



CHRONIC DISEASE BURDEN UPDATE

■ This update focuses on increased confusion or memory loss and the challenges faced by caregivers in Illinois.

Cognition is the ability to think, learn and remember. It is the basis for how we reason, judge, concentrate, plan and organize. Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. Some declines in cognition and memory with age are normal, but sometimes they can signal problems. Lack of cognitive health can have profound implications for a person's everyday life, as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities

of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern.

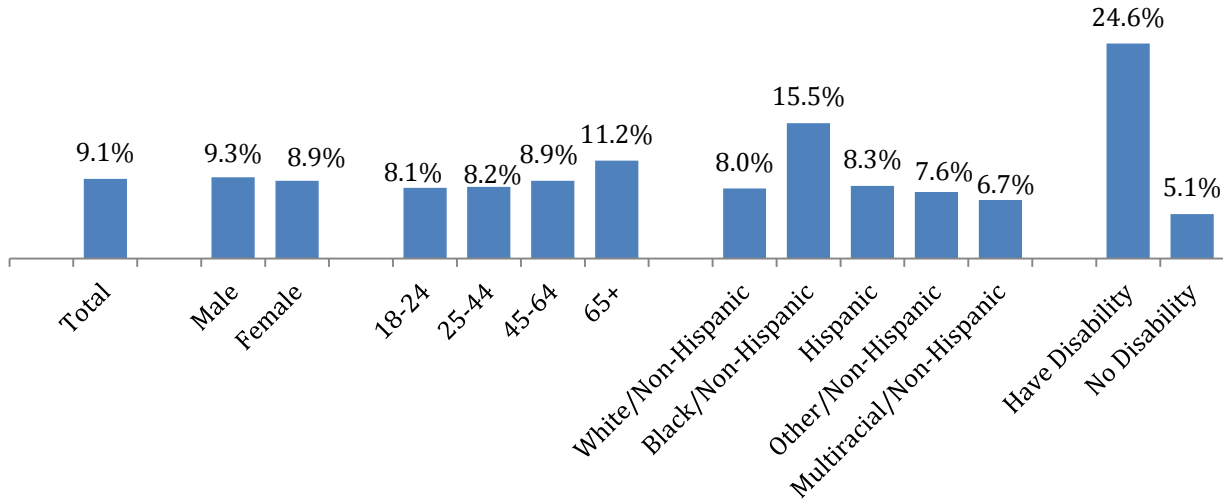
In 2014, *The Healthy Brain Initiative* grant was awarded to the Illinois Department of Public Health by the National Association of Chronic Disease Directors, through the U.S. Centers for Disease Control and Prevention. Through this grant, Illinois will focus on activities included in the Public Health Road Map for State and National Partnerships, 2013-2018, to increase surveillance and promote use of data regarding the burden of ICML in Illinois, assess the ability of state and local organizations to address ICML and caregiver needs, and identify priority recommendations of the *Illinois Alzheimer's Disease State Plan-2014*.

According to the Behavioral Risk Factor Surveillance System (BRFSS), in 2013, more than 1.2 million households in Illinois had someone with ICML. Approximately five percent of adults had been diagnosed with Alzheimer's disease and 12 percent with dementia other than Alzheimer's disease. Many individuals with ICML require a caregiver for assistance with safety concerns, transportation, household activities, personal care or other needs. According to BRFSS, in 2013, approximately one third of individuals with ICML in Illinois had been provided care or assistance from a friend or family member in the past thirty days. Of caregivers in Illinois, annually seven percent provide care for someone with Alzheimer's disease and 21 percent for someone with dementia other than Alzheimer's disease. It is important to remember that the BRFSS is used to survey households and does not include residents of nursing homes, group homes or other facilities.

INCREASED CONFUSION OR MEMORY LOSS

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. Respondents were asked if they had ever experienced ICML. For those Illinois adults who have experienced ICML, there were differences based on age, income and disability status. Adults with a disability (24.6%) were significantly more likely to have ICML than adults without a disability (5.1%).

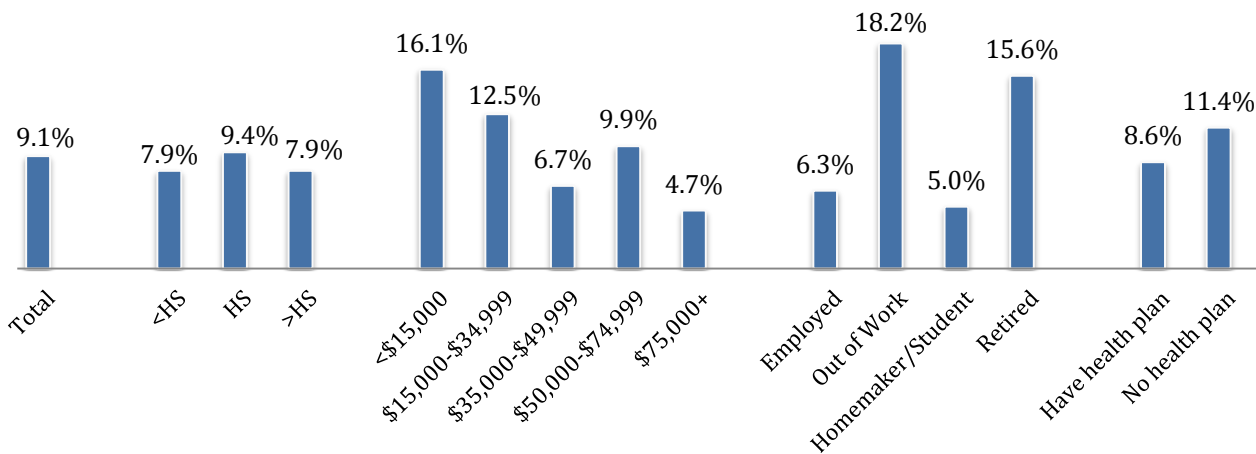
ICML by Demographics, Illinois, 2013



Source: ILL. BRFSS, 2013

Illinois adults who were employed (6.3%) or homemakers or students (5.0%) were significantly less likely than adults who were out of work (18.2%) or retired or unable to work (15.6%) to experience ICML. Adults who earn less than \$15,000 a year (16.1%) or between \$15,000 and \$34,999 a year (12.5%) were significantly more likely to have ICML than those who earn \$35,000 to \$49,999 (6.7%) or \$50,000 to \$74,999 (9.9%). Adults who earn \$75,000 or higher were least likely to have ICML (4.7%).

ICML by Demographics, Illinois, 2013



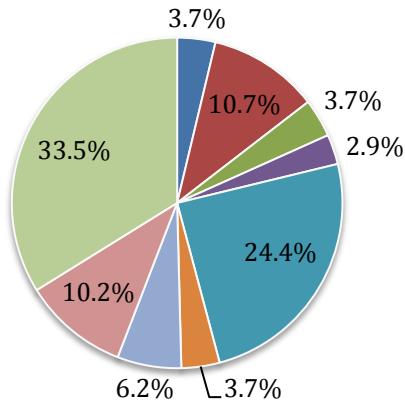
Source: ILL. BRFSS, 2013

CAREGIVING NEEDS

The BRFSS classifies a caregiver as someone who provides care or assistance to a friend or family member who has a health problem, long-term illness, or disability. Caregivers can face many difficulties. The care and assistance they provide affects their everyday lives. According to BRFSS, in 2013, when caregivers in Illinois were given a list of difficulties often experienced by caregivers and asked which one was the greatest difficulty they have faced, the difficulty reported most was the stress it creates (24.4%).

A combined 14 percent of caregivers felt lack of time for themselves (10.7%) or family (3.7%) was most difficult. Approximately 6 percent felt the effect it had on family relationships was the greatest difficulty.

Greatest Difficulty Faced by Caregivers, Illinois, 2013

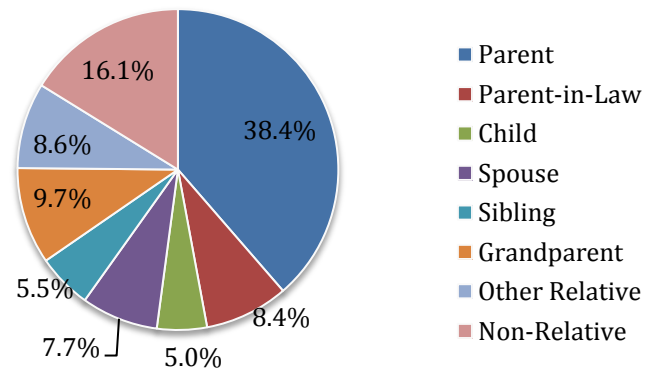


- Creates a financial burden
- Not enough time for yourself
- Not enough time for your family
- Interferes with your work
- Creates stress
- Creates or aggravates your own health problems
- Affects family relationships
- Other
- None

Source: ILL. BRFSS, 2013

According to BRFSS, in 2013, 20 percent of adults in Illinois had provided care or assistance to a friend or family member within the past 30 days. Approximately 80 percent (83.3%) of caregivers provided care or assistance to a relative. Seventy percent provided care to a family member or friend 65 years of age or above. The majority of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (47.3%) rather than mental problem (22.7%). Most often the person for whom the caregiver provides care or assistance is a parent (38.4%) or non-relative (16.1%).

Caregiver Relationship to Person They Provided Care, Illinois, 2013



Source: ILL. BRFSS, 2013

TIME SPENT PROVIDING CARE

Caregivers can spend years providing care to a friend or family member. More than 20 percent of caregivers had spent more than five years providing care to one person. According to BRFSS, in 2013, an estimated 121,334 hours were spent by caregivers in Illinois providing assistance to someone with Alzheimer’s disease or dementia. Approximately 8 percent of caregivers were spouses providing an estimated 19,292 hours spent providing care by spouses, leaving less time for employment. To compound the complexity of caregiving, spouses serving as caregivers are not eligible for disability benefits for providing such care, reducing household earnings to create a large financial burden.

SELF VS. HOUSEHOLD MEMBER ASSESSMENT

The 2013 Illinois BRFSS included questions to be answered by individuals with ICML and for people who have a household member with ICML. When individuals with cognitive impairment were asked in which area most assistance is needed, the most frequent response was no assistance needed. The percentage of individuals with ICML who reported no assistance needed in any area (38.3%) is significantly higher than reported by a household member (15.7%).

| Area Assistance is Needed Most | Self | Household member |
|--|------|------------------|
| Safety | 7.6 | 10.6 |
| Transportation | 15.4 | 21.4 |
| Household activities | 20.6 | 30.4 |
| Personal care | 12.4 | 17.7 |
| Needs assistance, but not in above areas | 3.9 | 1.25 |
| No assistance in any area | 38.3 | 15.7 |

Source: ILL. BRFSS, 2013

When asked how often ICML affects household chores or activities in the past 30 days, more individuals with ICML themselves than those sharing a household with an individual with ICML reported never (63.2% and 55.3% respectively) than always/usually (9.2% and 15.5% respectively), and sometimes (27.4% and 28.3% respectively). A significantly higher percentage of individuals with ICML themselves reported sometimes/rarely (27.4%) than always (9.2%). When asked how often ICML has affected ability to work or social activities 37 percent of people with ICML reported always or sometimes/rarely and 44 percent of people who share a household with someone with ICML reported always or sometimes/rarely.

| Questions | Always | | Sometimes/Rarely | | Never | |
|---|--------|------|------------------|------|-------|------|
| | Self | HH | Self | HH | Self | HH |
| During the past 12 months: How often did ICML affect household chores/activities? | 9.2 | 15.5 | 27.4 | 28.3 | 63.2 | 55.3 |
| During the past 12 months: How often has ICML affected ability to work/social activities? | 12.3 | 15.7 | 24.2 | 28.8 | 63.1 | 54.9 |

Source: ILL. BRFSS, 2013

WORKING WITH PROVIDERS

Often the level of ICML increases over time. The majority of caregivers reported the person for whom they provided care experienced changes in thinking/remembering within the past year (55.9%). Individuals with ICML and individuals who have a household member with ICML were asked if ICML or medication for ICML were discussed with a health care professional. Significantly more individuals with ICML reported not discussing increase in ICML with their health care professional (68.3%) than discussing it (30.3%). The majority of individuals who have a household member with ICML reported discussing medication for ICML (61.0%) than not discussing it (36.3%). Keeping health care providers informed of changes in the status of the cognitive impairment is essential to maintaining or to improving the health of the individual. Having a household member advocate for their health management can increase the chance these changes are being discussed and help to ensure they are receiving proper treatment.

| Questions | Yes | | No | |
|---|------|------|------|------|
| | Self | HH | Self | HH |
| Discussed increase in ICML with health care professional | 30.3 | 42.3 | 68.3 | 56.4 |
| Discussed medication for ICML with health care professional | 45.0 | 61.0 | 54.5 | 36.3 |

Source: ILL. BRFSS, 2013