

Older North Dakotans as Caregivers to the Elderly

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Although caregivers to the elderly range in age, many of them are elderly themselves. Caregivers are usually spouses or children (Cantor, 1983) and the spouses are likely to be over 65 years old. Even sons and daughters may be of retirement age and caring for a very old parent. In the rural areas where fewer formal services are available, it seems even more likely that the older person would be responsible for part of someone's care. With nearly one-fourth of the population in some rural North Dakota counties being elderly (Dawes, Molvig and Kickok, 1983), the caregiving role may affect many older citizens.

The purpose of this study was to determine the role of elderly North Dakotans in providing care to those who need it. Specifically, this paper includes a discussion of who gives care, who they give care to, others in the helping network, use and perceptions of professional support, types of care given, and rewards and stresses of caregiving.

METHOD

Fargo, Bismarck, and Minot were selected as urban sites for the sample and three rural counties, each at least 50 miles from these towns, were selected for sampling. Persons over 65 were randomly chosen from these areas from a list of all North Dakota licensed drivers over 65. These persons were mailed a questionnaire with a self-addressed envelope for return. Postcards were sent to all after 10 days as a reminder to complete the survey or to thank them for completing it.

All elderly were asked to complete demographic information, health ratings, and income adequacy. Then respondents were asked to indicate whether they provide help weekly or more often to a person who does not or could not live alone without assistance. Those who responded "no" to this question were asked to indicate the reason they do not, such as, "No one close to me needs this type of help," "Those I know who need help are provided for by others," "I am unable to provide help because of health problems," and "other." Those who do provide some care were asked to complete the remainder of the questionnaire focused on relationship to care receiver, the care network, types of care provided, and caregiver strain.

Instrumentation

The questionnaire contained demographic variables including gender, age, race, education, pre-retirement occupation, marital status, perceived health rating, perceived income adequacy, current employment status, relationship to the person for whom care is provided, and care receiver's age, physical and mental problems, health rating, and living situation. Questions on the caregiving situation included asking if the respondent was the major care provider, who others in the care network were, rating of satisfaction with the amount of help the caregivers get from others, types of community or professional care services used, satisfaction with these services, and the rewarding aspects of caring for the person.

Caregiver Strain Index. The experience of strain as a result of providing care was measured using Robinson's (1983) Caregiver Strain Index. The 13-item scale includes a variety of potential strain areas, such as physical strain, inconvenience, emotional adjustments, etc. Responses to the item are yes or no, and a total caregiving strain score is calculated by summing the yes responses.

Description of Total Sample

Of 1,000 questionnaires sent, a total of 460 persons responded for a return rate of 46 percent. A total of 190 (41.5 percent) rural and 224 (48.9 percent) urban elderly responded. In addition, 44 (9.6 percent) respondents returned their questionnaires from winter homes in the south. While it was impossible to determine if the questionnaires had been originally sent to a rural or urban area, the fact that these individuals were "snowbirds" is valuable information.

More females (241, or 52.9 percent) than males (215, or 47.1 percent) returned the questionnaires. Ages ranged from 60 to 81 with a mean age of 69.9. Nearly all the respondents (98.9 percent) were white. Education ranged from 2 to 22 years; 39.5 percent had less than a high school education. Most (76.2 percent) were married, 74 (16.2 percent) were widowed, 11 (2.4 percent) were divorced, and 23 (5 percent) were single. Concerning perceived health status, 66 (14.5 percent) rated their health as very good, 248 (54.6 percent) as good, 118 (26 percent) as fair, 19 (4.2 percent) poor, and only 2 (.4 percent) as very poor. Income adequacy was rated as very adequate by 52 (11.5 percent) respondents, adequate by 288 (63.4 percent), barely adequate by 94 (20.7 percent) and inadequate by 19 (4.2 percent). Of those who responded to the questionnaire, 109 (23.6 percent) stated that they did provide care for someone who does not or could not live alone without assistance. The remainder of the paper describes this group of elderly persons who provide care for other elderly.

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RESULTS

Of those in the sample who were not caregivers, 50.5 percent responded that this was because no one close to them needed help. Others indicated that such help was provided by someone else (34.2 percent) or that they were not able to provide care (10.8 percent). A few mentioned other factors (4.4 percent).

For those who did provide care, it was sometimes to more than one older person. Nearly one-fourth care for two elderly and 11.3 percent care for three. A few (7.2 percent) care for more than three elderly persons, and one person was providing some care to eight different persons. Most (56.7 percent) did provide care for only one person and in asking questions about caregiving we asked all caregivers to respond with a focus on the one individual for whom they provided the most care. About a third provided the most care for a spouse (32 percent). Parents were the care receivers in 14.5 percent of the cases, friends for 17.3 percent, a brother or sister for 14.5 percent, a neighbor for 8.2 percent and 12.7 percent indicated that the care receiver was someone other than those listed (cousin, aunt or uncle, etc.).

The support of the elderly who need care is often provided by a network of people with a major caregiver who coordinates the support and may provide most of the actual care.

The Person Receiving Care

The elderly persons who were the target of the care had an average age of 78.2 years. By age group, 18.7 percent of those receiving care were under 70, 32.7 percent were in their 70s, 36.5 percent were in their 80s, and 12.1 percent were in their 90s.

Health problems experienced by those needing care included loss of sight (14.8 percent), loss of hearing (12.5 percent), heart problems (34.1 percent), high blood pressure, (15.9 percent), arthritis (22.7 percent), malignancy (9 percent), stomach problems (3.4 percent), and mental problems (3.4 percent). Interestingly, none of the caregivers mentioned bowel/bladder control or Alzheimer's disease as health problems experienced by those for whom they provided care. The percentages indicating certain health problems add to more than 100 percent because some of the individuals experienced several health problems. For those receiving care, 7.5 percent were rated by the respondent as being in very poor health, 19.6 percent in poor health, 50.5 percent in fair health, and 22.4 percent in good health.

Living arrangements for the persons receiving care varied. About a third (32.1 percent) lived alone, 37.6 percent lived with the respondent, 11.9 percent lived with someone other than the respondent, 12.8 percent lived in a nursing home, and 4.6 percent had some other living arrangement.

The Caregiving Network

As mentioned, caregiving is often done through a whole system of support rather than one person. Frequently mentioned as an informal part of that network was the spouse (17.4 percent). Siblings were mentioned as part of the network by 15.6 percent of the respondents, and 18.3 percent indicated that friends played a role. Children (18.3 percent), grandchildren (8.3 percent) and others (11.0 percent) were also part of the support system.

A total of 43.1 percent mentioned no one else as part of the support network. Again, percentages total over 100, because respondents could indicate up to three others who took part in providing care. Most of these caregivers were satisfied (36.7 percent) or very satisfied (25.7 percent) with the help the care receiver got from others in the network. A few were unsatisfied (5.5 percent) or very unsatisfied (2.7 percent) and 13.8 percent were neutral on this issue.

Only 29.4 percent claimed that the person for whom they provided care also received professional help. Of this group (32 respondents), 68.7 percent received home health aid and 43.7 percent received home delivered meals. Fewer than three respondents mentioned health programs, housing assistance, volunteer services, nutrition sites, or homemaker service. No other services were mentioned. For respondents whose care receiver did obtain professional services, 27.3 percent were very satisfied, 45.5 percent were satisfied, 20.0 percent were neutral, 5.5 percent were unsatisfied and 1.8 percent were very unsatisfied with these services.

Support By The Caregiver

As shown in Table 1, these caregivers provided a variety of services to different extents. Over half (50.7 percent) of the respondents helped to manage finances of the care receiver weekly or daily. However, 56.5 percent indicated that they never contribute financially to the caregiver's support; 20.8 percent did contribute in this way weekly or daily. Many (43.5 percent) provided personal care on a regular weekly/daily basis, while 46.8 percent never provided personal care (i.e., help with bathing, dressing, etc.).

A majority of these caregivers regularly (weekly/daily) helped with household care (62.1 percent), meals (61.5 percent), and doing errands or providing transportation (57.0 percent). Companionship and help with worries were the most frequent supports given. Over half provided these supports on a daily basis and over 80 percent provided companionship and help with worries either weekly or daily.

Table 1. Type and Frequency of Support Provided by the Caregivers.

	Frequency				
	Never % (n)	Less than Monthly % (n)	Monthly % (n)	Weekly % (n)	Daily % (n)
Manage finances	18.8 (13)	5.8 (4)	24.6 (17)	15.9 (11)	34.8 (24)
Contribute financially	56.6 (30)	5.7 (3)	17.0 (9)	3.8 (2)	17.0 (9)
Personal care	46.8 (29)	6.5 (4)	.4 (2)	16.1 (10)	27.4 (17)
Household care	24.2 (16)	7.6 (5)	6.1 (4)	24.2 (16)	37.9 (25)
Meals	17.1 (12)	14.3 (10)	7.1 (5)	18.6 (13)	42.9 (30)
Errands or transportation	5.1 (4)	19.0 (15)	19.0 (15)	38.0 (30)	19.0 (15)
Companionship	1.4 (1)	5.7 (4)	2.9 (2)	37.1 (26)	52.9 (37)
Help with worries	8.5 (5)	10.2 (6)	0.0 (0)	22.0 (13)	59.3 (35)

Strains of Caregiving

Providing care to an older person did result in certain strains for a minority of caregivers. Some indicated that their sleep was disturbed by the care receiver (20.3 percent) and some received their role as inconveniencing them (20.9 percent). A total of 16.2 percent responded that caregiving was a physical strain for them and about one-fourth (25.8 percent) received caregiving as confining. A few caregivers had had to make family adjustments (22.6 percent) in order to carry out these responsibilities. Many (37.3 percent) had to change plans in order to provide care.

For some, it was not the caregiving role alone which created strain but rather caregiving along with the other demands (work, children, etc.). About 20 percent viewed this as a strain. Emotional adjustments to the situation were difficult for 14.1 percent of caregivers. Related to emotional adjustments was upsetting behavior by the person receiving care, a strain for 26.9 percent of the respondents. Additionally, 27.5 percent felt that seeing the changes in the person receiving care was stressful. Along with these difficulties, some caregivers had to make work adjustments (19.7 percent), such as retiring earlier than desired, and 13.4 percent said they had financial adjustments which created strain. Overall, 24.6 percent of the caregivers indicated that the role of caregiving was overwhelming.

Rewards

Whereas the caregiving role was stressful for some, for many it was also rewarding. All of the caregivers who responded to the question (75) indicated that the friendship and companionship of the person for whom they cared was rewarding. Caregivers also stated that they got personal satisfaction by giving (20 percent), that it was rewarding to provide comfort and happiness (32 percent), that fulfilling this responsibility gave them peace of mind (26.7 percent), or that it was a learning experience (5.3 percent). A few (14.7 percent) indicated that there were no rewards for them through caregiving.

DISCUSSION

A common myth in our society is that older persons need to be taken care of. The results of this study indicate that many older persons actually provide care to others rather than receive it themselves. This is another example of contributions the elderly make in our society. However, it is also important to note that these caregivers are not alone in this situation. There is often a system or network of care consisting of family, friends, and the community. The principal caregiver needs to be aware of the potential for such networking. Involving others in providing care can alleviate some of the stresses resulting from caregiving support.

One resource often overlooked by the respondents was the professional services available. Less than a third used such services, but those who did were mostly satisfied with them. Further information to caregivers is needed to deal

with the stigma of turning to the professional community for help.

Caregivers in this study provided a variety of support and were especially active in managing finances, personal care, household care, meals, companionship and help with worries. Much of this support could be enhanced through education for caregivers. For example, special knowledge is needed to adequately manage the finances of an individual. Knowledge about providing physical care, nutrition, and relationship skills (listening, and communication skills) are also necessary. This information should be targeted to the current or potential caregiver.

The stress indicated by caregivers may in part be lessened by the suggestions given above. Legislation giving tax credit or other supports to caregivers might be helpful. Services such as respite care, adult day care and home health care are valuable and need to be developed, especially in rural areas. Such services should be developed and presented in a way which caregivers can accept without feeling stigmatized. Stress from feeling confined, family adjustments, changing plans, and inconvenience might be alleviated if such services were used as part of the caregiving networks.

Knowledge of the illnesses or problems the person receiving care has could help with some of the emotional adjustment to caregiving. Seeing a person you have known for many years to change and perhaps even turn against you or become unaware of who you are is very painful for many caregivers.

Whereas caregiving can be stressful, it can also be rewarding. Caregivers in this study indicated several rewards, especially companionship. The experience of these rewards could be enhanced through appropriate supports to alleviate stress, and through education, enrichment, or counseling to improve the quality of the relationship for some caregivers.

Caregiving is an event experienced by many elderly either as the givers or receivers of care. Supports which alleviate stress and enhance the rewards of caregiving need to continue to be developed and promoted.

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