Informal Caregivers: Challenges in Providing Care

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The information contained in this fact sheet is from a study comparing informal caregiving in American Indians and the North Dakota general population. The original report by Richard Ludtke, Ph.D., Leander McDonald, Ph.D. and Lene Vallestad (June 2003) "National Family Caregiver Support Program: North Dakota's American Indian Caregivers" can be found at http://medicine.nodak.edu/crh.

Family caregiving is experiencing significant growth as the U.S. population ages. Care is also shifting away from institutions to home and community based care. Family-based care is an important component in the array of services available to the aged.

What is an informal caregiver?

Informal caregivers are volunteers who provide care on a long term basis. The majority of informal caregivers on reservations are females between the ages 45-54. They tend to be either employed full-time or not working at all. The reservations also have a high number of informal caregivers under the age of 35 who are not working. A small number of informal caregivers have multiple jobs and they are also the people who experience the highest level of difficulty providing care.

For whom does an informal caregiver provide care?

Caregivers most frequently provide care to a spouse or mother over the age of 60.

Why do informal caregivers provide care?

Caregivers provide care to persons with physical disabilities and/or cognitive impairment. Cognitive impairment is reported more frequently in the general population than in American Indians.

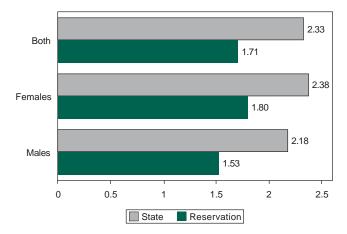
What kinds of tasks do caregivers provide?

The tasks depend on the amount of cognitive impairment, physical limitations, and how long the recipient can be left alone. More American Indians receiving care can be left alone for longer time periods than the general population.

Are their gender differences in difficulty providing care?

Females have more difficulty providing care. There is a higher percentage of female caregivers in the general population as compared to the Native American population (see Figure 1).

Figure 1. Gender Difference in Difficulty Providing Care¹



Is difficulty with providing care related to caregiver employment?

Caregivers with the highest level of difficulty providing care in the general population are those with part-time jobs. The majority of caregivers with part-time jobs are women and most of them are older than those with full-time jobs. Those most frequently experiencing difficulties in providing care are women between the ages of 55-64, who either work full time or not at all, and those that are divorced or separated.

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Is there a difference in the amount of difficulty due to relationship with recipient?

The caregiver's relationship to the recipient of care affects the experience of difficulty in providing care. Figure 2 presents the level of difficulty depending on relationship. Caregivers who provide care to their mothers or mothers-in-laws experience the highest level of difficulty. Those who care for a friend or an adult child experience the lowest level of difficulty.

Figure 2. Level of Difficulty in Providing

Care Related to Relationship to Recipient¹

0 Adult Sibling Relative Friend Father- Mother- Spouse child in-law in-law

Are there differences in difficulty providing care between caregivers on reservations versus the general population?

General population caregivers had a higher amount of difficulty than American Indian caregivers from the reservations. This suggests that American Indian caregivers providing informal care tend to adapt well. This could be due to differences in age. American Indian elders and caregivers, as a group, are younger than the general population. Because the general population of caregivers tends to be older, they might have a harder time performing caregiving tasks. The caregivers in the general population are also more likely to be widowed and retired. The difference in age pattern is expected to change with time as the longevity among American Indian elders increases.

In addition to a difference in age, American Indians have strong traditions of extended family support, which represents the primary option for providing care to their elders. This does not imply that American Indian informal caregivers do not have difficulties in providing care. Rather, they may not voice their difficulty to the same extent as caregivers in the general population.

What services are needed to support informal caregivers?

Improving the availability of support services is critical to assuring quality in family caregiving. Services that were identified as needed included:

- Home health
- Personal Care
- Nutrition (dietician, home delivered meals, congregate meals)
- Homemaker services
- Chore services
- Transportation
- Respite care
- Outreach information and training

Footnotes:

¹ Caregivers were asked to rate from one to five (score of five is "very serious") how concerned they are about several potential difficulties including having less time for themselves and family, conflicts with their social life, emotional aspects, less privacy, interference with job, financial obligations, lifestyle change, responsibility for making major decisions, deteriorating physical health and lack of sleep. The items are combined into a single score reflecting general difficulty in providing care for each caregiver.

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