

2008 Minnesota Behavioral Risk Factor Surveillance Survey Caregiving Module

Background

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS)¹ is a randomized telephone-based survey designed to measure behavioral risk factors for the adult population (18 years of age and older) living in households. It is a collaborative project of the Center for Disease Control and Prevention (CDC) and all U.S. States and territories. Its objective is to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries and preventable infectious diseases that affect the adult population. Data is used to identify demographic variation in health-related behaviors, for targeting services, addressing emergent and critical health issues, proposing legislative initiatives, and measuring progress towards state and national health objectives.

Family Caregiving in Minnesota and the BRFSS Caregiving Module

Family or informal caregivers provide the majority of Minnesota's long-term care (92%) for older adults with chronic health conditions and physical or cognitive limitations². Caregivers fill large gaps in health and long-term care due to recent medical advances, shorter hospital stays, limited discharge planning and worker shortages. Each percentage point decline in support provided by family and informal caregivers costs the State an estimated \$30 million additional each year in publicly funded long-term care³. While it is generally known that caregivers provide significant amounts of care, there is a lack of specific, Minnesota data on unpaid caregivers including: prevalence, demographics, length and duration of care provided, challenges and impacts of caregiving on their own health status. Minnesota-specific data on caregiving can be useful for planning and program development purposes, including targeting limited resources, setting priorities for programs and services, and developing legislative proposals.

In 2008, the Minnesota Department of Health (MDH) added a standardized CDC approved caregiving module to its BRFSS survey. The 13 question caregiving module was developed and tested in North Carolina in 2005. The module identifies many caregiver and care recipient characteristics, including: the age and gender of the care recipient, the relationship between caregivers and recipients, the length and hours of care provided, the difficulties faced by caregivers, the distance traveled to provide care, major health conditions of the care recipient, concerns about care recipients' memory or thinking, and injuries sustained by caregivers while

¹ CDC BRFSS website [BRFSS- CDC's Behavioral Risk Factor Surveillance System](http://www.cdc.gov/brfss/)

² The Survey of Older Minnesotans. (2005). Minnesota Board on Aging.

³ Transform 2010 Report. (2005). Minnesota Department of Human Services – Aging Division.

assisting care recipients (see Appendix A for the complete BRFSS Caregiving Module Questionnaire). In addition, the full BRFSS survey provides additional data on caregivers, such as age, gender, income, educational level and employment status.

The number of survey respondents for the 2008 BRFSS survey was 4,271 and of this total, 780 people identified themselves as caregivers and completed the 13 question caregiving module. The survey data is weighted so that responses in each age group represent the proportion of people in that group in Minnesota's general population. The raw data was compiled, analyzed and organized by the MDH. The Minnesota Department of Human Services (DHS) Aging and Adult Services Division and the Minnesota Board on Aging are grateful for the time and expertise of MDH in completing this task.

National Context and Future of the MN BRFSS Caregiving Module

The BRFSS survey defines family or informal caregivers as adults who are caring for a family member or friend *regardless of age* with a health condition, illness, or disability. The initial screening question used to identify family and informal caregivers in the BRFSS Caregiving Module reads as follows:

- 29.1 “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a family member or friend?” Yes, No, Don't Know/Not Sure or Refused

The most recent version of *Caregiving in the U.S.*⁴, a 2009 national randomized telephone-based survey of 1,480 caregivers, like the BRFSS Caregiving Module, addresses caregivers caring for a family member or friend regardless of age. It also includes additional interviews and comparisons for caregivers of older adults (50+ years of age), ethnicity of caregivers of older adults (50+ years of age), caregivers of children with special needs, and caregivers of young adults (18 – 49 years of age). Another survey report, *Caregiving: A National Profile and Assessment of Caregiver Services and Needs*⁵, compares the 2000 National BRFSS caregiver survey and *Caregiving in the U.S.*

Some limitations of Minnesota's 2008 BRFSS survey include not enough responses for accurate estimates of racial/ethnic distribution of caregivers, or regional analysis beyond Metro and non-Metro areas. The income distribution of caregivers is not available because the data set is missing about 10% of respondents. In addition, the BRFSS survey was not able to include all of

⁴ Caregiving in the U.S. (2009). National Alliance for Caregiving and AARP with funding from the Met Life Foundation.

⁵ Caregiving: A National Profile and Assessment of Caregiver Services and Needs. (2006). Rosalynn Carter Institute and the University of Florida.

the questions found in *Caregiving in the U.S.*, such as the Level of Care Index and utilization of caregiver supports as well as other paid and unpaid help, preclude full comparison between the two surveys.

The 13 question caregiving module reported here is not likely to be used in the future due to phone interview time constraints, efforts to limit the volume of questions and competing priorities for the content of the BRFSS survey. However, the key question used to identify caregivers (stated above) will remain in full BRFSS survey in future years, so limited data on the prevalence and demographic characteristics of caregivers in Minnesota will likely be available.

Summary Points

Here are five summary points based review of 2008 BRFSS caregiving data, as well as comparison of caregiving data with the full BRFSS survey, and with 2009 *Caregiving in the U.S.* data. These are general points based on available data. Further analysis of raw data would be needed to obtain additional information about various subgroups of caregivers.

- 1) Overall, the demographic characteristics of Minnesota caregivers surveyed are quite similar to those of the full BRFSS survey. This includes marital status, Metro or non-Metro residency, education and employment status. Two exceptions include differences in the age distribution and gender of caregivers compared to the full survey.
- 2) The majority of Minnesota caregivers are female, middle-aged and older (45 – 64 years), employed, in good or excellent health, and provide less than 10 hours of care each week (68.9%). However, one in seven caregivers (14.4%) is providing 21 to 40 hours of care per week, including nearly 6% providing more than 40 hours weekly which can increase one's vulnerability to physical strain, emotional stress and financial hardship. This "group" of caregivers is predominantly female, more likely to be 60 years of age or older, is caring for a spouse with memory concerns, or a child, and lives in the same household as care recipient. These caregivers are also more likely to be caregiving for extended periods of time (six or more years) and are more likely to report poor or fair health status and limitations of activity due to physical, emotional and mental problems, compared to those providing fewer hours of care each week.
- 3) The most frequently reported challenges faced by all caregivers surveyed include: 1) managing stress, 2) finding more time for self and family, 3) coping with finances, and 4) balancing work and caregiving. Caregivers describe the top four types of help most needed by care recipients as: 1) mobility issues, 2) taking care of self, 3) memory or thinking concerns (e.g., learning, remembering, confusion) and 4) feeling anxious or depressed.
- 4) Minnesota caregiving data is quite similar to national *Caregiving in the U.S.* survey data with respect to caregiver age, gender, the proportion caring for a relative versus a non-

relative, education and employment status. Some notable differences include the rate of caregiving and the proportion of caregivers providing 21 or more hours of care each week. National survey also shows more caregivers living in the same household as the care recipient, and more caregivers reporting fair to poor health status, as compared to MN BRFSS caregivers.

- 5) Minnesota caregivers who are caring for people who are reported to have memory or thinking concerns provide care for more years than caregivers caring for people without memory concerns. Caregivers of people with memory concerns also reported greater stress and a lack of time for self and family, as well as greater limitations to their activity due to their own health problems.

Demographic Characteristics of Family Caregivers (See Table A in Appendix B)

Age: The age of Minnesota caregivers is divided into four age ranges. The majority of respondents (53.8%) were in the 45 – 64 year age range. This age range is consistent with national caregiving data showing that caregivers, on average, are 48 years of age (and 50 years for caregivers of adults who are 50+ years of age). Minnesota’s percentage of 65+ caregivers is higher than national data (23.4% versus 13.0%, respectively). This could be attributable to longer life expectancies among Minnesotans.

The prevalence or rate of caregiving is 18.3% for caregivers caring for persons of all ages. Based on this information, the number of family or informal caregivers in Minnesota who are 18 years or older caring for persons of all ages is estimated to be 725,700⁶. According to this survey, Minnesota’s rate of caregiving is lower than the national rate (18.3% versus 28.5%, respectively).

Gender: Seven in ten caregivers are female (70.4%) and three in ten are male (29.6%) which is consistent with national caregiving survey data (66% female). The gap in the numbers of female and male caregivers is gradually closing as more men become caregivers.

Marital Status: Six in ten caregivers are married (61.9%) which is also consistent with national data (62%). The remaining categories as organized by the MDH are divorced (14.1%), widowed (8.5%), and single/separated/unmarried couples as a single category (15.5%).

Residence: There is a fairly even split between caregivers living in the Metro area versus Non-Metro counties (52.3% versus 47.7%, respectively). There are insufficient numbers of respondents in this survey for more regional analysis.

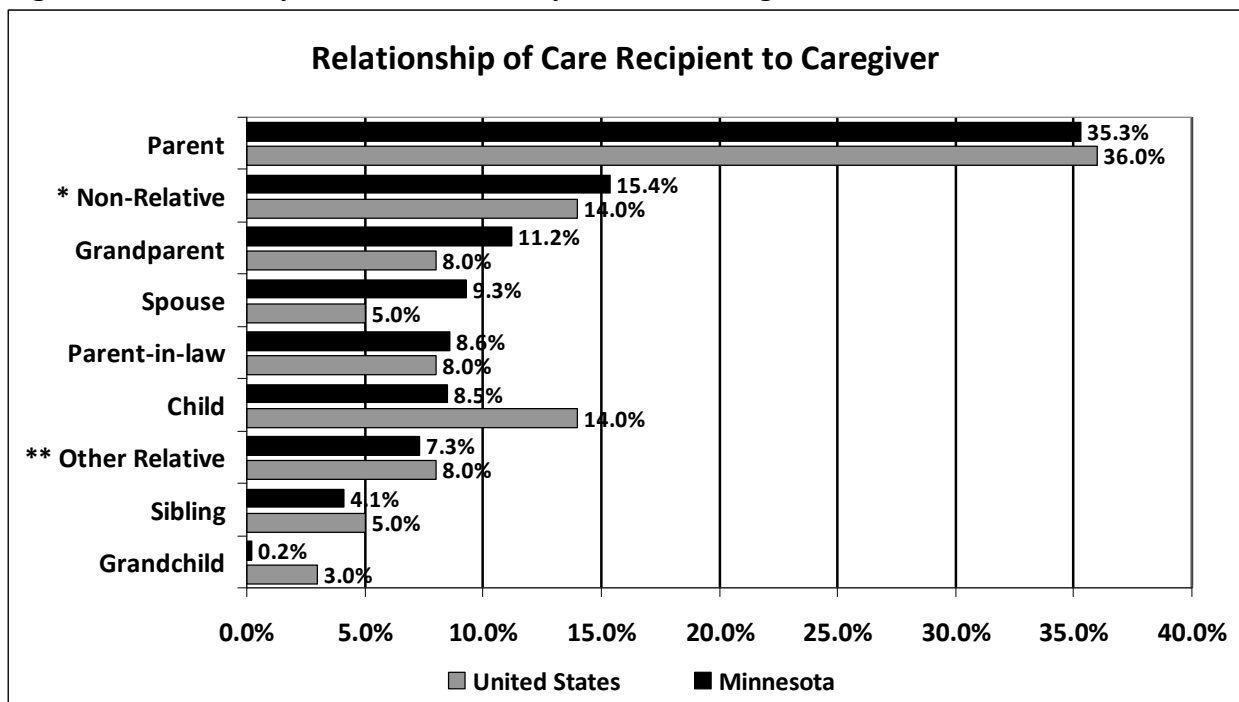
Race/Ethnicity: A larger data response set is needed to obtain accurate estimates of the racial distribution of caregivers in Minnesota. The 2000 BRFSS Caregiver survey shows the racial

⁶ MN State Demographer. 2000 Census Data for Minnesota Adults Age 18 Years or Older.

distribution of caregivers among the U.S. Plains States⁷ as: White (91.9%), African American (2.6%), Hispanic (2.5%), American Indian (1.7%), Asian/Pacific Islander (0.7%) and Other (0.8%). The 2009 *Caregiving in the U.S.* survey data on race and ethnicity shows the national distribution to be: White (72%), African American (13%), Hispanic (12%), American Indian/Other (2%), and Asian/Pacific Islander (2%). In addition, the 2009 *Caregiving in the U.S.* survey includes a supplemental report focusing on ethnicity of caregivers of persons who are 50 years or older⁸.

Relationship to Care Recipient: Minnesota’s ratio of relative to non-relative caregivers is 85% to 15% which is very similar to national *Caregiving in the U.S.* survey data (86% to 14%). Figure 1. provides breakdown of relative and non-relative caregivers in comparison with national data.

Figure 1. Relationship between Care Recipients and Caregivers in Minnesota, United States



* Examples of Non-relatives include: partners, significant others, friends or neighbors.

** Examples of Other Relatives include: sister-in-laws, aunts, uncles, nieces or nephews.

Sources: *Caregiving in the U.S., 2009*; Minnesota BRFSS Caregiving module, 2008.

Two in every five caregivers (46%) are caring for a parent or parent-in-law. One in seven caregivers is a non-relative caregiver (partner, friend or neighbor) reinforcing the importance of informal caregiving. One in nine Minnesota caregivers (11.2%) is caring for a grandparent, followed by nearly one in ten caring for a spouse (9.3%). The percentage of spousal caregivers is quite a bit lower in these surveys because respondents are caring for persons of all ages. In

⁷ U.S. Plains States are defined as Iowa, Kansas, Minnesota, Missouri, Nebraska, North and South Dakota. Source: *Caregiving: A National Profile and Assessment of Caregiver Services and Needs*.

⁸ *Caregiving in the US: (2009). A Focused Look at the Ethnicity of Those Caring for Someone Age 50 or Older.* www.caregiving.org

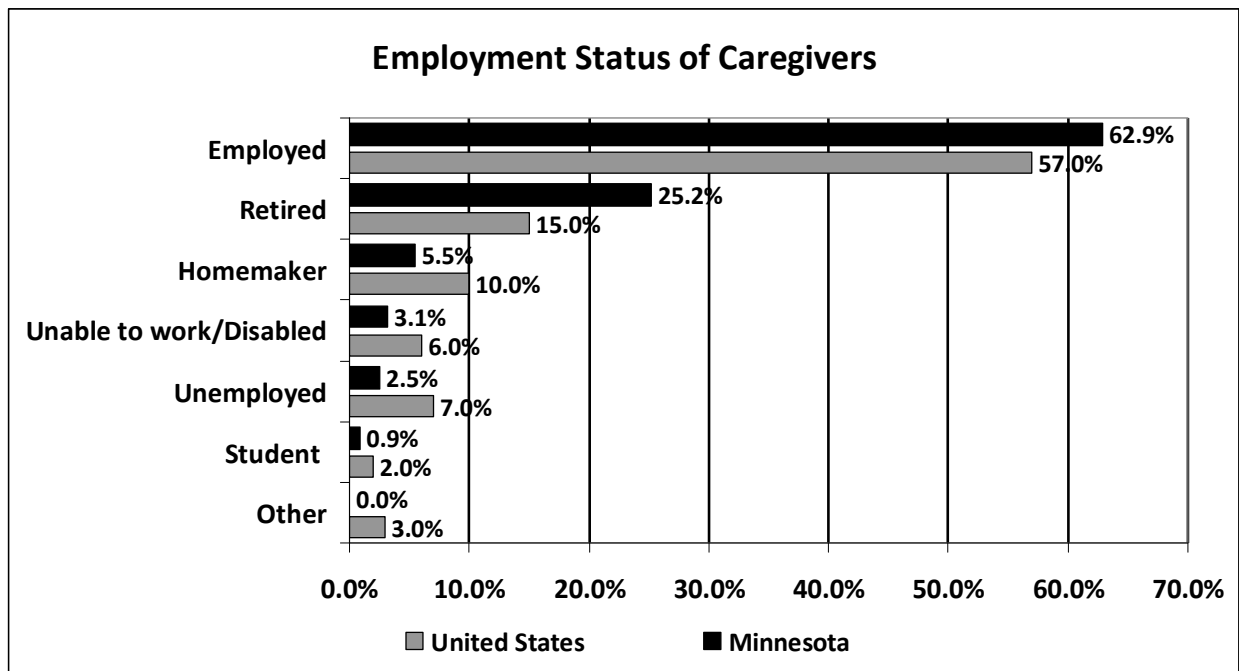
addition, one in 12 Minnesota caregivers is caring for a child with a health problem or a disability. The *Caregiving in the U.S.* conducted additional interviews of caregivers of children with special needs, and caregivers of young adults (18 – 49 years of age).

Income: The household income of Minnesota caregivers is not available due to missing data on 10% of survey respondents. In addition, income is not reported uniformly (e.g., net versus gross income, household vs. individual income). National survey data shows the majority (55%) reporting an annual household income of \$50,000 or more, and two in five caregivers (43%) with an annual income of less than \$50,000 (net). Caregiving can create financial strain particularly for lower income households due to out-of-pocket costs for care recipients such as insurance premiums and co-pays, over-the-counter medications, food and medical supplies.

Education: Nearly seven in ten caregivers (69.2%) have attended some college or are college graduates. This is consistent with the percentages found in the full BRFSS survey as well as the national *Caregiving in the U.S.* survey data (70%).

Employment Status: Six in ten Minnesota caregivers are employed (62.9%) either full-time or part-time which is slightly higher than national survey data (57%). Figure 2. provides more information about employment status of caregivers and compares it with national survey data.

Figure 2. Employment Status of Caregivers in Minnesota, United States



Note: The national survey results for “disabled” compared to MN BRFSS results for “unable to work.”

Note: “Employed” is the sum of “working full-time” and “working part-time” from the national survey, and the sum of “wages” and “self-employed” from the MN BRFSS survey.

Sources: Caregiving in the U.S., 2009; Minnesota Behavioral Risk Factor Surveillance System, Caregiving Module, 2008

Characteristics of the Family Caregiving Experience (See Table B in Appendix B)

Caregiver's Time of Travel to Provide Care: Five in every ten caregivers (50.2%) live less than 20 minutes from the care recipient, while only one in five (20.7%) live in the same house with care recipient. One in six caregivers (16.5%) live 20 – 60 minutes away, 5.4% live 1 – 2 hours, and 7.2% live more than two hours away. The national survey found three in ten caregivers (29%) living together with the care recipient versus one in five Minnesota caregivers.

Average Number Hours of Care Provided Per Week: More than two-thirds of Minnesota caregivers (68.8%) provide 10 or fewer hours of care per week. One in every seven caregivers surveyed (14.4%) provide 21 or more hours per week, as compared to 28% nationally. On average, caregivers reported spending 20 hours a week providing care for the care recipient.

Duration of Care Provided by Caregiver: One-third of caregivers surveyed (34.6%) are providing care for 12 months or less, one in four (25.6%) for 13 months to two years. Four in ten caregivers (39.8%) are providing care for three or more years including one in five (20.4%) who are providing care for six years or more. Nationally, the average length of caregiving is 4.6 years.

Caregiver Self-Reported Health Status: Fair or poor health status is not significantly different among caregivers versus non-caregivers surveyed (12% and 11.2%, respectively). However, the longer a caregiver has been providing care, the more likely she or he is to report poor or fair health. Nationally, 23% of those caregiving for five years or more report their health status as fair or poor.

Limitation of Activity: Survey respondents were asked if they are limited in any way in any activities because of physical, mental or emotional problems. Caregivers were slightly more likely to report a limitation of activity than non-caregivers (26.7% versus 21.5%, respectively).

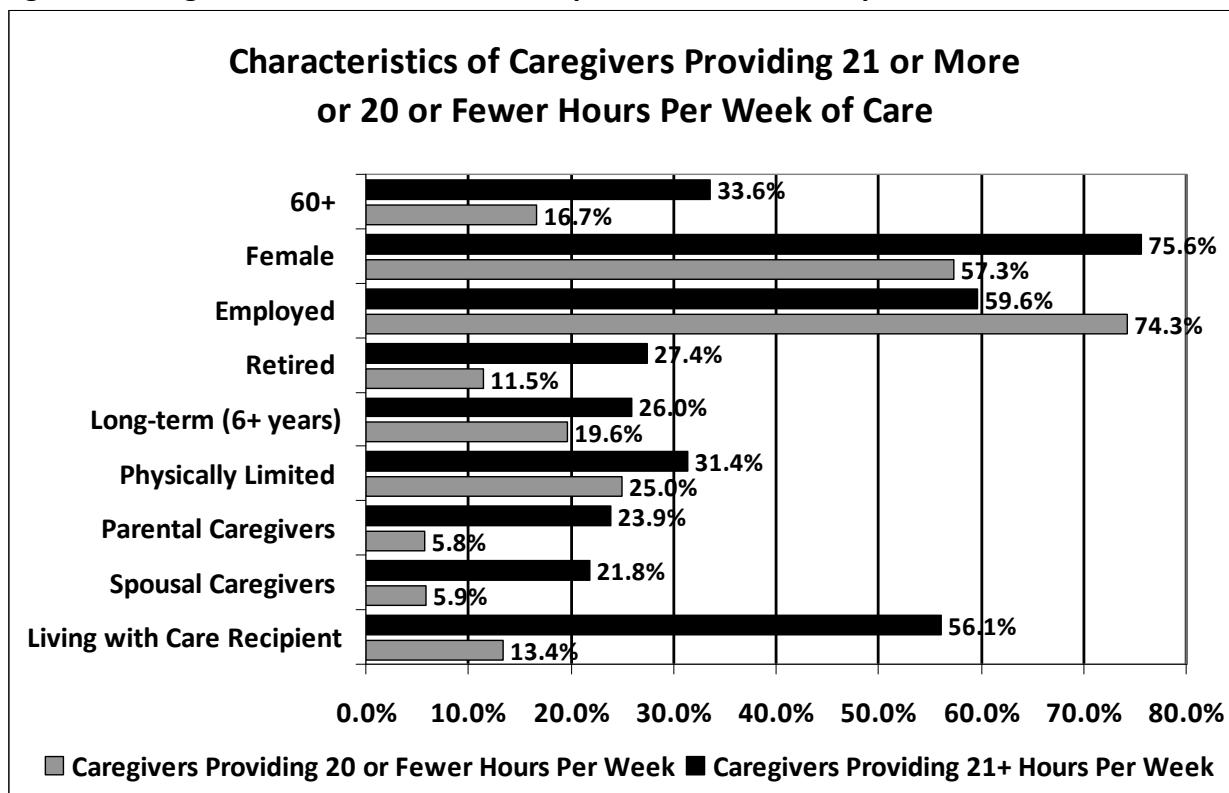
Difficulties Faced by Caregivers: Survey respondents were asked to check up to two responses regarding difficulties they face as caregivers. The 764 responses were ranked according to the total number of responses in each category. The top four responses were: 1) Creates stress (288 responses), 2) Not enough time for self and family (241 responses), 3) Financial burden (76 responses), and 4) Interferes with work (60 responses). These areas are common difficulties faced by caregivers. Nationally, 31% of caregivers consider their caregiving situation to be emotionally stressful (rating their stress as 4 to 5 on a 5-point scale), with co-residence and burden of care being key factors related to stress.

Types of Help Most Needed by Care Recipient: Survey respondents were asked identify the areas where the care recipient needs the most help. Again, respondents were asked to check up to two responses to this question. A total of 1,022 responses were provided and the top four needs identified were: moving around (353 responses); taking care of oneself (185 responses); learning, remembering, confusion (162 responses); and feeling anxious or depressed (148 responses). See Table B for additional response categories.

Characteristics of Family Caregivers by Hours of Care Provided (See Table C in Appendix B)

The MN BRFSS caregiving module inquires about hours of care provided but does not use the Level of Burden Scale⁹ an index based on the amount of time spent caregiving each week and the types of activities (standard ADLs and IADLs) performed for the care recipient. Nationally, caregivers providing 21 or more hours of care per week are more likely to report worsening health than those providing 20 or fewer hours of care per week (29% vs. 13%, respectively). Figure 3. shows the characteristics of Minnesota BRFSS caregivers providing 21 or more hours of care and those providing 20 or fewer hours per week.

Figure 3. Caregiver Characteristics with Respect to Hours of Care per Week



Source: Minnesota Behavioral Risk Factor Surveillance System, Caregiving Module, 2008

In summary, caregiver providing 21 or more hours of care weekly are more likely to be 60+ years of age, female, retired, caring for longer periods of time, caring for a child or spouse, living with the person they care for, and a slightly more likely to have a physical than those providing 20 or fewer hours of care each week. National data shows that caregivers providing 21 or more hours of care each week, particularly those providing more than 40 hours are at a greater risk for physical strain, emotional stress and financial hardship than caregivers providing fewer hours of care. See Table C for more information.

⁹ Caregiving in the U.S. Findings from a National Survey: National Alliance for Caregiving and AARP, 1997.

Relationship of Care Recipient to Caregiver: Caregivers providing 21 hours or more of care each week were more likely to be caring for a child (23.9%) or spouse (21.8%) than those providing 20 or fewer hours of care each week. Caregivers providing 20 or fewer hours of care per week were more likely to be caring for a parent or parent-in-law (46.7%) followed by a non-relative (16.3%), and less likely to be caring for a spouse (5.9%) or child (5.8%) than those providing 21 or more hours of care each week.

Concern about Memory of Care Recipient: More than one-third of caregivers expressed concerns about care recipient's memory. There was little difference between caregivers providing 21 or more hours of care versus those providing 20 hours or fewer of care each week (39.8% and 38.6%, respectively).

Demographic Characteristics of Care Recipients (See Table D in Appendix B)

Minnesota care recipients are predominantly female (61%), six in ten (63.7%) are 65 years of age or older. This is consistent with national data showing the majority of care recipients as female (62%) with an average age of 61 years. Refer to Figure 1. for information about the relationship of care recipients and caregivers. One in ten (9.3%) care recipients is caring for a spouse. More than two in every five care recipients is a parent or parent-in-law (43.9%).

The top four health conditions of care recipients reported by caregivers include cancer, heart disease, diabetes and dementia. Those caregivers providing 21 hours or more each week were slightly less likely to be report cancer as a top health problem compared to caregivers providing 20 hours or fewer each week (8.1% versus 13.7%, respectively). Nearly 40% of caregivers expressed concerns about the care recipients memory or thinking, and related quality of life.

Characteristics of Family Caregivers Providing Care to Recipients with Memory Concerns (See Table E in Appendix B)

National literature frequently reports higher levels of stress, or burden, among caregivers of people with Alzheimer's Disease or Related Disorders (ADRD). This added stress is attributed to the longer duration and greater demands of care, including challenging behaviors that are commonly associated with ADRD. There is currently increased, local interest in caregiving for people with ADRD because the 2009 Legislature requested the Minnesota Board on Aging to convene an Alzheimer's Disease Working Group and submit a report with findings and recommendations in January 2011¹⁰. For these reasons and others, the MN BRFSS Caregiver Module data has been analyzed to highlight this issue.

However, it is important to note a few limitations in conducting this analysis. First, as a result of splitting the sample of caregivers into two portions, there were sometimes too few

¹⁰ Laws of Minnesota 2009, Chapter 159, Section 110.

<https://www.revisor.mn.gov/laws/?id=159&doctype=Chapter&year=2009&type=0>

respondents (i.e. too little data) to draw valid comparisons. Second, since there was an interest in capturing younger adults with memory concerns (e.g. people with younger onset Alzheimer’s disease), caregivers of people 45 or older were analyzed, rather than people 60 or 65 and older, which some may have preferred. Finally, the survey questions did not specifically ask caregivers about ADRD, but rather “memory concerns” in general. The questions on the survey related to this issue are as follows:

- 29.11 “Do you have concerns about your [care recipient’s] memory or thinking?” Yes/No/Don’t know/Not Sure/Refused
- 29.12 “Does your [care recipient’s] memory or thinking interfere with everyday activities or quality of life?” Yes/No/Don’t know/Not Sure/Refused

Since the language used in the survey did not refer to ADRD, the findings presented here cannot be used to make or defend claims about care for people with ADRD specifically. However, the survey results provide important general information about the unique experience of caregivers who provide care for a person memory concern, whether ADRD or some other or lesser concern. The full set of MN BRFSS data on memory concern is available in Tables E and F. Three summary points are noted here.

Duration of Care Provided by Caregiver: The duration of care is longer for caregivers providing care to a person with memory concerns. Twenty-three percent of respondents who care for someone with memory concerns reported duration of three to five years compared to 17% of respondents who care for someone without memory concerns. The difference was also notable among caregivers with duration of 6 years or more. Twenty-two percent of respondents who care for someone with memory concerns reported duration of 6 years or more compared to 16% of respondents who care for someone without these concerns.

Difficulties Faced by Caregivers: Caregivers of people with memory concerns also reported greater stress and a lack of time for self and family. Twenty-three percent of respondents who care for someone with memory concerns indicated that they face difficult amounts of stress, compared to 15% of respondents who care for someone without memory concerns. Nineteen percent of respondents who care for someone with memory concerns reported having too little time for self and family, compared to 14% of respondents who care for someone without memory concerns.

Limitation of Activity: Caregivers of people with memory concerns indicated that they experience greater limitations of activity due to their own health problems. Thirty-two percent of respondents who care for someone with memory concerns reported that they face limitations of activity due to their own health, compared to 22% of respondents who care for someone without memory concerns.

Characteristics of Care Recipients Reported to have Memory Concerns (See Table F in Appendix B)

Approximately 37% of caregivers responding to the 2008 MN BRFSS Caregiving Module reported that they had concerns about the memory or thinking of their care recipient. Data from the survey also suggest that concerns about memory increase with care recipient age, as do caregiver concerns about memory interfering with quality of life of the care recipient.

A greater portion of care recipients with memory or thinking concerns are women (66.4%), as compared to care recipients in general (61%). More care recipients with memory concerns are a parent (45.1%) or parent-in-law (15.7%) of their caregiver, as compared to care recipients in general (35.3% and 8.6%, respectively).

The most significant difference between the care needs of people with memory concerns and those without is their need for assistance with “Learning, Remembering, and Confusion.” Twenty-two percent of caregivers of people with memory concerns reported providing this type of support, whereas only 15% of caregivers without this concern reported offering this assistance.

Conclusions

Family and informal caregivers are a diverse and changing group that brings a wealth of strengths and experiences to their caregiving situation. The majority of Minnesota’s 725,000 family and informal caregivers surveyed report their health as good or better (88%) and are providing less than 10 hours of care each week (68.9%). However, caregiving roles and responsibilities can shift rapidly with changes in care recipients’ health status. One in every seven Minnesota caregivers (14.4%) surveyed provides significant amounts of care each week, including six percent providing more than 40 hours of care weekly.

This survey reinforces opportunities for improving caregiver outcomes such as reducing stress, depression and improving self-efficacy skills, to improve the quality of and duration of care provided for care recipients, and prevent or delay spend down to MA and reliance on more costly forms of long-term care (e.g., nursing facility placement).

- Raise awareness about the role and importance of caregivers as key partners in chronic disease management, their needs, how communities can “share the care”, tied to improving outcomes for caregivers and care recipients among the general public including physicians, clinics, employers and others.
- Develop partnerships with physicians, clinics, long-term care consultants, care coordinators, disease organizations, respite care programs and others to integrate standardized questions to identify caregivers as part of routine medical visits, hospital or nursing facility discharge planning, long-term care assessments and home care visits.
- Link caregivers screened to be at moderate to high levels of stress with referrals for evidence-based/informed caregiver screening and assessment such as TCARE™ (Tailored Caregiver Assessment and Referral or other comparable tool) and customized supports

such as caregiver coaching and consultation, support planners, Family and Early Memory care for caregivers of persons with ADRD, Powerful Tools and others.

- Increase targeting of evidence-based/informed caregiver supports for caregivers with moderate to high levels of stress (e.g., intense personal care demands, those caring for a person with ADRD or behavioral issues, caregivers of persons with health and safety issues, caregivers with poor or fair health status, and limited finances.
- Partner with organizations serving diverse caregivers to develop caregiver education and supports, including adapting evidence-based/informed caregiver supports to address caregiver needs, where feasible. Includes targeting to grandparents and relative caregivers caring for children with special needs.
- Promote the use of technology to enhance in-person services and supports, (e.g., personal emergency response systems, home modifications/adaptive equipment and others) to monitor health and vital signs, decrease reliance on paid caregivers and reduce caregiver workload.

National Caregiving Surveys/Reports:

National Alliance for Caregiving, AARP and MetLife (2009, 2004). *Caregiving in the U.S.*

Retrieved on December 22, 2009 from:

<http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf>

Alzheimer's Association and National Alliance for Caregiving (2004). *Families care: Alzheimer's caregiving in the United States*. Retrieved on December 22, 2009 from:

<http://www.caregiving.org/data/alzcaregivers04.pdf>

Additional Resources:

National Family Caregiver Alliance, U.S. Administration on Aging and National Conference of State Legislatures (2007, 2004). *State of the States in Family Caregiver Support: A 50 State Study*. Retrieved on December 22, 2009 from:

http://www.caregiver.org/caregiver/jsp/content/pdfs/state_profile_mn.pdf

BRFSS Caregiving Reports from other States

North Carolina: [Characteristics and Health of Caregivers and Care Recipients --- North Carolina, 2005](#)

Florida: [University of Florida » PHHP » Florida Office on Disability & Health » Publications & Reports](#)).

Prepared by MN Department of Human Services Aging and Adult Services – December 2009

APPENDIX A

BRFSS Caregiving Module Questionnaire

Section 29: Care Giving

29.1 People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past month, did you provide any such care or assistance to a family member or friend?

- 1 Yes
- 2 No **[Go to the next section]**
- 7 Don't know / Not sure **[Go to the next section]**
- 9 Refused **[Go to the next section]**

29.2 What age is the person to whom you are giving care?
(**PROBE** for age – If more than one, ask, “What is the age of the person to whom you are giving the most care?”)

- -- Code age in years
- 777 Don't know/Not sure
- 999 Refused

29.3 What is the gender of the person you are caring for?

- 1 Male
- 2 Female
- 7 Don't know/Not sure
- 9 Refused

29.4 What is his/her relationship to you? **DO NOT READ.**

(**PROBE** for relationship – If more than one, ask “Which is the person you take care of the most often?”)

(**OPTIONAL PROBE** – If more than one relationship applies, say “I can only record ONE answer choice”, or something similar to ensure respondent chooses only one option)

- 1 Parent
 - 2 Parent-in-law
 - 3 Child
 - 4 Spouse
 - 5 Sibling
 - 6 Grandparent
 - 7 Grandchild
 - 8 Other Relative
 - 9 Non-relative
-
- 77 Don't Know or Not Sure
 - 99 Refused

29.5

What do you think or what has a doctor said is the major health problem that your ____ (Q4 code) has? **CHECK ONE CONDITION ONLY. DO NOT READ.**

- 1 ADD/ADHD
- 2 AIDS/HIV
- 3 Arthritis/rheumatism
- 4 Asthma
- 5 Cancer
- 6 Cerebral Palsy
- 7 Chromosomal anomaly
- 8 Dementia
- 9 Depression
- 10 Down's syndrome
- 11 Anxiety other emotional
- 12 Developmental delays
- 13 Diabetes
- 14 Eye/vision problem (blindness)
- 15 Hearing problems (deafness)
- 16 Heart disease
- 17 Hypertension/high blood pressure
- 18 Lung disease/emphysema
- 19 Multiple Sclerosis
- 20 Muscular Dystrophy
- 21 Osteoporosis
- 22 Parkinson's
- 23 Spinal Cord Injury (SCI)
- 24 Stroke
- 25 Traumatic Brain Injury (TBI)
- 26 Other (_____)

- 77 Don't know/Not sure
- 99 Refuse

29.6

Which **TWO** of the following areas does your ____ (Q4 code) most need your help?
CHECK UP TO TWO

- 1 Learning, remembering, & confusion
- 2 Seeing or hearing
- 3 Taking care of oneself, such as eating, dressing, bathing, or toileting
- 4 Communicating with others
- 5 Moving around;
- 6 Getting along with people; or
- 7 Feeling anxious or depressed

- 77 Don't Know
- 99 Refused

29.7 For how long have you provided care for your ____ (Q4 code)? **DO NOT READ.** Code using respondent's unit of time.

- 1 __ Days
- 2 __ Weeks
- 3 __ Months
- 4 __ Years

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

29.8 In an average week, how many hours do you provide care for your ____ (Q4 code) because of his/her long-term illness or disability? **DO NOT READ**

__ Hours per week

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

29.9 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 (specify_____)

77 Don't know/Not sure
99 Refused

29.10 How far away do you live from your ____ (Q4 code)? Do you live:

- 1 In the same house
- 2 Less than 20 minutes away
- 3 Between 20 & 60 minutes away
- 4 Between 1 & 2 hours away or
- 5 More than two hours away?

7 Don't know/Not sure
9 Refused

29.11 Do you have concerns about your ____ (Q4 code)'s memory or thinking?

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

29.12 Does your ____ (Q4 code)'s memory or thinking interfere with everyday activities or quality of life?

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

29.13 In the past 12 months have you sustained an injury while helping your ____ (Q4 code)?

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