Characteristics of Caregivers in Florida

Caregiving: A Societal Challenge

Caregivers serve an integral and often unrecognized role in the United States health care system, providing thousands of hours of unpaid care to adults who have a disability or other health issue. It is estimated that caregivers provide $257 to $389 billion in unpaid care to individuals with disabilities and chronic diseases.

Providing care for an older adult has been linked to mental and physical problems for the caregiver. However, the prevalence of caregiving and the health impacts of caregiving are not known at the state and local levels. Federal and state agencies should employ population-based caregiving data to design the needed programs and interventions to address this increasingly important public health issue.

By supporting caregivers, care recipients may maintain independence and experience an improved quality of life.

Caregiving in Florida

According to US Census Bureau projections, Florida's age distribution will change considerably by 2030.

- In 2000, 18% of Floridians, 2.8 million people, were age 65 or older.
- By 2030, this age group is expected to grow to 7.8 million, or 27% of Florida's population.

Because the risk of disability increases with age, it is expected that as the population ages, the need for informal caregivers will increase as well.

The Caregiver Module

In 2008, a series of questions about caregiving, known as the Caregiver Module, were included on Florida's Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is a state-based, random-digit-dialed telephone survey of non-institutionalized US adults age 18 and older. The Caregiver Module was added to collect information about a population-based sample of adult caregivers who care for individuals with a disability or chronic condition. Data are weighted so that people who respond to the survey represent the entire State of Florida based on age, gender and race.

2008 Florida Caregiver Module Results: Caregivers

During 2008, 10,217 Florida BRFSS respondents were asked the caregiver screening question. A total of 1,461 people, or 13% (weighted) of these respondents, said “yes” and were classified as caregivers.

- Most caregivers (64%) in Florida reported race/ethnicity as white, non-Hispanic.
- The majority of caregivers (58%) identified in the survey were women.
- The mean age of caregivers was 48 years.
- 62% of caregivers reported having some education beyond high school.
- 59% of caregivers were employed.

Caregivers could choose up to two areas in which caregiving created a difficulty. Stress was the most prevalent difficulty at 41%.

Respondents were categorized as a caregiver if they affirmatively responded to the following question:

• "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?"

Respondents were categorized as having a disability, based on the BRFSS definition, determined by the following two questions:

• "Are you limited in any way in any activities because of physical, mental, or emotional problems?"
• "Do you now have any health problems that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?"
Greatest Difficulty Faced by Caregivers

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage of Respondents</th>
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<tbody>
<tr>
<td>Creates Stress</td>
<td>41</td>
</tr>
<tr>
<td>Financial Burden</td>
<td>21</td>
</tr>
<tr>
<td>Not enough time for him/herself</td>
<td>15</td>
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<tr>
<td>Interferes with work</td>
<td>7</td>
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Disparities between caregivers and non-caregivers.

Understanding health-related quality of life between caregivers and non-caregivers will provide valuable insight to address the healthcare needs and support mechanisms necessary to this growing segment of the community.

Key Recommendations

- Regularly collect data about the health and needs of caregivers and care recipients to detect changes in needs and outcomes over time.
- Educate healthcare providers about informal caregiving and the needs of caregivers to reduce barriers to health care.
- Educate the public about programs, services, and training programs available to informal caregivers to reduce difficulties and negative health outcomes associated with caregiving.
- Strengthen consumer-directed care and evidence-based caregiver education programs in Florida.
- Implement evidence-based caregiving programs at the local level and evaluate local programs for impact, effectiveness, and efficacy.
- Provide tax incentives or grants to health care facilities to implement evidence-based training programs to caregivers before care recipients are discharged from the hospital.
- Expand family-centered services and supports.

2008 Florida Caregiver Module Results: Care Recipients

Many community and public health groups express interest in specific conditions as they relate to caregiving – notably cancer, Alzheimer's disease, dementia, and developmental disabilities.

Care Recipient’s Major Health Problem Requiring Caregiver Assistance

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage of Respondents</th>
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<tbody>
<tr>
<td>Cancer</td>
<td>19</td>
</tr>
<tr>
<td>Heart Disease and Stroke</td>
<td>10</td>
</tr>
<tr>
<td>Arthritis or Rheumatism</td>
<td>8</td>
</tr>
<tr>
<td>Alzheimer's disease or dementia</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7</td>
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Learning more about caregivers and how their caregiving activities impact their risk of poor health outcomes will improve our understanding of how to provide support to them; this will improve the ability of care recipients to maintain independence and experience an improved quality of life.

- The prevalence of disability was higher among caregivers than non-caregivers (27% compared to 20%).
- Caregivers reported more days per month of poor mental health in the past month (5.7 days) than non-caregivers (3.3 days).
- 21% of caregivers needed to see a doctor but could not because of cost while 15% of non-caregivers reported to have the same problem.