Caregivers provide assistance to people who are, in some degree, incapacitated and need help. They typically have a chronic illness or disabling condition and need ongoing assistance with everyday tasks to function on a daily basis. Caregiving plays a unique and valuable role in our society. As the number of caregivers grows, the issues surrounding caregiving have gained national attention from a variety of sectors. Only recently, however, has caregiving received increased attention as an important public health issue. Caregiver demand is partially driven by the steady increase in our older adult population [Family Caregiver Alliance, 2005, 2006a]. During the past century, the leading causes of death for all age groups, including older adults, has shifted from infectious and acute illnesses to chronic diseases and degenerative illnesses. More than 25% of all Americans and two-thirds of older Americans have multiple chronic conditions. Heart disease, cancer, and other chronic diseases and conditions pose their greatest risks as people age, and this can affect a person’s ability to perform essential activities inside and outside the home. The need for caregiving for older adults by professional caregivers or family members will increase sharply during the next several decades. [CDC]

Many health conditions are not reportable; hence, prevalence data must be obtained from another source. The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based system of health surveys created by the Centers for Disease Control and Prevention (CDC) in 1984 to gather information on the health of adults ages 18 years and older. The BRFSS is an annual random digit-dial telephone survey conducted through a cooperative agreement with the CDC, and all states and the District of Columbia participate.

State health departments conduct the BRFSS surveys continuously through the year using a standardized core questionnaire and optional modules. More than 475,000 interviews were completed via landline and cell phone in 2012. The BRFSS is the sole source of state-level health risk factors, behaviors and prevalence of certain chronic conditions. The BRFSS relies on self-reported data. This type of survey has certain limitations that should be understood when interpreting the data. Respondents have the tendency to underreport behaviors that may be considered socially unacceptable, such as smoking and driving after drinking alcohol. Conversely, respondents may overreport behaviors that are desirable, such as physical activity. The differences reported on the following pages are statistically significant (p<0.05) unless otherwise noted.
For a number of years, the Indiana BRFSS survey has included state-added questions to address topics of interest. Through financial support from the Alzheimer’s Association, Greater Indiana Chapter, 10 questions on caregiving were included in the 2012 Indiana BRFSS survey. The questions were included on the landline version of the questionnaire.

**Background**

The introduction to the 10 caregiving questions was “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 and such care or assistance to a friend or family member?” Those respondents reporting ‘yes’ were then asked additional questions, including the age and sex of the person to whom they give care, their relationship to the person, length of time providing care and average hours per week, the health problem of the person, the areas the person needed the most help, and difficulties faced as a caregiver.

**Results**

Approximately 18% (18.2) of respondents (corresponding to 850,000 adults) reported that they provided regular care or assistance to a friend or family member. Women were more likely than men to report providing care (22.5% vs. 13.6%, respectively). Respondents in the 55-64 age group (21.3%) were more likely than those in the 65+ age group (15.3%) to report caregiving. There were no other differences among age groups. Hispanic adults were less likely to report being caregivers (8.0%) than non-Hispanic whites (18.4%) and non-Hispanic blacks (20.7%). College graduates (16.6%) were less likely to be caregivers than those with some college or technical school (22.5%), but were not different than those with less than high school education (14.4%) or high school graduates (17.5%).

Less than 10% (8.8) of the persons to whom the respondents provided care were under the age of 30 years, 28% were between the ages of 30 and 59, and 63.1% were age 60 years and older. The person cared for was more likely to be female (61.7%) than male (38.3%). When caregivers were asked their relationship to the person, 34.0% reported the person was a parent, 12.2% reported non-relative, 11.5% reported grandparent, and 10.7% reported spouse. The remaining 31.7% consisted of parent-in-law, child, sibling, grandchild or other relative.

The main health problems, long-term illnesses, or disabilities of the person needing care was Alzheimer’s disease or dementia (8.9%), arthritis/rheumatism (7.1%), diabetes (6.2%) and heart disease (5.9%). Other listed conditions, including blindness, lung disease or emphysema, and stroke disability comprised 22.4%. Other conditions (not listed) comprised 40.9%.

Over half (53.9%) of the respondents reported spending up to 10 hours in an average week providing care, followed by 11-29 hours (23.5%), 50 or more hours (15.0%) and 30-49 hours (7.5%). College graduates were the most likely to report providing up to 10 caregiving hours in an average week while those with less than a high school education were the most likely to report providing 50 or more caregiving hours (see Figure 1).

When spending up to 10 hours in a week in caregiving, the most common areas where help was needed was taking care of the person’s residence of personal live spaces (e.g., cleaning, managing money, preparing meals) with 34.3% followed by transportation outside of the home (25.7%).
When spending 11-29 hours per week, the most common areas where help was needed was taking care of the person’s residence of personal living spaces (32.5%) followed by taking care of the person (e.g., eating, dressing, bathing) with 29.5%. When spending 30-49 hours, the most common areas were the same as for 11-29 hours: taking care of the person’s residence [personal living spaces] (34.0%) followed by taking care of himself/herself (20.3%). For respondents spending 50 or more hours per week, taking care of himself/herself accounted for 42.7%, followed by taking care of his/her residence [personal living spaces] 14.9% and transportation outside of the home (14.8%).

Respondents were asked how long they have provided care for the person. Approximately 34% (34.1) reported providing care for less than one year, 10.4% for one year, 21.1% for two to three years, and 34.3% for four years or more. The response of ‘other’ for the major health problem, long-term illness or disability for the person being provided care had the highest percent for each of time periods. The following information is for a specific condition listed. Cancer had the highest percent for caregiving up to one year (11.4%). Alzheimer’s Disease or dementia had the highest percent for one year (10.4%) and 2-3 years (11.8%) of caregiving. Diabetes had the highest percent for four or more years (8.3%) of caregiving.

Respondents were asked about the greatest difficulty they have faced as a caregiver. Almost 53% (52.7) reported no difficulty, followed by creates stress (19.3%), doesn’t leave enough time for yourself (5.4%) and creates financial burden (5.3%). Respondents ages 35-44 were more likely to report that caregiving creates or aggravates health problems (36.9%). Respondents ages 45-54 were most likely to report that caregiving creates a financial burden (31.0%) and doesn’t leave enough time for family (44.8%). Respondents ages 55-64 were most likely to report that it doesn’t leave enough time for yourself (30.5%), interferes with their work (23.5%), creates stress (24.9%) and affects family relationships (25.7%).

The response of ‘other’ for the major health problem, long-term illness or disability for the person being provided care had the highest percent for each of the greatest difficulty faced as a caregiver. The following information is for a specific condition listed for the person being provided care:

- Heart disease had the highest percent for creates a financial burden (13.2%).
- Alzheimer’s disease had the highest percent for doesn’t leave enough time for yourself (11.5%).
- Cancer had the highest percent for doesn’t leave enough time for your family (17.2%).
- Diabetes had the highest percent for interferes with your work (31.1%).

For additional information on caregiving, please visit the CDC at http://www.cdc.gov/aging/caregiving/.
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