A Psychoeducational Model for Hispanic Alzheimer’s Disease Caregivers

Carmen L. Morano, PhD, and Marina Bravo, LCSW

Purpose: More than 14 million persons are projected to be diagnosed with Alzheimer’s disease (AD) by the year 2020; therefore, it is not surprising that the literature contains numerous caregiver intervention studies. What is surprising is that although minority elders represent one of the fastest growing segments of the older population, they are seldom discussed in the intervention literature. Design and Methods: A purposive sample of Hispanic caregivers participated in a 5-day, 20-hr psychoeducational program to increase the caregivers’ understanding and acceptance of AD, repertoire of coping skills, knowledge of resources, and expression of concerns and emotions of caregiving. Pre- and posttests were administered to determine if participation in the program improved caregivers’ knowledge of the progression and management of AD, as well as knowledge of appropriate community-based services. Results: Caregivers demonstrated a significant improvement on the Caregiver Knowledge Survey, an increased awareness of community-based services, increased willingness to attend support groups, and overall satisfaction with the program. Implications: Culturally sensitive intervention research with minority AD caregivers provides the opportunity to increase understanding and improve coping skills.

Key Words: Psychoeducational intervention, Caregiver education, Support groups

Currently, more than 4 million persons have been diagnosed with Alzheimer’s disease (AD), and it is projected that by the year 2020 there will be more than 14 million AD patients (Alzheimer’s Association, 2000). Therefore, it is not surprising that the literature contains numerous reports about the “success” or “failure” of a variety of caregiver intervention strategies. Perhaps what is surprising is that within this literature there is limited intervention research with minority, specifically Hispanic, caregivers, particularly as Hispanic elderly persons will represent one of the fastest growing segments of the older-than-65 population over the next 50 years (U.S. Bureau of the Census, 2000).

By far the overwhelming majority of the existing AD caregiving research has not included sufficient numbers of Hispanic or, for that matter, any other minority caregivers (Aranda & Knight, 1997). The Aranda and Knight (1997) meta-analysis revealed a total of 12 caregiving studies that included minority caregivers, of which only 2 studies specifically included Hispanic caregivers. The majority of those limited studies including minority caregivers had homogeneous groups of Hispanics or African Americans to compare levels of depression, anxiety, or other negative outcomes of providing care. Although there has been a slight increase in studies that have included Hispanic caregivers, there continues to be little mention of Hispanic caregivers in the intervention research.

An examination of the meta-analysis of AD caregiver intervention research by Bourgeois, Schulz, and Burgio (1996) revealed that Hispanic representation, if present at all, was usually less than 15% of a given total overall sample. Of the more than 40 studies included in their analysis, only 6 studies included any minority caregivers; of those, only 2 studies included Hispanic caregivers, and neither contained samples large enough to evaluate the intervention’s effect on the Hispanic caregivers.

Given the current state of intervention research, we discuss in this article the development and implementation of a psychoeducational group model for Hispanic AD caregivers. Following a brief discussion of intervention research and some of the suggested reasons for the lack of Hispanic inclusion in the intervention research, we present a culturally sensitive model developed to address the unique needs of Hispanic caregivers. This article concludes with a discussion about what was learned from this effort and suggestions for future development and testing of intervention research with Hispanic AD caregivers.

Review of Intervention Literature

Professional or peer-led support groups (Toseland, Rossiter, & Labrecque, 1989), comprehensive educational and support groups (Greene & Monahan,
Hispanic Use of Formal Services

There is a growing body of literature that examines the use of formal services by minorities, and more specifically by Hispanics (Burnette & Mui, 1995; Damron-Rodriguez, Wallace, & Kington, 1994; Delgado & Tennstedt, 1997; Miller, Campbell, Davis, & Furner, 1996). The extensive use of informal support, such as family members, has been suggested as one reason why Hispanics underuse formal services (Hinrichsen & Ramirez, 1992; Purdy & Arguello, 1992). Wallace, Campbell, and Lew-Ting (1994) identified structural barriers, such as limited access to multilingual case managers or office locations, that discourage the use of formal in-home services by elderly Latinos. Starrett, Decker, Araujo, & Walters (1989) found that the discretionary nature of social services were additional barriers to Hispanics’ use of formal services. Restrictive hours, such as being open only during the traditional hours of 9 a.m. to 5 p.m., and the location of agency offices are two structural barriers limiting use by Hispanic caregivers (Starrett et al., 1989), and Damron-Rodriguez and colleagues (1994) identified limited income and lack of insurance as additional structural barriers.

Discrimination and language barriers, particularly for older and less acculturated Hispanics, have also been suggested as reasons why Hispanics underuse formal services (Wallace et al., 1994). In addition to the suggested barriers that limit use of formal services, the caregivers’ perception of the illness could also limit intervention participation (Husaini, Moore, & Cain, 1994). The belief that AD is a mental illness or that nothing will help could also affect a caregiver’s willingness to seek assistance. Fabrega (1990) found that Hispanics’ negative perception of mental illness and psychological services increased their resistance to seeking assistance.

Proposed Psychoeducational Model

We propose a psychoeducational model to reduce potential resistance that might accompany a psychological or mental health program and to remove some of the suggested barriers to the use of formal services. The primary goals of this intervention were (a) to increase Hispanic caregivers’ knowledge of the progression and treatment of AD, (b) to improve awareness of supportive services, (c) to develop more effective coping skills, and (d) to enhance caregivers’ ability to care for themselves.

The Program Model

The proposed model was a 20-hr program that met on five consecutive mornings from 9 a.m. to 1 p.m. As the intervention was developed for primary caregivers, free respite care and transportation were made available to participants. In one of the few intervention studies to examine Hispanic AD caregiver participation, Monahan, Greene, and Coleman (1992) found that groups conducted in Spanish were attended more regularly than groups for Hispanics conducted in English; therefore, bilingual professionals from the Hispanic community were recruited to conduct sessions in their area of expertise (i.e., nursing, social work, pharmacy, day care, legal, assisted living, etc). As is discussed further in the Results section, the participants were given a choice at the start of the program to have sessions conducted in English or Spanish and overwhelmingly indicated a preference for Spanish. To ensure consistency among presenters, the goals and format of each session were discussed before the start of the program.

Program Content

Day 1.—The program began with caregiver introductions and a brief presentation about the scheduled sessions. The first sessions were devoted to providing factual information about AD and its pro-
Day 2.—The second day was devoted to teaching caregivers how to recognize the antecedents of problematic behaviors and how to better manage these behaviors when they occurred. Specifically, caregivers were taught how to use redirecting and distracting techniques, as well as how to manage wandering behaviors. Information on how to improve home safety was also presented during this session. The following session focused on techniques used for personal care (i.e., feeding, grooming, and bathing).

Communication skills training was the focus of the next session. Instructions on communicating with the person with AD, as well as communicating expectations and needs to other family members, were presented. An important component of the communication session was instruction on how to communicate more effectively with physicians and other health care providers. During this session, caregivers expressed a number of issues related to their experiences communicating with physicians and other health care providers, particularly with those providers from the non-Hispanic community. Caregivers reported feeling intimidated or uncertain about how to communicate their observations. They commented that physicians did not appear to take their concerns seriously, provided little time to listen to what the caregivers had to say, and made insensitive responses indicating there was nothing they could do or saying, “after all [your loved one] is over 70 years old, what do you expect?”

The session focusing on cultural expectations was the last session of the second day. We expected that this session would tap sensitive issues among the caregivers; therefore, waiting until the second day enabled the participants to become more comfortable with each other and group cohesion to develop. As expected, the caregivers participated in spirited discussions about roles and responsibilities. Listening to perceptions of expectations and what it means to be responsible for care appeared to be difficult and painful for the caregivers. Discussions about familial and cultural expectations throughout the future sessions became an important dynamic of the overall group process.

Day 3.—The third day began with a session discussing the importance of structure for the person with AD and the type of activities that could be used in the home. The next speaker presented information on various AD services (day care, respite care, etc.) that provide caregiver assistance. The speaker was instructed to focus on why day care or respite care is important for the well-being of the person with AD, as well as for the caregiver. Information about accessing services and techniques for managing the resistance of the person with AD was also covered in this session.

During the next session, a representative from the local Alzheimer’s Association discussed services the association provides and how to access them. Although the local Alzheimer’s Association chapter has a number of outreach programs for the Hispanic community, as would be expected, they are reported to be underused. The third day concluded with a session on support groups. The focus was on how support groups can provide caregivers with the latest techniques and information from the “real” experts (other caregivers), as well as an ongoing source of support. Fortunately, a few caregivers who had previously attended a support group were able to speak of their positive experience with the other caregivers.

Day 4.—The fourth day began with a session devoted to the various community-based programs (Medicaid waiver programs, transportation, nutrition, etc.) available to caregivers. Information about the different programs, qualifying requirements, how to apply, and what to expect was presented. The next two sessions focused on alternate living settings (assisted living and long-term nursing homes). These two sessions provoked much discussion among the caregivers about why they were the least acceptable option of care and how using such programs would represent an abandoning of their responsibilities.

Day 5.—The final day of the program started with a session devoted to understanding the legal issues that could arise when there is a question of competency. An elder law attorney discussed issues such as advance directives, power of attorney, and guardianship and why such legal documents are particularly important for both the person with AD and the caregivers. The final session of the program focused on the emotional consequences of being a caregiver. The session was directed at helping the caregivers recognize the presence of feelings and develop appropriate mechanisms for expressing them. The facilitator of this session worked at normalizing the full range of the caregiver’s emotions, particularly the grief that frequently accompanies AD caregiving. As expected, the pending termination of this group experience proved to be a catalyst for exploring these issues. Caregivers openly discussed their grieving of various losses (spouse, parent, friend, time, family, and freedom) and the importance of support in helping them to cope with the progressive loss of their loved ones. The program concluded with assisting the caregivers to initiate the process of developing a support system.
Methods

Sample Description

A total of 20 caregivers were recruited from a local memory disorder center, local clinics, and physicians. Although most of the adult children (n = 10) found out about the group from these traditional sources, spousal caregivers proved to be more difficult to locate. A snowball sampling procedure, caregivers referred by other caregivers, was used to achieve the desired number of spousal caregivers (n = 10). The mean level of education was 12 years, and the combined household income was approximately $2,000 per month for the entire sample. There were no significant differences in education or income between the spouses and adult children.

Measures

Before the first session, caregivers completed the Caregiver Knowledge Survey (Dieckmann, Zarit, Zarit, & Gatz, 1988) and a service utilization survey. Items on this measure examined caregivers’ knowledge of the origin, treatment, prognosis, and management of AD. Caregivers were also questioned about their knowledge and use of community resources and caregiver support groups. A translation–back-translation methodology was used to ensure the accuracy of all measures. Although English versions were available, all caregivers requested the Hispanic version of the instrument. At the conclusion of the program, caregivers completed an exit survey to determine changes in these measures, as well as impressions of the program.

Results

Compared with a similar (age, education, and income) group of non-Hispanic spouse and adult children caregivers attending a similar psychoeducational intervention, the Hispanic caregivers scored significantly lower on the pretest total scores on the Caregiver Knowledge Survey, t(38) = 2.51, p < .05. Posttest scores on the survey indicated caregivers significantly improved, t(19) = 3.23, p < .05. Caregivers averaged only two incorrect answers (compared with an average of seven wrong on the pretest). An examination of the individual questions demonstrated significant improvement on questions related to the cause, treatment, and progression of AD; knowledge of community-based services; and the role of the local Alzheimer’s Association. An exit survey assessing perception and satisfaction with the program found the caregivers reported satisfaction with the program and perceived their individual needs as having been met. They indicated that the program design of including formal presentations, group discussions, and time for informal discussions among the caregivers was particularly helpful and informative.

The implementation of this intervention presented us with a variety of challenges, as well as numerous opportunities to learn. Unlike previous psychoeducational groups conducted by Carmen L. Morano with non-Hispanic caregivers, one of the most important things learned from this group was the relevance of time. The ambitious program schedule required maintaining fairly strict times for starting and ending the sessions. From the first meeting, it became evident that this group would not watch the clock and would establish their own time frame. The socialization time was as important to the caregivers as the educational time; therefore, adequate socialization time had to be built into each day.

A unique phenomenon of this group of Hispanic caregivers was the caregivers’ insistence on bringing home-cooked treats to share with the group. Caregivers took a great deal of pride in being able to contribute in some way to the group. Fulfilling a need to reciprocate appeared to be a prerequisite for allowing the caregivers to accept what the facilitators were attempting to give to them. The caregivers also used this time of sharing their food to discuss their caregiving experiences. Some caregivers reported that the conversation during these informal discussions was as helpful as, or more helpful than, some of the formal presentations.

An unexpected problem was finding qualified bilingual speakers. Although there was some feedback that at times some of the speakers used words or phrases that some caregivers found a little difficult to understand, the caregivers overwhelmingly indicated they appreciated the program’s being presented in their native language. This feedback indicates a need for greater awareness of the heterogeneity, or within-group differences, in the presentation of translated material, either verbal or written.

The session on cultural expectations proved to be one of the highest rated sessions in the intervention. Including adult children and spouses provided numerous opportunities for discussion of the different perceptions. As one caregiver stated, “It was good to hear from someone my children’s age . . . now I can better understand why they find being around their father so difficult and how they feel pulled in different directions.” The adult children also had an opportunity to better understand the importance of concepts such as familialism and allocentrism (Zea, Quezada, & Belgrave, 1994) to the older caregivers. As one adult child stated, “Now I can understand what my mother means when she says it would be too embarrassing to seek help from outside the family.”

Feeling captive to one’s caregiving role, regardless of ethnic background, has been demonstrated to create a perception of role captivity (Aneshensel, Pearlin, & Schuler, 1993). Cultural expectations related to familial obligation, gender role expectations, and sense of duty can exacerbate the already difficult strain of caregiving for Hispanic caregivers (Valle, 1994; Zea et al., 1994). This program provided an opportunity for both groups of caregivers to examine the role of familial and cultural expectations while exploring a variety of supportive alternatives.

Caregivers rated the sessions on services and how to access them as the second most helpful sessions,
indicating they gained a better understanding of the multiple roles of supportive programs. As one caregiver expressed, “If I had known how important day care was for my husband, I would have started him going a long time ago.” Another caregiver stated, “I never went to a support group because I didn’t want to hear everyone complain about their situation. Having been part of this experience I can see how we can all help and learn from each other.”

Although no conclusions can be drawn from this effort, the results indicate that a psychoeducational model is appropriate for working with minority caregivers. Evaluating culturally sensitive intervention strategies is an important next step to meeting the needs of other minority caregivers. Although the results of this project indicate an overall improvement in caregiver knowledge and an increased willingness to use supportive services, future research must evaluate the long-term effects of similar models with more diverse groups in a variety of settings.

References
Aneshensel, C. S., Pearlson, L. I., & Schuler, R. H. (1993). Stress, role cap-

Received December 12, 2000
Accepted September 26, 2001
Decision Editor: Eleanor S. McConnell, RN, PhD

126 The Gerontologist