

Meeting the Needs of Caregivers of Individuals with Alzheimer's Disease: Recommendations for Health Care Providers

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Abstract

It is estimated that the prevalence of Alzheimer's disease in the United States will increase from 4.5 million in 2000 to 13.2 million by 2050, unless new discoveries and treatment facilitate prevention of the disease (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). This article expands upon the findings of a phenomenological investigation by Hogan et al. (2004) which examined the nature of role changes experienced by family caregivers of individuals with Alzheimer's disease. Family caregivers need support to help them adapt to the role changes brought forth by caregiving. Such support is essential to caregiver quality of life. Caregiver needs related to role performance are presented in this report, along with strategies which health care providers can use to meet those needs.

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This report illustrates how the family caregiver in the home is vulnerable to a unique set of problems. It provides suggestions for how health care professionals can help alleviate the challenges and stresses of caring for a family member who has Alzheimer's disease.

The need to more comprehensively assist caregivers has been noted by many (Hellen, 1998; Morris & Gainer, 1997). Moody (2002) and Lewis (2003) describes how caregiver stress can lead to serious problems such as elder neglect and abuse. The importance of helping caregivers cannot be understated.

Gifford, Wooster, Gray, and Chromiak (2001) point out that decreased funding of public programs has heightened the need for more informal supporting mechanisms for caregivers. This trend is exemplified by helpful "self-help" publications such as Yousey's (2002) useful guide for helping families care for their elderly members. However, the challenge of helping family caregivers is complex, and cannot be easily remedied.

A recent phenomenological research investigation in which both of the authors of this report were involved examined role change in family caregivers of individuals with Alzheimer's disease (Hogan et al., 2004). The study illustrated how the experience of caring for persons with Alzheimer's disease altered the quality of life of family caregivers. The study indicated how changes in role performance brought forth by the caregiving experience affected the well-being of family caregivers.

Data in the Hogan et al. study (2004) were collected from 15 caregivers via questionnaires and from 8 caregivers via interviews. This information was analyzed via thematic analysis (Morse & Field, 1995). First, this involved the identification of common categories in the data. Second, broader common themes were found. The study's report (Hogan et al., 2004) describes this data analysis process in depth.

Poster presentations of the findings of the Hogan et al. study (2004) are found in [Appendix A](#) (Kuo et al., 2004) and [Appendix B](#) (Fisher et al., 2004). [Appendix A](#) illustrates the themes of the

investigation, and [Appendix B](#) provides further explanation of these caregiver concerns.

Six major themes were identified in the Hogan et al. study (2004). The following six quotes were chosen as theme titles because they best illustrate the caregiver concerns and sentiments associated with the emergent themes below. These themes illustrate the frequent and emphatic concerns voiced by the study participants.

1. "I Feel Guilty Leaving Her."
2. "Our Roles Have Been Reversed."
3. "Adapt... to What You are Going Through."
4. "I Have to Cook, I Have to Clean... I am Always Busy."

5. "Some People Shy Away."
6. "My Health Care Comes After His." (Hogan et al., 2004)

Meeting Caregiver Needs: Suggestions for Healthcare Professionals

This report expands upon the Hogan et al. (2004) research report findings by giving further description of the caregiver needs revealed through the thematic analysis process. Suggestions for health care intervention are given to address each of the needs and thereby improve caregiver quality of life. The caregiver needs are summarized in Table 1.

Table 1
Needs of Family Caregivers of Individuals with Alzheimer’s Disease

Need to Improve Caregiver Well-Being
Need for Support Groups and Other Coping Strategies
Need for Support in Adjusting to Role Reversal
Need to Strengthen Family Support
Need to Resolve Gender Issues in Family Caregiving
Need for Support in Household Tasks
Need to Increase Caregiver Involvement in Leisure Pursuits and Social Activities

Need to Improve Caregiver Well-Being

The Hogan et al. study (2004) demonstrated a large need to improve caregiver well-being. This included the need for increased attention to the physical and mental health of the caregivers. Often the caregivers chose to neglect their own health needs and focused their attention on the person with Alzheimer’s disease. Sometimes this resulted in increased emotional strain and sickness in the caregivers. Health care providers need to emphasize the importance of caregiver health. For example, they need to encourage caregiver to keeping their own doctor’s appointments and staying current with their own schedule of physical examinations and medical check-ups. Attention to diet and exercise is

important for caregivers, as well as for persons with Alzheimer’s disease.

Stress reduction may also be very important for family caregivers. There are numerous resources available to help health care providers in this regard. For example, Katie & Hendrix (2004) describe simple techniques for improving one’s own mental well-being. They offer suggestions for sharing and expressing love between family members. These simple techniques may be important for caregivers and individuals with Alzheimer’s disease whose relationships may be compromised by the stress of cognitive decline and increasing caregiver responsibility.

Innovative wellness programs are beginning to be increasingly available. Scott (1999) described how occupational therapy students provided health promotion instruction and support via group sessions in a community environment. This wellness programming was positively received. More community-based programs of this nature are needed. They need to be delivered in a format which encourages caregiver access and participation to programming.

Need for Support Groups and Other Coping Strategies

The caregivers in the Hogan et al. study (2004) found support groups to be particularly beneficial. Health care professionals need to emphasize and promote the use of coping mechanisms such as training in coping skills and problem solving in Alzheimer's caregiver support groups. Attending religious services or participating in other community activities may also help the caregiver deal with the challenges of his or her situation. Transportation problems and scheduling may often limit caregivers from participating in helpful community groups or events. It is recommended that health care professionals emphasize the importance of these supportive mechanisms to caregivers. Health care professionals may provide lists of support groups, including corresponding contact information and meeting schedules. It may be helpful to ask caregivers about their desire to participate in religious services or other community groups, and health care professionals are encouraged to help facilitate this process. If caregivers are unable to participate in community activities, due to problems such as transportation difficulties or time restrictions, other coping avenues are available. For example, caregiver participation in yoga or Tai Chi exercises in the home can be encouraged. There are numerous home videos available which can assist caregivers who are interested in pursuing these activities. Relaxation exercises may also be important to caregivers who need to learn strategies for dealing with the stresses of their situations.

Need for Support in Adjusting to Role Reversal

Role reversal was a phenomenon which often occurred in the family dynamics of caregivers in the Hogan et al. study (2004). The caregivers stated that whereas once they were the spouse or child of the person with the disease, they now felt more like that person's parent. This "role reversal" may result in major feelings of loss in caregivers. They may mourn the loss of the role of husband or wife. They need to be encouraged to express these feelings, and to pursue the remaining roles which they still have, such as grandparent, parent, or friend. They need to be encouraged to participate in all remaining roles, so they can experience the satisfaction that comes from role performance. For instance, health care professionals may need to reinforce to caregivers the need to take the time to visit with grandchildren or go out to lunch with their children.

Need to Strengthen Family Support

A need for family support was definitely displayed by the caregiver participants in the Hogan et al. study (2004). Many of the caregivers interviewed felt they needed more support from other individuals in their families. Health care professionals can be pivotal in helping to facilitate the involvement of other individuals. For example, they may encourage families to develop a schedule for rotating caregiving responsibilities among all adult family members. It may be important for health care providers to reinforce to family members the need for primary caregivers to have some time off for themselves. Health care providers often limit their "family education" efforts to the primary caregiver. It is important to remember to coach additional family members the various skills which they may need to better care for their loved ones who have Alzheimer's disease. This may involve providing reality orientation through the use of pictures and calendars. This may also entail teaching caregivers how to best communicate with the loved one. Instruction in positioning and transferring techniques for maintaining optimal patient mobility may need to be delivered to a number of family members.

Need to Resolve Gender Issues in Family Caregiving

Previous studies revealed the responsibility of caring for aging parents has largely been taken on by women (Spitze & Logan, 1990). It is worth noting that 6 of the 8 caregivers who volunteered to be interviewed for the Hogan et al. study were females. Historically, in American culture, caregiving was a role more common to females than males. In spite of increased blending of traditional gender roles in our society, there may still be the expectation for the female to be the caregiver and nurturer. Health care professionals are encouraged to recruit male family members into the caregiving arena. This may be accomplished informally by including male family members in family teaching sessions whenever they are available. It may also be accomplished by more formal measures such as inviting male family members to educational programs and support groups.

Need for Support in Household Tasks

The caregivers in the Hogan et al. study (2004) experienced an increase in participation in household tasks during the caregiving experience. Their caregiving responsibilities required additional emphasis on cooking, cleaning, and other household duties related to the care of the person with Alzheimer's disease. Many caregivers may be unable to secure assistance for household tasks, due to financial restrictions. Another problem is that caregivers may be unwilling to relinquish their former household responsibilities even while performing the added responsibilities of caregiving. Health care providers need to be alert to situations of caregiver overwork and exhaustion. They need to strategize with caregivers how they may obtain household help from family members, neighbors, friends and/or seeking paid help. Religious organizations may also serve as sources of additional human resources who can help caregivers.

Need to Increase Caregiver Involvement in Leisure Pursuits and Social Activities

The Hogan et al. study (2004) also showed a decrease in caregiver participation in leisure activities. Health care professionals are encouraged to discuss this issue with caregivers.

Caregivers may feel guilty about enjoying themselves while their loved ones are experiencing the functional and cognitive deterioration of Alzheimer's disease. This may be keeping the caregivers from engaging in activities which they find relaxing and enjoyable.

The caregivers who participated in the Hogan et al. study (2004) also reported a decrease in social activity due to having limited time off from caregiving responsibilities. Caregivers who previously participated in community organizations, clubs, religious groups, and other social groups did not find it feasible to continue such activities. This resulted in feelings of isolation. Health care providers need to help caregivers find ways to continue their social involvement, as socialization is an important source of emotional support. It promotes feelings of belonging which are needed by caregivers who may feel lonely, depressed, and deserted as they work as sole providers of care to their family members.

A summary of the aforementioned suggestions for helping caregivers is given in Figure 1, with an added suggestion for health care professionals to inform caregivers about the availability of community resources. Attention to all of these concerns may play an important role in improving quality of life for both the caregiver and the person with Alzheimer's disease.

In examining the caregiver needs revealed in the study, it is apparent that caregivers have limited time for activities other than caregiving. Many caregivers may benefit from improved access to respite care services. Respite care may be found in adult day care and/or senior centers. Such programs often include transportation arrangements.

There are some interesting models for respite care and adult day care programming. The Robert Wood Johnson Foundation (RWJF) and the Wake Forest University School of Medicine created a program entitled "Partners in Caregiving (PIC): The Dementia Services Program" in 1992 to provide funding and

technical assistance to 50 adult day care centers nationwide (Robert Wood Johnson Foundation, 2004). The PIC Program was based upon the Dementia Care and Respite Services Program (DCRSP) conducted from 1988 to 1992. The outcomes of the DCRSP demonstrated the

effectiveness of adult day centers for individuals with Alzheimer’s disease and their caregivers. The program was designed to be financially accessible and provided services to individuals in different levels of disease severity.

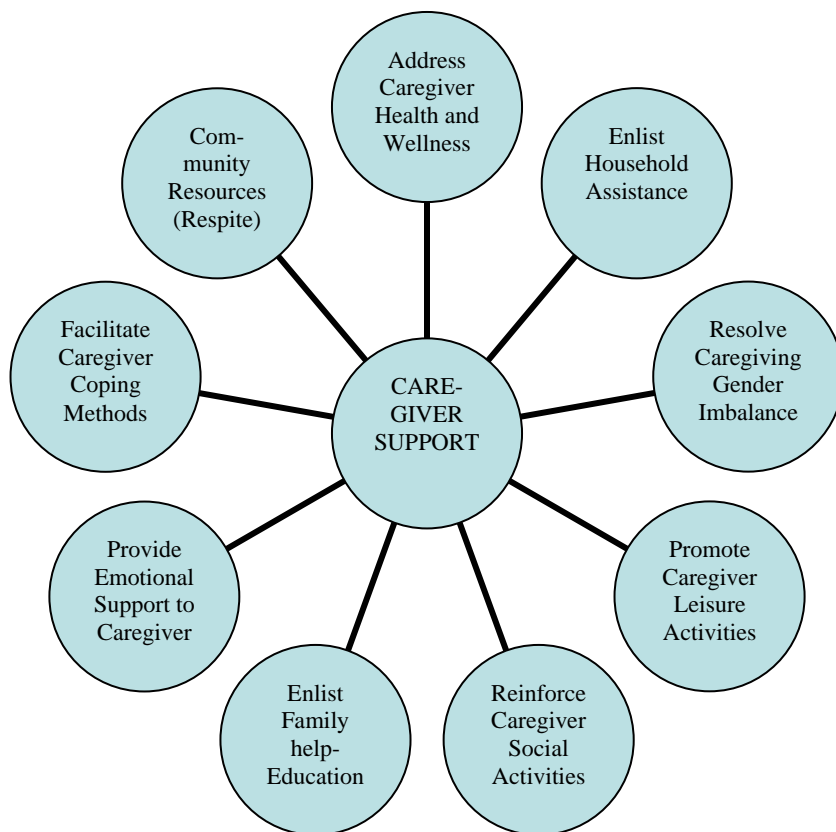


Figure 1
Caregiver Support Strategies

An intensive program, started in 1998 by the Wake Forest University School of Medicine and the PIC program, distributed information to adult day centers across the United States (Robert Wood Johnson Foundation, 2004). It provides a promising approach to addressing caregiver needs. However, resources and technical assistance are still needed in many locations.

Caring for a person with Alzheimer’s disease can be physically and psychologically demanding. Individuals with this condition usually need more care as the disease progresses. Older caregivers, such as spouses (who make up half of all caregivers), are often physically strained (Kornstein, 2002). The average amount of time that caregivers spend on caregiving is about 20 hours per week (Moore, Zhu, & Clipp, 2001). Studies also indicate that more caregiving time is required when the care

receiver has multiple disabilities, a situation often seen in Alzheimer's disease (Kornstein, 2002).

There is a high demand for funding for community resources for caregivers. Nonetheless, some very helpful resources for caregivers do exist. Community-based services for the person with Alzheimer's disease may include meals, transportation assistance, household cleaning, personal care services, home modification, adult day care, senior centers, and/or home health care.

The Alzheimer's Association has chapters throughout the United States which offers educational programs and support groups for caregivers of individuals with Alzheimer's disease. The local Agency on Aging (AAA) is typically listed in either the city or county government section of the telephone directory. It provides resources for family caregivers in local communities (Kornstein, 2002). The National Eldercare Locator, funded by the Administration on Aging (AoA), can help a caregiver find a local or state AAA. Individuals with Alzheimer's disease who have limited incomes may be eligible for AAA homemaker aide services. Other community-based services may include transportation, meals-on-wheels, household chores, home repair, and legal assistance. Referrals for resources such as food stamps, subsidized housing, Supplemental Security Income, and Medicaid may be made through the local office of AAA.

The National Family Caregiver Support Program (NFCSP) is a federally-funded program through the Older Americans Act (NFCSP, 2004). The program's website highlights caregiver resources in nine different languages. The NFCSP offers information about services, access to programs, counseling, support groups, caregiver training, and respite care.

The Resource Directory for Older People (NIA, 2001) is a publication designed to help health care providers and caregivers find information. This document is a cooperative effort of the National Institute on Aging (NIA) and the Administration on Aging (AoA). It lists contact information for Federal agencies, AoA resource centers, professional societies, private groups, and volunteer programs which are in alphabetical orders.

Caregivers who are employed outside of the home may also want to inquire about their employers' leave of absence policies. Some employers, under the federal Family and Medical Leave Act, allow employees to take up to 12 weeks of unpaid leave per year to care for relatives who are in need.

Conclusion

This report highlights how caregiver quality of life is often affected by the experience of providing care to individuals with Alzheimer's disease. Suggestions for helping caregivers improve their own quality of life were presented. Additionally, there were recommendations for finding relief from caregiving by enlisting family support and utilizing respite and other community resources. It is essential for health care professionals to help family caregivers in this regard.

This report has focused on the challenges of caregiving. It must also be emphasized that many rewards and joys can be obtained through participation in a caregiving experience. If health care providers become increasingly aware of the challenges of caregiving, and if they commit themselves to providing support and instruction to caregivers, they may increase the positive aspects of the caregiving experience for the patients and families they serve. This may lead to caregivers who more deeply treasure the opportunity of providing care to their loved ones in the home environment.

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Appendix B

Role Change Experienced by Family Caregivers of Adults with Alzheimer's Disease: Discussion and Implications for Therapy (Poster Presented at the 9th International Conference on Alzheimer's Disease and Related Disorders, Philadelphia, PA, July 19, 2004)

Note to Appendix B. From "Role change experienced by family caregivers of adults with Alzheimer's disease: Implications for occupational therapy." By V. M. Hogan, E. D. Lisy, R. L. Savannah, L. Henry, F. Kuo, & G. S. Fisher, 2004, Physical and Occupational Therapy in Geriatrics, 22(1), 21-43. Copyright 2004 by the Journal of Physical and Occupational Therapy in Geriatrics. Adapted with permission.

Available: Poster in PowerPoint Presentation (PPT)

Role Change Experienced by Family Caregivers of Adults with Alzheimer's Disease

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OBJECTIVE

RESULTS

Theme 1: "I have to Cook, I have to Clean... I am Always Busy"

Theme 2: "Adapt...In What You are Going Through"

Theme 3: "I Feel Guilty Leaving Him"

Theme 4: "Some People Sky Away"

Theme 5: "Our Roles Have Been Reversed"

Theme 6: "My Health Care Comes After His"

CONCLUSIONS

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References

METHOD

Data Analysis