin to collect data on caregiving in this fashion, we must be aware of variations in data collection and quality among states. The CDC mandates that all states collect data on the core BRFSS questions. Some states have BRFSS offices that conduct this research in-house while others outsource the data collection. Some states use the additional revenue created by offering additional modules to special interest groups (such as the caregiving module in North Carolina) to supplement their budget, therefore allowing for a larger sample size than might otherwise be feasible. Minimally,

most states will need external financial support to increase the amount of caregiving surveillance data via the BRFSS. Variations in data collection may also lead to differences in response rates and data quality. Further research on where and how this variability occurs will be helpful in understanding how to effectively compare data across states.

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APPENDICES

1. North Carolina BRFSS 2005 Caregiving Question Module
2. North Carolina BRFSS-linked Caregiver follow back survey

Questions highlighted in yellow were asked as part of the NC state-planned BRFSS
Questions highlighted in blue are the CDC-Project Caregiver Module
Questions highlighted in green are not counted in the 10 Caregiver Module questions

Section 1: Health Status

1.1 Would you say that in general your health is: (73)

Please read

- 1 Excellent
- 2 Very Good
- 3 Good
- 4 Fair
- or
- 5 Poor

DO NOT READ

- 7 Don't know / Not sure
- 9 Refused

Section 2: Healthy Days - Health-related Quality of Life

2.1. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? (74-75)

- Number of days
- 8 8 None
- 7 7 Don't know / Not sure
- 9 9 Refused

2.2. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? (76-77)

- Number of days
- 8 8 None
- 7 7 Don't know / Not sure
- 9 9 Refused

CATI Note: If Q2.1 and Q2.2=88 (None), ⇒Go to next section.

Section 15: Disability

The following questions are about health problems or impairments you may have.

15.1. Are you limited in any way in any activities because of physical, mental, or emotional problems?(151)

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

15.2. Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone? (152)

NOTE: Include occasional use or use in certain circumstances.

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

NC Module 19: Caregiving

1. People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend? (660)

- 1 Yes
- 2 No go to the closing
- 7 Don't know / Not sure go to the closing
- 9 Refused go to the closing

2. What age is the whom person to you are giving care?

(661-662)

Code age in years [0-115]

- 777 Don't know/Not sure
- 999 Refused

→IF MORE THAN ONE: What is the age of the person to whom you are giving the most care.

Ask, if age of the person (NC19Q02) is 60 or older

3. Did that person have a problem with memory loss or confusion or a disorder like Alzheimer's Disease? (663)

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

NC Module 20: Care Giving Supplement (ASK ONLY: April-June 2005)

20.1 What is the gender of the person you are caring for? Male Female

20.2 What is your relationship to the person who needs care or assistance? For example are you his/her (mother/father)?

(program for gender)(probe for relationship – if more than one, ask “Which is the person you take care of the most often?”)

- | | | | |
|----|--------------------|----|--------------------------|
| 1 | Aunt | 15 | Mother-in-law |
| 2 | Brother | 16 | Neighbor |
| 3 | Daughter | 17 | Nephew |
| 4 | Daughter-in-law | 18 | Niece |
| 5 | Father | 19 | Other Relative |
| 6 | Father-in-law | 20 | Paid caregiver/assistant |
| 7 | Friend | 21 | Partner |
| 8 | Granddaughter | 22 | Sister |
| 9 | Grandfather | 23 | Son |
| 10 | Grandmother | 24 | Son-in-law |
| 11 | Grandparent-in-law | 25 | Uncle |
| 12 | Grandson | 26 | Wife |
| 13 | Husband | 77 | Don't Know or Not Sure |
| 14 | Mother | 99 | Refused |

20.3. What do you think or what has a doctor said is the major health problem that s/he has? CHECK ONE CONDITION ONLY

- | | | | |
|----|--------------------------------|----|----------------------------------|
| 1 | (ADD/ADHD) | 16 | Heart disease |
| 2 | AIDS/HIV | 17 | Hypertension/high blood pressure |
| 3 | Arthritis/rheumatism | 18 | Lung disease/emphysema |
| 4 | Asthma | 19 | Multiple Sclerosis |
| 5 | Cancer | 20 | Muscular Dystrophy |
| 6 | Cerebral Palsy | 21 | Osteoporosis |
| 7 | Chromosomal anomaly | 22 | Parkinson's |
| 8 | Dementia | 23 | Spinal Cord Injury (SCI) |
| 9 | Depression | 24 | Stroke |
| 10 | Down's syndrome | 25 | Traumatic Brain Injury (TBI) |
| 11 | Anxiety other emotional | 26 | Other (_____) |
| 12 | Developmental delays | | Do not read |
| 13 | Diabetes | 77 | Don't know/Not sure |
| 14 | Eye/vision problem (blindness) | 99 | Refuse |
| 15 | Hearing problems (deafness) | | |

20.4. Given this condition, with which TWO of the following areas does s/he most need your help?

CHECK UP TO TWO

- | | | | |
|---|--|----|-------------------------------|
| 1 | Learning, remembering, and confusion; | 5 | Moving around; |
| 2 | Seeing or hearing; | 6 | Getting along with people; or |
| 3 | Taking care of oneself, such as eating, dressing, bathing, or toileting; | 7 | Feeling anxious or depressed |
| 4 | Communicating with others; | 9 | Don't Know |
| | | 10 | Refused |

20.5. For how long have you provided care for him/her? (672-674) Do Not Read; Code using respondent's unit of time

- 1_ _ Days
- 2_ _ Weeks
- 3_ _ Months
- 4_ _ Years
- 777 Don't know/Not sure
- 999 Refused

20.6. In an average week, how many hours do you provide care for him/her because of his/her long-term illness or disability?

___ hours per week

777 Don't know/ Not sure

999 Refused

20.7. I am going to read a list of difficulties you may have faced as a caregiver. Please indicate which TWO of the following is the greatest difficulty you have faced in your caregiving; CHECK UP TO TWO

- 1 Caregiving creates a financial burden;
- 2 Caregiving doesn't leave enough time for yourself;
- 3 Caregiving doesn't leave enough time for your family;
- 4 Caregiving interferes with your work;
- 5 Caregiving creates or aggravates health problems;
- 6 Caregiving affects your family relationships;
- 7 Caregiving creates stress; or
- 8 Another difficulty (TEXT FIELD)
- 77 Don't know/Not sure
- 99 Refused

20.8. In the past 12 months have you sustained an injury while helping him/her?

- 1 Yes
- 2 No
- 777 Don't know/Not sure
- 999 Refused

20.9. How far away do you live from him/her? Do you live

- 1 In the same house
- 2 Less than 20 minutes away
- 3 Between 20 and 60 minutes away
- 4 Between 1 and 2 hours away, or
- 5 More than two hours away?
- 777 Don't know/Not sure
- 999 Refused

20.10. We are conducting a study to assess the amount of care-giving in North Carolina. Can we call you back in two weeks to ask some additional questions? (679)

- 1 Yes Go to Q5
- 2 No Go to Closing Statement

20.11. When we call you back, just so we're talking about right person, please tell the first name of the person to whom you are giving care. (680)

_____ care recipient (export field)

9 Refused - use proxy name (e.g. Jane or John) if respondent refuses name

North Carolina 2005 Caregiver 20-minute Follow-back Questionnaire

If NC Module Caregiving Q19.1= 1; INTERVIEWER:

“HELLO, my name is (name), and I’m calling for the North Carolina Health Department and the Centers for Disease Control and Prevention. My I please speak with (NC Caregiving Supplement 20.12)? Hello (NC Module Caregiving Supplement 20.12).

IF ANOTHER PERSON: My name is (name), and I’m calling for the North Carolina Health Department and the Centers for Disease Control and Prevention.

IF YOU ARE SPEAKING WITH THE CAREGIVER: (skip to next sentence)

When we spoke with you a few weeks ago, you indicated that you provide care or assistance to someone who has a long-term illness or disability. You also indicated that you would be willing to answer a few questions about the care you provide this person.

Characteristics of relationship

1. In the past 12 months how many people did you provide this type of care for?

(Probe if necessary: regular care or assistance to a friend or family member [adults or child]who has long-term illness or disability.) (ENTER NUMBER) _____ DK REF

→IF ONE PERSON: Now, I’d like to ask you some questions about the person for whom you provide care.

→IF MORE THAN ONE: Let’s focus on the person for whom you provide the most assistance.

2. What is this person’s relationship to you?

AUNT	NEIGHBOR
BROTHER	NEPHEW
DAUGHTER	NIECE
DAUGHTER-IN-LAW	OTHER RELATIVE
FATHER	PARTNER
FATHER-IN-LAW	EMPLOYER/CLIENT?
FRIEND	SISTER
GRANDDAUGHTER	SON
GRANDFATHER	SON-IN-LAW
GRANDMOTHER	UNCLE
GRANDPARENT-IN-LAW	WIFE
GRANDSON	DK
HUSBAND	REFUSE
MOTHER	
MOTHER-IN-LAW	

3. IF “SPOUSE”, “AUNT/UNCLE”, “GRANDPARENT IN-LAW” : RECORD GENDER OF THE RESPONDENT’S (Q2 CODE): MALE FEMALE DK

3a. IF “OTHER RELATIVE”, “FRIEND”, “NEIGHBOR”, “PARTNER”, PAID CAREGIVER/ASSISTANT : Would you mind telling me if your (Q2 CODE) is male or female? MALE FEMALE REF

4. Is your (Q2 CODE) currently widowed, married, living with a partner, separated, divorced, or single - that is never been married?

WIDOWED MARRIED LIVING WITH A PARTNER SEPARATED DIVORCED SINGLE
DK REF

5. How old is your (Q2 CODE)? PROMPT: Your best estimate is fine. _____ DK REF

6. Does your (Q2 CODE) live....
 In the same household as you, (GO TO Q9) A one to two hour drive from your home, or
 Within twenty minutes of your home, More than two hours away?
 Between 20 minutes and an hour from your DK (GO TO Q7)
 home, REF (GO TO Q7)

7. IF NOT IN HOUSEHOLD: On average, how often do you visit your (Q1B CODE)? More than once a week, once a week, few times a month, once a month, few times a year, or less often?
 MORE THAN ONCE A WEEK FEW TIMES A YEAR
 ONCE A WEEK LESS OFTEN
 FEW TIMES A MONTH DK
 ONCE A MONTH REF

8. IF NOT IN HOUSEHOLD: Does your (Q2 CODE) live in: READ
 His or her own home, A nursing home or facility, (GO TO Q10)
 Someone else's home, Or somewhere else? (SPECIFY _____)
 An independent living or retirement community, DK
 In an assisted living facility where some care may be provided, REF

9. Does your (Q2 CODE) live: CHECK ALL THAT APPLY
 Alone, (SKIP TO q10) With an aide, housekeeper, or other staff,
 With her/his spouse, Or with someone else? (SPECIFY _____)
 With her/his grown children, DK
 With other family members, REF
 With friends,

10. Does your (Q2 CODE) live in an urban, suburban, or rural area?
 URBAN DK
 SUBURBAN REF
 RURAL AREA

Environmental Factors

I am going to ask you a set of questions about barriers that you may have experienced while providing care for your (Q2 CODE). Think about the past year, and tell me whether each item on the list *I will read* has been a problem daily, weekly, monthly, less than monthly, or never. If the item has occurred, then answer the question as to how big a problem the barrier has been. (Note: if a question asks specifically about school or work and your (Q2 CODE) neither works nor attends school, answer *not applicable*).
 Probe: Please remember to answer the question as it relates to your caregiving experience with your (Q2 CODE). (REPEAT PROBE IF NECESSARY.)

11a. In the past 12 months, how often has the availability of transportation been a problem?
 (READ IF NECESSARY)
 DAILY LESS THAN MONTHLY
 WEEKLY NEVER (GO TO 12a)
 MONTHLY NOT APPLICABLE (GO TO 12a)

11b. When this problem occurs has it been a big problem or a little problem?
 BIG PROBLEM DK
 LITTLE PROBLEM REF

12a. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult for your (Q2 CODE) to do what he/she wants or needs to do?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 13a)
MONTHLY	NOT APPLICABLE (GO TO 13a)

12b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

13a. In the past 12 months, how often have other aspects of the surroundings – lighting, noise, crowds, etc – made it difficult to do what your (Q2 CODE) wants or needs to do?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 14a)
MONTHLY	NOT APPLICABLE (GO TO 14a)

13b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

14a. In the past 12 months, how often has the information you or your (Q2 CODE) wanted or needed not been available in a format that your (Q2 CODE) uses or understands?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 15a)
MONTHLY	NOT APPLICABLE (GO TO 15a)

14b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

15a. In the past 12 months, how often has the availability of health care services and medical care been a problem for your (Q2 CODE)?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 16a)
MONTHLY	NOT APPLICABLE (GO TO 16a)

15b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

16a. In the past 12 months, how often did your (Q2 CODE) need someone else's help at home, school or work and could not get it easily?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 17a)
MONTHLY	NOT APPLICABLE (GO TO 17a)

16b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

17a. In the past 12 months, how often have other people's attitudes been a problem for your (Q2 CODE) at home, school or work?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 18A)
MONTHLY	NOT APPLICABLE (GO TO 18A)

17b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

18a. In the past 12 months, how often did your (Q2 CODE) experience prejudice or discrimination?

DAILY	LESS THAN MONTHLY
WEEKLY	NEVER (GO TO 19)
MONTHLY	NOT APPLICABLE (GO TO 19)

18b. When this problem occurs has it been a big problem or a little problem?

BIG PROBLEM	DK
LITTLE PROBLEM	REF

Characteristics of relationship

19. Is your (Q2 CODE) frail, sick, disabled, or none of these? (ACCEPT MULTIPLE RESPONSES)

FRAIL	NONE OF THESE
SICK	DK
DISABLED	REF

IF NC Caregiving Module 19.2 CODE < or = 2 THEN GOTO Q35

ADULTS ONLY. IF NC Caregiving Module 19.2 CODE > or = 18 THEN: I'm going to read a list of day-to-day activities for which you may provide assistance to your (___). For each activity, please tell me if you provide some, full, or no assistance to your (___). (Repeat stem if necessary)

SOME ASSISTANCE	DK
FULL ASSISTANCE	REF
NO ASSISTANCE	

20. Getting in and out of beds and chairs

21. Getting dressed

22. Getting to and from the toilet

23. Bathing or showering

24. Dealing with incontinence or diapers

25. Eating

26. Taking medicines, pills, or injections

Using the same responses, "some, full or no assistance", please tell me what level of assistance you provide to your (___) for the following activities. If you do these tasks entirely, please indicated "full assistance".

SOME ASSISTANCE	DK
FULL ASSISTANCE	REF
NO ASSISTANCE	

27. Managing finances, such as paying bills, or filling out insurance claims

28. Grocery shopping

29. Housework, such as doing dishes, laundry, or straightening up

30. Preparing meals

31. Transportation, such driving, or helping arrange other transportation

32. Arranging or supervising services from an agency, such as nurses or aides

**IF NO/DK/REF TO ALL Q20-Q32: TERMINATE (TREAT AS NON CAREGIVER HOUSEHOLD)
GOTO Q39**

CHILDREN 3-18

33. Compared to other (NC Caregiving Module 19.2)-year-old children, would you say that your (Q2 CODE) experiences any difficulty taking care of (himself/herself), for example, doing things like eating, dressing and bathing?

YES	DON'T KNOW
NO	REFUSED
N/A	

34. Compared to other (NC Caregiving Mole 19.2)-year-old children, would you say (he/she) experiences any difficulty) Learning, understanding, or paying attention?

YES	DON'T KNOW
NO	REFUSED
N/A	GOTO Q39

CHILDREN 2 AND under

35. Your (Q2 CODE) is how many months old?

36. Compared to other (Q35 CODE)-month-old children, would you say that your (Q2 CODE) experiences any difficulty with coordination or moving around, such as....?

IF 0-10 MONTHS OLDS SAY: "sitting, crawling or moving arms or legs?"

IF 10 - 23 MONTHS OLD, SAY: "walking or crawling?"

IF 24+ MONTHS OLD, SAY: "walking or running?"

YES	DON'T KNOW
NO	REFUSED
NOT APPLICABLE	

37. Compared to other (Q35 CODE)-month-old children, would you say (he/she) experiences any difficulty using (his/her) hands such as....?

IF 0-7 MONTHS, SAY: " grabbing small objects?"

IF 8-23 MONTHS, SAY: " holding a cup or eating finger foods?"

IF 24+ MONTHS, SAY: "using scissors, a pencil, or a fork?"

YES	DON'T KNOW
NO	REFUSED
NOT APPLICABLE	

38. [IF CHILD IS YOUNGER THAN 12 MONTHS, SKIP TO 37]

Compared to other (Q35 CODE)-month-old children, would you say (he/she) experiences any difficulty) Learning, understanding, or paying attention?

YES	NOT APPLICABLE
NO	DON'T KNOW
	REFUSED

ALL RESPONDENTS (SKIP IF NO ADL/IADL FOR ADULTS, AND NO SUPPORT ACTIVATES CHECKED FOR KIDS?)

39. Thinking now of all the kinds of help you provide for your (Q2 CODE), about how many hours do you spend in an average week, doing these things? __ HOURS PER WEEK DK REF

Medical Care

40. Does your (Q2 CODE) take any prescription medicine?

YES DK. SKIP TO 42
NO . SKIP TO 42 REF. SKIP TO 42

41. Do you feel you know as much as you need to about the prescription medicine your (Q2 CODE) takes, or that you need to know more about it?

KNOW AS MUCH AS NEED TO KNOW DK
NEEDED TO KNOW MORE ABOUT IT REF

There are many other ways that a caregiver may provide medical support. Do you ...

YES DON'T KNOW
NO REFUSED

42. Accompany your (Q2 CODE) to the doctor?

43. Help your (Q2 CODE) with the use of intravenous fluids (IV use)?

44. Change bandages or wound dressings for your (Q2 CODE)?

45. Help your (Q2 CODE) with medical equipment, such as a ventilator or oxygen?

46. Help your (Q2 CODE) with rehabilitation, such as exercise?

47. Are there other ways that you provide medical support to your (Q2 CODE)? What are they?

YES (TEXT) DON'T KNOW
NO REFUSED

48. During the past 12 months has your (Q2 CODE) been admitted to the hospital?

YES DON'T KNOW
NO REFUSED

Other caregiver support

49. Has anyone else provided unpaid help to your (Q2 CODE) during the last 12 months?

YES DK SKIP TO Q52
NO SKIP TO Q52 REF SKIP TO Q52

50. What relationship are they to your (Q2 CODE)? CODE UP TO TWO

IF CHILDREN, PROBE: Would that be your (Q2 CODE)'s son or daughter or both?

CODE IN TWO SEPARATE COLUMNS.

SPOUSE (gender)

MOTHER

FATHER

SON

DAUGHTER

FATHER-IN-LAW/MOTHER-IN-LAW

BROTHER

SISTER

BROTHER-IN-LAW/SISTER-IN-LAW

GRANDSON/GRANDDAUGHTER

OTHER RELATIVE (gender)

ALL FAMILY

NON-

RELATIVE/FRIEND/COMPANION/NEIGHBO
R (gender)

VOLUNTEER (E.G., RED CROSS) (gender)

NIECE/NEPHEW

SON-IN-LAW/DAUGHTER-IN-LAW

OTHER (SPECIFY ____ & gender)

NO ONE ELSE (GO TO Q52)

DK (GO TO Q52)

REF (GO TO Q52)

51. Who would you consider to be the person who provides *most* of the unpaid care for your (Q2 CODE): you or someone else?

SELF DK
SOMEONE ELSE REF
WE SPLIT IT 50-50 (VOLUNTEERED)

(52 – 65)

During the last 12 months, did your (Q2 CODE) receive paid help from any of the following, regardless of who paid for it. REPEAT STEM AS NECESSARY

YES	DK
NO	REF

52. An aide or nurse hired through an agency or service?

53. An aide or nurse hired *independently* - that is not through an agency or service?

54. A housekeeper hired to clean or cook?

55. Any other people who are paid to help her/him?

56. (IF YES TO ANY IN Q52-55 ABOVE, OTHERWISE SKIP TO 57): Who would you say provides more of your (Q2 CODE)'s care: you, other unpaid helpers, or paid helpers such as nurses or aides?

YOU (THE RESPONDENT)	DK
OTHER UNPAID HELPERS	REF
PAID HELPERS	

57. If you are sick and unable to provide care for your (___), is there someone else can provide care for him/her.

YES	DK
NO	REF

Stress on working caregivers

58. Have you been employed at any time since you began helping your (Q1B CODE)?

YES	DK (SKIP TO Q66)
NO (SKIP TO Q66)	REF (SKIP TO Q66)

Because of your experience as a working caregiver, did you ever:

YES	DK
NO	REF

59. Have to go in late, leave early, or take time off during the day to provide care

60. Have to take a leave of absence from work

61. Have to go from working full-time to part-time, or take a less demanding job

62. Have to turn down a promotion at work

63. Lose any of your job benefits at work

64. Have to give up working entirely

65. Choose early retirement

66. We have been talking about the help you provide for your (___). Do you feel you had a choice in taking on this responsibility of caring for him/her.

Had a choice	Don't know/Not sure
Had no choice	Refused

Change of roles due to caregiving

When people become caregivers, they often do many things for the care recipient.

67. Besides traditional caregiving activities, have you assumed other roles in your household since becoming a caregiver?

Yes
No

68. Please identify what other roles you have assumed since becoming a caregiver. CHECK ALL THAT APPLY

PAYING BILLS	BUYING GROCERIES
CHILD CARE	OTHER (TEXT)
HAD TO GO BACK TO WORK	

Physical, emotional and financial stress of caregiving

69. ONLY ASK IF CARE RECIPIENT DOES NOT LIVE WITH CAREGIVER (IF Q6 CODE = 1, SKIP TO Q70)

How much of your money would you estimate you spend in a typical month for groceries, medicines, or other out of pocket expenses because of your role as a caregiver? PROBE: Your best estimate is fine.

_____ RECORD AMOUNT TO NEAREST DOLLAR DK REF

There may have been other ways in which providing care to your (Q2 CODE) has affected your life. As a caregiver,

YES	DK
NO	REF

- 70. Do you have less time for friends or other family members than before?
- 71. Do you have to give up vacations, hobbies, or your own social activities?
- 72. Do you get less exercise than before?

73. Now, think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (Q2 CODE) is for you?

1 NOT AT ALL A STRAIN	5 VERY MUCH OF A STRAIN
2	DK
3	REF
4	

74. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your (Q2 CODE) is for you?

1 NOT AT ALL STRESSFUL	5 VERY STRESSFUL
2	DK
3	REF
4	

75. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your (Q2 CODE) is for you?

1 NO FINANCIAL HARDSHIP AT ALL	5 GREAT DEAL OF FINANCIAL HARDSHIP
2	DK
3	REF
4	

Injury

76. Have you experienced any injury related to your caregiving activities in the past 12 months?

YES	REF
NO (skip to Q82)	
DK	

77. What type of injury did you sustain? (Probe if necessary: such as back injury, neck injury, etc.)
(DO NOT READ)

BACK	KNEE
NECK	OTHER (TEXT)
SHOULDER	DK
ANKLE	REF

78. Did you see a doctor or other health care worker or have to go to the Emergency Department because of your injury?

Health Care Worker	DK
Emergency Department	REF
Did not have any medical care	

79. Did you miss any work days because of your injury?

YES	DK
NO (SKIP TO Q79)	REF

80. How many days of work did you miss? _____(ENTER NUMBER) DK REF

81. Did your injury interfere with your ability to take care of your ()?

Yes	DK
No	REF

Coping

I'm going to read a list of ways that caregivers such as you have coped with the demands of caregiving. For each one, please tell me whether you have used any of these. Have you ever tried to cope with caregiving stress by: READ LIST

YES	DK
NO	REF

82. talking with or seeking advice from friends or relatives?

83. exercising or working out?

84. taking any kind of medication?

85. talking to a professional or spiritual counselor?

86. praying?

87. going on the Internet to find information?

88. reading about caregiving in books or other materials?

Information/Services

In your experience as a caregiver, have you ever....

YES
NO
DK
REF

89. Requested information about how to get financial help for your (Q2 CODE)?
90. Taken part in a support group for caregivers?
91. Used a respite (**RESS** . PIT) service to take care of your (Q2 CODE) to free up your time?
92. Helped enroll your (Q2 CODE) in Adult Day Care?
93. Helped enroll your (Q2 CODE) in a recreation program or camp?
94. Had an outside service such as Meals on Wheels deliver meals to your (Q2 CODE)'s home?
95. Had an outside service provide transportation for your (Q2 CODE) instead of you providing the transportation?
96. Had modifications made in the house or apartment where your (Q2 CODE) lives to make things easier for your (Q2 CODE)?
97. Obtained formal training of some sort about how to care for a person with your (Q2 CODE)'s needs?
98. Obtained a raised toilet seat, handrail, bathing bench, magnifying lens for reading, or any other assistive device for your (Q2 CODE)?

I am going to read a list of issues. As a caregiver, on which of the following do you feel you need more help or information:

YES
NO
DK
REF

99. Keeping the person I care for safe at home
100. Managing challenging behaviors, such as wandering
101. Easy activities I can do with the person I care for
102. Managing incontinence or toileting problems
103. Moving or lifting the person I care for
104. Balancing my work and family responsibilities
105. Finding time for myself
106. Choosing an assisted living facility
107. Choosing a nursing home
108. Choosing a home care agency
109. How to talk with doctors and other healthcare professionals
110. Managing my emotional and physical stress
111. Making end-of-life decisions
112. Finding non-English language educational materials
113. Managing the health insurance issues of the person I care for

114. If you were looking for information about some aspect of helping take care of your (Q2 CODE), where would you turn? DO NOT READ CODES; CHECK ALL IF RESPONDANT VOLUNTEERS MORE THAN ONE ANSWER.

DOCTOR
NURSE, OTHER HEALTH PROFESSIONALS
INTERNET
BOOKS, MAGAZINES, LIBRARY
EMPLOYER
SENIOR CITIZEN.S CENTER

OTHER (SPECIFY _____)

DK

REF

Positive aspects of caregiving

115. How would you respond to this statement: Providing help to my (___) has made me feel good about myself? Do you

DISAGREE A LOT

DISAGREE A LITTLE

NEITHER AGREE NOR DISAGREE

AGREE A LITTLE

AGREE A LOT?

Thank you very much for your time. Your responses have been very helpful to this research.