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# Long-term consequences of the Alzheimer's caregiver role: A qualitative analysis

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## Abstract

*A qualitative analysis was performed on responses of 51 participants to open-ended questions about the experience of being family caregivers for a loved one affected by Alzheimer's disease. Participants had been in the caregiver role for at least eight years. Results indicated a pattern of adapting successfully or unsuccessfully to the caregiver role, experiencing initial caregiver burden, finding relief in social support when available, and long-term distress or long-term positive change. Memories and feelings were strong about individuals and institutions that had been helpful or indifferent many years earlier as the caregivers struggled to cope with their unplanned predicament.*

*Key words: Alzheimer's disease, caregiving, caregivers' role, family caregivers*

## Introduction

Alzheimer's disease (AD) affects approximately 10 percent of those over age 65, and 50 percent of those over age 85.<sup>1</sup> Typically, the family assumes caregiving duties for the first few years of cognitive and functional decline associated with dementia, but, over the three-year to 30-year course of the disease, the family relies on a continuum of professional care that eventually ends in institutionalization.<sup>2,3</sup> For the family caregiver, the most commonly cited experience in this role is one of distress, despair, and depression, although there are reports of the

experience resulting in positive coping and a sense of accomplishment.<sup>4-9</sup>

Social support seems to be a critical variable in how well family caregivers cope with the decline of their loved one and the duties of caregiving. From support of other family members and friends to participation in Alzheimer-specific support groups and thoughtful attention from professional health care providers, the evidence indicates that social support leads to more favorable outcomes in both mental and physical health of the caregiver.<sup>6,10-12</sup>

Yet, although quantitatively documented, the dynamics of the caregiver's burden, distress, and coping are not well understood in ways to guide potential interventions that would yield a marked, reliable, positive outcome. Some caregivers find support groups to be beneficial, others do not; some caregivers perceive adequate emotional support, others do not; and some endure the caregiving experience with depression and guilt, while others survive it with confidence and a renewed sense of well-being.<sup>13,14</sup> Much of the research yielding these various results is based on a time period of three years or less in the caregiving role. The current study reports a qualitative analysis of individuals who have been in the caregiver role for at least eight years.

A qualitative examination of open-ended questions would be expected to yield insights about common expectations and frustrations of long-term caregivers. Patterns were expected to emerge in the longer-term coping experiences of these individuals.

## Method

A phenomenological method was used to investigate the experience of caregiving for 51 family members with Alzheimer's disease. This qualitative investigation was a follow-up study from an original quantitative investigation

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that involved 174 caregivers eight years earlier.<sup>13,15</sup> Of the 51 (29.3 percent) participants who were available for the follow-up study, 22 (43.1 percent) were male and 29 (56.9 percent) were female. Caregivers were primarily Caucasian (94 percent) with the exception of one African-American and two indicating Hispanic as their ethnic background. Of the caregivers reporting their age (n = 44), the average was 67.3 years. Approximately half (53 percent) were married, 22 (43 percent) widowed, and two never married. All of the subjects participating in this study had taken on the responsibility of primary caregiver for a parent (n = 19, 37.2 percent), spouse (n = 28, 54.9 percent), sibling (n = 2, 3.9 percent), grandchild (N = 1, 2 percent), or distant relative (n=1, 2 percent) with Alzheimer's disease. Participants indicated having been in the caregiving role an average of 8.4 years with the years ranging from 1.3 to 22.

### *Procedure*

Participants were asked to describe their caregiving experience in terms of their thoughts and feelings, and to talk about anything that would help the researcher to understand the experience. Prompts were given to the subjects, such as "Is there anything else that you would like to tell me?" or "How did that make you feel?" In addition, specific questions concerning the role of caregiver were included along with various support group aspects. The interviews took between 30 and 90 minutes to complete. In one instance, a male spouse was clearly experiencing some memory impairment; therefore, the data from the second collection period were suspect and not included in the current analysis.

### *Data analysis*

Following the interview, the researchers transcribed the comments onto individual strips of paper, where they were sorted for theme. With the themes identified, the researchers then began the process of having them placed on individual cards, so that individual comments matched the theme of the card. Sorting continued until the researchers felt the themes and the relationships between them captured as accurately as possible the way the participants experienced caregiving.

## **Results**

Seven themes were identified from the data: role issues and role reversal; problems and burden of being a caregiver; support sources and resources; support group issues; protection, nursing home placement, and guilt; research awareness and participation; and additional contributions as a caregiver.

### *Role issues*

A first theme emerged surrounding the issue of role identification. Participants described the difficulty of finding their role as caregiver: "I am a nurse, so it was difficult to decipher between job demands and caregiver demands." They related how tough it could be to become the "mother" for a parent: "Since it was my mom, the role reversal during caregiving made it difficult."

What kept these caregivers going? Was it role acceptance? For one of the spouses, it was acceptance of the role and still having time for her husband: "I had things to get done, so I did them and also made time for my husband." Role acceptance was also seen in statements such as: "I have five siblings and none of them helped with my dad. You must be able to care for them willingly or else bitterness sets in." Another caregiver stated: "I accepted my responsibilities, so I did not desire anything else," Yet another said: "I am not a real social person and I work a lot, so the caregiving did not really keep me from doing things."

For many, caregiving meant little role adjustment. For these participants, help was usually available from other family members or from professional caregivers. Others reported: "My sister and I would share the caregiving until mom was put in a nursing home." Or, "For years I would keep my mother for approximately three months. She would stay with my sister for approximately three months. We eventually put her in assisted-living and then a nursing home. Between the two of us, we could do and plan anything we wanted." One caregiver reported that the activities of caregiving were not overwhelming: "The caregiving did not reduce my activities at all. I had plenty of time for everything." Another stated: "I had plenty of time for everything. Others encouraged me to put her in a nursing home to keep a better relationship [mainly leisure time together rather than maintenance]." Others recognized that their ability to adjust was due to the placement of the family member in a nursing home. "I was still able to do everything, since mom did not live with me." One individual who probably had the least to say about the whole process—but had only positive comments when he said anything—was a gentleman who was the primary caregiver for his spouse, mother, aunt, and uncle at various times throughout the last several years. His composure and grace were inspiring.

### *Problems and burden of being a caregiver*

The reported level of burden did not differ between those who were currently attending, no longer attending, and had never attended a support group. However, these participants clearly vocalized unmet needs as a caregiver.

Two reported: "I never felt as though I got enough emotional support"; "I did not get enough emotional support." Others also reported a lack of emotional support: "I needed more emotional support from friends and community." "The worst part is the lack of support from my family. Nobody wants to help." Emotional problems are often reactions to the care process. The amount of commitment required in being a care provider can often be overwhelming to many of the individuals. Several reported suffering from emotional traumas. For example, "I could have used some psychiatric support"; "I am having emotional problems from the stress and sadness of seeing such a low quality of life in my mother. My husband has recently had his second stroke and resents me for the time I spend with my mother."

Many of the problems experienced as a caregiver can further complicate the situation by developing into additional problems. Caregivers reported a wide range of issues: "The lack of my own memory triggers fear. My daughter had to see a school psychologist because of the way her grandmother treated her." For those who agree to be the primary caregiver, being the provider is not a part-time matter. "Caring for my step-mom was all-encompassing. I was always on call and there was no hope for recovery." Even for the nonprimary caregiver, the care process can have an effect. "I thought my brother's pill-taking was a problem. I wanted him to call the drug hotline"; "I never experienced any problems as a result of my caregiving, but my aunt and uncle that helped out were recovering alcoholics and relapsed during their caregiving."

### *Support sources and resources*

A third theme was that of additional support sources and resources. The circumstances of the caregiving experience caused caregivers to look for additional sources of support. Support came from a wide range of gatherings. Caregivers maintained: "The staff at the veteran's home was wonderful and always there if I needed to talk"; "Most, or really all, of my support came from friends who had experienced the same situation. This was....one-on-one support"; "I think that sharing the caregiving time between siblings and adult day care prevented stress and other subsequent problems within the family"; "I now go to Friends and Family of Alcoholics and it has become extremely important to me"; "My aunt, uncle, and brother go to Alcoholics Anonymous."

Caregivers tended to be very appreciative of programs that allowed for time away from the family member. "I was very grateful for adult day care. The carpool basically served as a support group"; "I could not have survived without [the program]." Not all support sources were

viewed in a positive fashion. Comments regarding problems with doctors, nursing homes, and family members were most prominent. Caregivers reported: "Doctors, nursing homes, etc. do not seem interested or hopeful, but rather passive and uninterested." "The real problem is with doctors, they do not support the caregiver. The key is to get good medical help." Nursing homes were not immune from criticism. "One problem was the deceitfulness of the nursing homes. I think that nursing homes and patient dignity need to be addressed and improved." "My anxiety was mainly from the nursing home quality. My main concern was the best possible care for my mom." Difficulties were not only seen with professional individuals or groups but with friends and family as well. "There were conflicts between siblings"; "People do not know how to interact with Alzheimer's patients. Isolation was the worst part."

A lack of resources was a theme reported by many of the participants. Caregivers indicated a great desire for more resources being available to them during the care process. For example, "It is important for people to know about resources, especially for the support groups"; "I attended lectures sponsored by the Alzheimer's Association, but never knew of any support groups in my area." Lack of accessibility seems to be another area that family members recognize as limiting their empowerment. One reports that: "Resources need to be more accessible. The support groups are not easily found or advertised. I need more information on what to look for and who to call for help." Another felt current or timely materials were the most relevant. "Books and testimonials should be recommended and made accessible. More assistance [and] resources are needed and treatments need to be current and better monitored."

### *Support group issues*

A prominent theme in caregivers' reports of their experiences was related to support group issues. Of the 51 participants, 12 had never attended a support group over the eight years of the study. Thirty-six had attended at one time, but had stopped, and three were still attending a support group. Caregivers were very willing to give suggestions toward the improvement of Alzheimer's support groups. One recurring theme surrounded statements such as: "I think support groups should provide care for the patients during the meetings"; "I think that patient care should be provided during support group meetings"; "I think there is a need for specific support groups, one for family members and one for actual caregivers." One caregiver commented: "I prefer closed support groups where no one can join once the six- to 10-week sessions begin. Outsiders joining later keep people from sharing everything."

Caregivers shared positive and negative aspects of support groups. Examples of reported positive statements include: “The support group my husband and I attended in early 1990 was very beneficial”; “My husband died in June 1993, but I am still attending the support group”; “I am in favor of support groups, just not for myself”; “I really liked the Alzheimer’s support group.”

These caregivers appeared to understand the use of the word “support” in support groups. These individuals seemed to know that the contact provided was intended to carry or sustain them for even just a little while. “I think groups are invaluable because of the friends [and] individuals that you meet. The people are what is important; the group simply provides the contact.” “I should have gone to the support group, but I am not one to ask for help. I think I would have benefited from it very much.” “The support group saved my life. It was either me or her. I am a strong advocate for support groups. If people, especially men, could drop their pride, they could find wonderful support in a group.” Caregivers appeared to recognize that differences exist between groups. “The second group had more to offer. We watched videos and learned more coping skills.” Because there are differences between groups, caregivers identified these important expressions that differentiated the experience of a positive support group from an unpleasant support system. One caregiver told us, “I support the efforts of the Alzheimer’s Association 100 percent, but support groups are not valuable for me.” Often, expressions of additional burden coming from the groups or associations were expressed. “The Alzheimer’s Association only sends materials so they can collect your money. I do not get anything out of the materials they send—no great knowledge or insight.” Caregivers sometimes appeared to feel burdened by others in the groups: “I didn’t attend support groups because I didn’t want to hear the horror stories or know what the future held.” “The first group I went to had three members and we went over the same problems. Others acted as martyrs.” Several of the participants commented on just wanting to free themselves from some of the burden of the day when coming to the support group. “I do not like the support groups. I think it would be more helpful to not talk about Alzheimer’s and just have fun.” Another stated: “The group in [city] was mostly people living with the patient giving 24-hour care—I did not. They looked down on me for this.” The remaining comments concerning support groups dealt with the lack of personal need for such groups. “I never even thought about going to a support group; it was too hard to get away.” Another caregiver said: “My family was fabulous and having a support system seemed to fulfill my emotional needs. I did not feel the need for a support group.”

One possible barrier to support group participation seems to be whether a physician recommends a support group. Of the 13 caregivers who participated in both measurements, only one (7.6 percent) was counseled by a physician to attend a support group. For those who were currently attending, eight (47 percent) stated that support groups had been recommended by a physician, while six (29 percent) of those no longer attending had been recommended to attend a support group.

### *Protection, nursing home placement, and guilt*

A theme that was conveyed by almost all of the participants was trying to protect the family member. At first, it was trying to protect them from the reactions of others. A caregiver stated: “Society was the main reason we put him in a nursing home—to keep him out of harm’s way.” To demonstrate how all-encompassing caregiving can be, one daughter stated: “When she lived with me, I would take her along most of the time.” The constant care was also demonstrated in the statements: “She was helpless and you had to watch her constantly. I had to lock her inside just to get the mail”; “I would take her with me most of the time or my family would stay with her. I lived across the street from grandma and stayed with her during the day and evening until we placed her in assisted-living with five other Alzheimer’s patients and 24-hour care.” There tends to be a lot of fear that accompanies this process. “Our biggest fear in the group was that our patient would get lost, cause a traffic accident, or harm themselves or others.” After the disease progresses, the protection process moves to protecting them from themselves. Sometimes, the protection meant placement in a nursing home or assisted-living facility. When nursing home or assisted-living placement occurred, often what followed was guilt. Repeatedly, participants expressed guilt feelings for putting loved ones in some type of facility. Just some of the statements in this area were: “I still feel guilty for putting her in a nursing home. The guilt is my biggest problem”; “Putting mom in the nursing home is a major guilt that I will never get over”; “My guilt for passing on the caregiving responsibilities is overwhelming. You need to prepare yourself for this and know that you do not have a choice”; “The hardest part was putting her into a nursing home. She had always told us kids that she did not ever want to be put into a nursing home”; “Putting mom in the nursing home was difficult. It was also hard to cope with my negative attitude toward her”; “The hardest thing was seeing her in the nursing home at the end—simply lifeless.” Caregivers indicate moving family members because of being unhappy with nursing homes and having a concern with finding high-quality care. One participant reported: “I was not happy with [nursing] homes, so I

moved her quite a few times.” Another stated that: “My biggest concern was finding the best care.”

### *Research awareness and participation*

During the care process, many of the participants had become very informed providers. These individuals were aware of brain and tissue donation, current research, and funding projects occurring around the country. Some of the participants had even become involved in writing scientific or invited articles for journals throughout the country. One of the participants became so motivated by the first phase of the current project as to submit an article to a refereed journal and having it accepted for publication. One caregiver declared: “I would like to encourage donating of the brain to science.” Another caregiver stated, “A research group in California requested a sample of my father’s brain, but when he finally died the research had been halted.”

### *Additional contributions of being a caregiver*

All of the participants were engaged in a search during the care process—a search to be a good provider (*i.e.*, knowledgeable, active, contributing, etc.). This statement is best seen in some of the contributions made by the caregivers. When first exposed to Alzheimer’s disease, the participants knew very little about the illness; after a while, many of these same individuals gained enough knowledge and experience to have major effects within their communities. “I helped create the support group”; “I worked on getting legislation passed regarding patient care and human rights in nursing homes”; “I was a member of the first board of the [city] Alzheimer’s Association chapter”; “I was part of the board that started the local support group. Mom died four and a half years ago. We have not been active in the Alzheimer’s Association since then, but I visit six senior facilities on a regular basis.” Many of those not volunteering are contributing financially. “I am a regular financial contributor to the Alzheimer’s Association.”

## Discussion

This qualitative analysis suggests that a predictable progression occurred for those in the role of caregiver for a loved one with Alzheimer’s. First, the role of the caregiver presents challenges such as becoming the “parent” to a parent that must be dealt with in one way or another.<sup>16</sup> For some, acceptance of the role comes with effort, support, and dedication. For others, the burden of the role leads to a substantial emotional toll with serious consequences. Second, there is a marked desire and need

for support in adapting to and carrying out the caregiver role. Support is expected from family members, health care professionals, and a range of others including friends, support groups, and not-for-profit organizations. The experience of caregivers in obtaining, accepting, and being satisfied with these support systems varies widely. Some are quite satisfied and grateful; others are not. Whether the desired level and quality of support is obtained seems to be well remembered as part of the caregiving experience. Third, there are strong feelings of a need to protect the loved one from the consequences of impairments, and these feelings typically lead to placement in some type of long-term care facility, accompanied by feelings of guilt that the caregiver cannot provide the needed intensity of care. Finally, many caregivers report that the experience changed their lives in a meaningful way—that they have taken steps to support others, to become advocates for more effective interventions, and to become financial supporters of the Alzheimer’s Association.

Most caregivers in the current study did not report being overburdened. However, when further questioned regarding emotional stress, many repeatedly stated how they felt they were suffering from emotional traumas, problems and stress. In fact, many of the participants indicated that they did not get enough emotional support from those around them. As one participant put it, “I am having emotional problems from the stress and sadness of seeing such a low quality of life in my mother.”

The current research also raises an interesting question regarding quality of care. What is the reason for some of those primary caregivers that have decided to place a family member in a nursing home or assisted-living facility continually moving the family member from facility to facility, never being fully satisfied? When a participant stated, “Putting mom in the nursing home is a major guilt that I will never get over,” it raises the notion that guilt may be a motivator behind the behavior of those that seem to be unhappy with care facilities and continually move family members. Adequate support from others, including access to appropriate educational materials, may help alleviate this problem, regardless of its source.

Participants often mentioned positive coping strategies. Research interest—either becoming informed or actually participating—became a reality. One gentleman even wrote a journal article to help others, as mentioned earlier. Other participants helped to start support groups, pushed for legislation, became board members of associations, or volunteered and gave financially. One cannot help but notice that the feelings expressed by the caregivers in our interviews run deep—even years after the

caregiving experience has ended. These include memories about the loved one's quality of life; whether other family members have helped or refused to help in the caregiving process; helpfulness or lack thereof on the part of physicians and nursing home staff; and positive and negative experiences with support groups. Moreover, caregiver memories and feelings differentiate between those groups and individuals considered supportive and those thought to be inconsiderate or indifferent.

There seems to be little preparation for the role of caregiver.<sup>17,18</sup> Those who adapt to the role most effectively seem to have support of family, friends, and health care providers. Whether they adapt well or not, caregivers do have strong feelings about their experience and about those individuals and institutions they encounter along the way. This is a finding that should help guide those who try to implement intervention programs.

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