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## Meeting the Needs of Rural Caregivers: The Development and Evaluation of an Alzheimer's Caregiving Series

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## Meeting the Needs of Rural Caregivers: The Development and Evaluation of an Alzheimer's Caregiving Series

### Abstract

Caregiving for a chronically ill person is challenging. On a daily basis, managing chronic illness requires balancing illness needs with day-to-day tasks. Informal caregivers such as friends and family members often disregard their own health needs, focusing on the loved one for whom they are caring. Additionally, caregivers generally begin caregiving without any information or training. To meet the needs of caregivers of Alzheimer's patients, Family and Consumer Science specialists developed a 5-week caregiving series. Evaluation data found that the caregivers gained more knowledge about caregiving and felt more comfortable in their caregiving roles after participating in the series.

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## Introduction

Caregiving for a chronically ill person is a challenging task. Chronic illness is characterized by its long-term nature and uncertainty of prognosis. On a daily basis, managing chronic illness requires balancing illness needs with tasks. There is difficulty in controlling emotions, such as pain, anxiety, grief, and depression, and physical problems, such as weight loss and reduced strength in the chronically ill person. Yet informal caregivers often do not define themselves as such, thus making it difficult for them to see the toll caregiving takes on their own health. The disruption of the lives of individuals and families along with financial drains, added stresses from efforts to normalize relationships, social isolation, and stigma affect all involved (Miller, 1993).

Trends indicate a continued increase in the number of adults who provide caregiving to family and friends (Berg-Weger & Tebb, 2004; Marks, Lambert, & Choi, 2002). It is estimated that one in four households have at least one person providing informal caregiving, defined as care provided by family, friends, and neighbors as opposed to paid or volunteer formal caregivers (U.S. Department of Health and Human Services Administration on Aging [AOA], 2004).

Caregivers assume a wide variety of responsibilities for which they have not been trained (Marks et al., 2002). The most common caregiver responsibilities can be categorized as personal care, emotional support, financial assistance, and linking with formal care providers, with each category representing an array of time-consuming tasks (Stone, Cafferata, & Sangl, 1987). Caregivers often suffer greatly from the demands of caregiving, with greater caregiver burden for those caring for people with complex chronic illnesses (Levine, Reinhard, Feinberg, Albert, & Heart, 2004).

These demands result in poorer physical and psychosocial health for the caregiver (AOA, 2004). A recent study documented that older, burdened caregivers of spouses have 63% higher mortality risks than their non-caregiving peers (Schultz & Beach, 1999). One particularly stressful caregiving situation is that of caring for a loved one with Alzheimer's disease.

Alzheimer's disease is the leading cause of dementia. It is a progressive disease that affects the individual physically and psychologically (Alzheimer's Association, 2005). The disease currently has no cure. Due to the progression of the disease and the lack of a cure, caregivers of Alzheimer's patients experience increasing burdens that can affect their own physical and psychological well-being.

There are an estimated 16,843 people in Montana diagnosed with Alzheimer's disease (Alzheimer's Association, 2005). More than 70% of Alzheimer's patients live at home and are primarily cared for by family members or friends (Alzheimer's Association, 2005). Because of the rural nature of the state, Alzheimer's patients and their families are often isolated, with few resources and supports, which creates greater challenges for caregiving.

Extension professionals in the state became aware of the situation from the Alzheimer's Association state chapter and Extension constituents in the state. To address this unmet need, Extension county agents and specialists developed the Alzheimer's Caregiver Series for informal caregivers. This article discusses the development of the series and evaluation of the project and provides information for replication in other states.

## **Family Caregiving**

Eighty percent of home care services are provided by family members who may live close to or in the same house as the ill person (U.S. Agency for Health Care Research and Quality [AHCQR], 2000). It is estimated that almost one out of every four U.S. households contains a caregiver for a relative or friend at least 50 years old (AOA, 2004). The likelihood of an adult becoming a family caregiver is increasing (Marks et al., 2002). In Montana, there are an estimated 88,154 family caregivers who annually provide 94,000,000 caregiving hours with a market value of \$832,000,000 (National Family Caregiver Association [NFCA], 2003).

A typical caregiver is a married woman who works outside the home; however, more men are assuming caregiver responsibilities (NFCA, 2003). Most caregivers receive great satisfaction from providing support to the chronically ill person, but it is common for caregivers to experience significant physical and psychosocial problems (Schultz & Beach, 1999; Marks et al., 2000). Common psychosocial problems include depression and lowered self-esteem (Marks et al., 2002), while physical problems include poorer nutritional status (Silver & Wellman, 2002). In addition, long-term caregiving can affect the caregiver's employment and interferes with providing for the needs of other family members and friends (AOA, 2004).

Caregivers assume many roles as the physical and mental health of the ill person deteriorates (Stone et al., 1987). The primary caregiver manages all or parts of tasks the chronically ill person is no longer capable of performing. Therefore, a primary caregiver may both manage a variety of needs of a household or individual as well as provide direct care to the chronically ill (Silver & Wellman, 2002).

As a result, caregivers can assume an overwhelming array of responsibilities that require the caregiver to be knowledgeable about and act upon needs such as legal, financial, medical, emotional, transportation, and home maintenance. The primary caregiver also interacts with, manages the responsibilities of, and provides updated information to a variety of other caregivers, who may include informal caregivers, such as the spouse, adult child, grandchild, relative, friend, neighbor, and formal caregivers, such as paid professionals or volunteers.

## **Challenges of Rural Caregivers**

Living in a rural setting further complicates the initiation and follow-through of a health maintenance program for caregivers of those with chronic illness. In Montana, 50 of the 56 counties are designated as frontier counties. This means that residents in the 50 counties have greater obstacles in accessing care for families. Additionally, the eastern portion of the state is experiencing a decline of population, leaving behind an aging population with fewer services. Caregivers of Alzheimer's afflicted friends and loved ones face particular challenges and obstacles. Typical obstacles include distance, terrain, climate, lack of providers, fewer available specialty services, and lack of social support (Krummel, Humphries, & Tessaro, 2002; Paul & Weinert, 1999).

As the length of time for caregiving increases, overall physical health of caregivers declines (AOA, 2004). It is imperative that caregivers for rural older adults have access to effective caregiver training to assist them in maintaining their own health and well-being. Only a few published studies document the outcomes of caregiver training with even fewer published studies documenting results of comprehensive caregiver training for rural, older adults with chronic illness (Kaasalainen, Craig, & Wells, 2000).

## **Preparation of Caregivers**

The majority of caregivers transition into caregiver roles without the knowledge or skills to provide effective caregiving (Marks et al., 2002). However, caregiver training can improve well-being and health for these two at-risk populations, the chronically ill and their caregivers (AOA, 2004; Silver, 2004). For example, training in nutrition information and skills can positively affect healthy food choices of the chronically ill person and the caregiver.

The goal of caregiver training is to ultimately improve the effectiveness of caregiving to the chronically ill person and reduce caregiver burden (AOA, 2004). Development of effective caregiver training addresses appropriate educational strategies for the burdened caregiver, provides comprehensive coverage of caregiver tasks, and considers an educational format and delivery system that is affordable, practical, and easily accessed. Effective caregiver training programs are formally evaluated to document that the program met training goals. Training content includes knowledge, skills, and resources for the ill person and the caregiver. Appropriate educational strategies are employed to meet the learning needs of individuals and their environmental context. The outcomes of effective caregiver training include improved indicators for health, finances, and other related categories.

## **Planning of the Alzheimer's Caregiver Series**

Since 2002, the MSU Extension Service has been working with the Alzheimer's Association state chapter to increase the awareness and support for caregivers in the form of in-kind assistance and monetary contributions for conferences and participation on the board of directors. Although conferences on the topic of Alzheimer's disease are held annually, the location and time away from caregiving often precludes many rural caregivers from attending. This need led to a request to hold a "conference" in the rural northeast portion of the state.

Originally the state Family and Consumer Science Extension specialists planned to have a 1-day conference in northeast Montana targeting informal caregivers of Alzheimer's patients. Feedback from Extension agents and constituents suggested that a better use of time and resources would be a 5-week series. In this format, each specialist would travel to northeast Montana (approximately a 500-mile drive one way from the university) and present his or her seminar six times in the five-county area over the course of a week. The result was the development of a 5-week educational series using didactic educational strategies emphasizing: 1) an introduction to the disease presented by county agents using a video or local expert; 2) family interactions and caregiver stress; 3) nutrition; 4) financial planning and legal issues; and 5) Alzheimer's-proofing the home.

Funding for the series was a collaborative effort with an MSU Extension Director's mini grant, a commitment from four Family and Consumer Science specialists' operations budgets, and county budget commitments. The total budget for the series was \$4,800.00. Additionally, in-kind contributions of brochures and other materials from the Alzheimer's Association, Montana Chapter, were provided, and local in-kind contributions of space to hold the series and refreshments were provided in the counties.

## **Evaluation**

More than 80 individuals attended the 5-week series. Although the series targeted the informal caregivers such as friends and family members, a variety of other individuals attended, including home healthcare providers, nursing assistants, and long-term care facility staff. A few participants attended because they had lost a loved one due to Alzheimer's. Several of these individuals indicated they wished the series had been available when they were caregiving.

This study reported here was exploratory in nature. All attendees were invited to participate in the evaluation; however, participation was voluntary. Demographic data from the evaluations revealed that the majority of participants were ages 50 years and older (75%), and most were Caucasian (98%) and female (87%). Although attendance varied somewhat from week to week, it was relatively consistent, and there was little attrition. The majority of participants resided in communities with fewer than 5,000 people.

## **Outcomes**

The evaluation of the project was based on the logic model of evaluation assessing short-term, medium-term, and longer-term outcomes. Data were gathered at three different points of time. Short-term outcomes were measured through a pencil and paper evaluation given at the end of each presentation. A telephone interview 6 weeks after the end of the series with a random sample of 14% (N = 11) of the participants assessed medium-term outcomes. A telephone interview conducted 4 months after the end of the series with another random sample of 11% (N=9) of participants assessed long-term outcomes.

### **Short-Term Outcomes**

The short-term evaluation assessed what the participants in the series learned related to financial planning issues, nutrition, home modifications, and family interactions related to caring for an Alzheimer's patient. The response rate varied depending upon the attendance at a particular class. The average response rate was approximately 69% of attendees at a particular class.

Results from the short-term evaluation of the presentations revealed:

- 48% of participants either planned to or had already started exploring alternatives for handling the financial affairs of the Alzheimer's patient.

- 44% of participants either planned to or had already started exploring legal guardianship or conservatorship for the Alzheimer's patient.
- 66% of participants either planned to or had already started to encourage the early stage Alzheimer's patient to have legal documents signed.
- 51% of participants either planned to or had already started to inform appropriate individuals of the location of financial documents of the Alzheimer's patient.
- 61% of those participants caregiving at home planned to use the housing checklist for home modifications.
- 53% of those participants caregiving at home planned to design a prioritized and phased plan of action to accommodate the Alzheimer's patient.
- 44% of those participants caregiving at home planned to research options for dependent Alzheimer's housing.
- 60% of the participants strongly agreed with the statement: "Based on the workshop, I better understand the food/nutritional needs of people with Alzheimer's."
- 31% of participants strongly agreed with the statement: "In the next week, I will try at least one practical tip for improving the food intake of my family member/friend with Alzheimer's."
- 82% of participants planned to try at least one of the stress reduction techniques learned within 2 weeks.
- 69% of participants caregiving at home planned to find respite care for themselves at least once in the next month.
- 81% of participants planned to or had started to find positive ways to channel their anger.
- 54% of participants caregiving at home planned to network with at least one other caregiver of an Alzheimer's patient in the next month.

Anecdotal and observational data also provided the project with valuable information. One woman attended who thought she might have early stages of Alzheimer's and wanted to learn more. Another woman who had not been able to be out of her husband's sight due to the disease started using respite care. Her husband was resistant to going to a daycare facility but by the third session he was comfortable with it, which allowed his wife to receive much needed respite. Nurses' aides and home health care workers commented on how the information would be useful for the families of the Alzheimer's patients for whom they were caregiving.

## Medium-Term Outcomes

The medium-term outcomes sought to assess if the participants had followed through and used the information from the series. A random sample of participants (11) was selected for telephone interviews 6 weeks after the series was completed. Eighty-one percent of those interviewed stated that they had shared the information with a family member, coworker, or friend, thus increasing the number of participants receiving benefit from the program. Nine out of the 11 participants interviewed had already used some of the information learned in the series.

A participant shared: "I am suspicious of a family member, and I have not had time yet to address any issues, but just having the information helps me look for more things and be more aware."

One person stated: "I am using the nutrition information, and it has helped me to more or less recuperate from the stress of taking care of my mom because I was the sole caregiver."

Ten out of the 11 participants (91%) planned to use the information with friends, family members, or co-workers. One person commented "[I am] more aware of people in the family and also at the business, here at the store. There was one lady who I think may have Alzheimer's and she was trying to write a check for more and just being aware of that and helping the family be aware of what she is doing. I think just having a general knowledge and awareness to use for everyday life."

## Longer-Term Outcomes

The longer-term outcome of the series was to assess if participants felt more comfortable in their caregiving role and had a greater understanding of how they can assist a loved one afflicted with Alzheimer's. Additionally, we wanted to know if participants were interested in more educational programming on caregiving.

Four months after the series ended, a random sample of nine participants was selected to participate in a telephone interview. This length of time was selected due to feasibility and propriety (The Joint Committee on Standards for Educational Evaluation, 1994). Those participants

who were interviewed at the mid-term evaluation were eliminated from the sample to avoid over evaluating any one participant.

Eight out of the nine participants or (89%) agreed or strongly agreed that they had increased their self-confidence in caregiving. All reported that they were better prepared for their role as a caregiver since participating in the series.

The evaluation of the series found that there was an interest in continuing to offer additional educational programming on caregiving. Extension professionals are now training class leaders in the Powerful Tools for Caregiving program so that county agents and others can offer the 6-week program in their communities. Another resource, Tenderhearts, (Parsons, 2004) is being adapted to our state. This is a project to assist caregivers in organizing information and keeping journals about their caregiving to assist them when working with health care professionals. These efforts along with fact sheets on topics of interest to caregivers have expanded Extension's role in caregiving educational programming.

## Implications for Replication

Because of the success of the program, a similar effort has been implemented in two other areas of the state. The program is also being packaged for national dissemination.

The evaluations of the series were overwhelmingly positive. The comments made for improvement were aimed at publicity for the series. Many participants commented that they knew of others who would benefit from participating in the series. We have formalized a brochure for the series with space for each county to add locally specific information. We have also scheduled conference calls with the participating county agents to discuss advertising and potential collaborators in their areas. Reaching out to community healthcare providers, registered dietitians, assisted living, and nursing home staff is important in getting the word out about the series.

The program was designed for the informal caregiver, yet caregivers and staff from nursing homes, home health care agencies, and hospitals attended. We found with the series that both informal and formal caregivers gained from the program, and we will continue to offer it to both groups. With little access to continued education available in remote communities, we found that the series was also of great interest to paid caregivers. Future plans include evaluating long-term impacts and providing continuing education credit to those who desire it.

The aging baby-boomers in the United States and the changing population in Montana have resulted in a need for Extension to focus on the issue of caregiving. Although our project began as a response to the needs of caregivers of Alzheimer's patients, we see that the project will grow as we enter into other areas of caregiving for our aging population.

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