

## CHAPTER 27

# Dementia in Cultural Context: Development and Decline of A Caregiver Support Group in A Latin Population

---

*J. Neil Henderson*

The Estradas of West Tampa, Florida, lived in a lower-middle-income neighborhood with several houses that had garages obviously converted into additional interior spaces. Numerous mailboxes lined the streets with Spanish surnames on them, and an occasional car was seen with a Puerto Rican license tag or a bumper sticker such as one which advertised a National Hispanic Chamber of Commerce meeting. This area has many people, like the Estradas, who moved here from Cuba in the early 1960s. The Estrada family was distinguished from others in their neighborhood by the fact that Mr. Estrada, although trained as a chemist, was severely impaired with Alzheimer's disease.<sup>1</sup>

Other members of the Estrada family included his wife's eighty-five-year-old mother (who lived in the house with them in order to help her daughter care for Mr. Estrada), his brother who lived next door and his sister who resided four miles away. While Mrs. Estrada implied that she provided nearly all the care, her mother and her husband's sister in fact participated in direct care on a regular basis. In addition, Mr. Estrada's brother provided limited assistance in the form of regular social visits.

The Estradas also have two sons, one of whom lived on the same block and another some six miles away. Mrs. Estrada reported that the two sons were of little help. One was unable to tolerate taking care of his father for even a few hours because it made him "nervous," a nonspecific condition mentioned by many of the Latino families as a very real and acceptable emotional category. The other son had offered to pay to bring in an extra caregiver. Mrs. Estrada rejected this for three reasons. One was that it would only create more difficulties with her husband because he was so irritable and argumentative. Second, Mrs. Estrada described herself as a meticulous housekeeper who was very concerned with odors in the house. She felt compelled to clean her home thoroughly each

time before a respite caregiver came to visit. Finally, she felt she would not get any respite anyway because she would have felt obligated to keep the person properly entertained as a guest in the home.

Mrs. Estrada said that at times she had trouble accepting “the disease” because it seemed as though her husband’s crazy demands were merely extensions of his very domineering personality from his intact and lucid days. For example, he demanded “real food,” meaning complete meals, which typically included a large portion of meat and seasoned vegetables.

When Mrs. Estrada first attended the support group meetings she was often in tears when trying to tell of her caregiving activities. In fact, for a time she was clinically depressed and was medicated by a psychiatrist on an outpatient basis. Therapy was unsuccessful, since she adjusted the medicine because the initial dosage made her “groggy,” and she did not know that the sedative effect would wear off with continued use.

During the time that Mrs. Estrada was being treated for depression, she continued to attend the support group meetings, and interviews in the home continued to take place. During one such interview, Mrs. Estrada simply sat by and watched as her husband tried to sit down in a chair in the living room in sort of a half-crouched position, but he was too far away from the edge of the chair. He then slowly and precariously inched his way backwards in the crouched position toward the chair. She gave him no help or instructions. This was clearly a departure from her earlier attentiveness. She also reported an instance when her husband refused medications, and she could not get him to take them by any strategy. He began calling her “dirty names” (which she would never specify), after which she began screaming and pounding the walls with her fists and forearms until they were sore.

Mrs. Estrada said she had never been depressed before. Much of her stress came from her belief that she was a failure because she was unable to maintain the household and caregiving activities unaided. She talked explicitly about holding a self-controlled “face” in front of her family and her children. She said her children had not seen her cry, although she had hidden in the bathroom to cry privately so she could maintain an outwardly powerful image in front of her family. She also reported that since joining the Alzheimer’s Latin Support Group she had become aware that other caregivers experience some of the same frustrations. She felt that gave her a better understanding of the disease and that she was better able to cope with the caregiving requirements.

As a Latina with a strong Catholic background, Mrs. Estrada said that her religion told her that she got married “for better or for worse.” She felt that she had already had the “for better” and now was getting the “for worse.” She referred to Alzheimer’s disease in a fatalistic sense, indicating that it was out of her control and that she had to simply endure her lot in life, which seemed in some way to have been supernaturally ordained.

Mrs. Estrada vacillated between the need for nursing home placement and the feeling that it indicated failure as a caregiver. During one interview Mrs. Estrada said, “Latin people, we are very stupid,” in regard to an unwillingness to put people in a nursing home as she saw Anglos do. She said, that this would “bury him before he dies,” in response to the question of what would happen if she went ahead with the nursing home placement. She reported that her husband was being put on a tranquilizing agent

which calmed his behavior so that she could cope with him. Shortly before, she had had a “fit” in which she broke all of the dishes in the house because she was angry with Mr. Estrada. After this episode, she called the support group leader to ask for the phone number of one of the other members with whom she felt she could talk.

Inevitably, Mr. Estrada’s dementia continued to worsen. For example, at the end of a very elaborate meal prepared by Mrs. Estrada and her stepdaughter, Mr. Estrada very matter-of-factly said, “We eat only air and water in this house.” In addition, he became incontinent and had to be bathed and dressed by Mrs. Estrada.

## **EPIDEMIOLOGY OF DEMENTIA**

The fourth leading cause of death in this nation is dementia, a group of diseases which destroys brain cells (Brody 1982). But, before death, the victim, family and friends can expect two to twenty years of slow, progressive decline in the victim’s ability to think, remember and control bodily functions. In fact, these losses are feared more than death by most older people. Family members who care for such patients refer to Alzheimer’s disease (AD) and related dementias as “the long goodbye.”

At any one time, almost two million older American adults are victims of Alzheimer’s disease.<sup>2</sup> In the United States, AD is the most common form of dementia, constituting about 50–65 percent of all cases (Mortimer 1995).<sup>3</sup> Alzheimer’s disease is a very complex disease but, in general, the brain cells die because a protein toxic to brain cells is deposited from the bloodstream into the brain tissues.<sup>4</sup> Those cells nearby are killed and cannot regrow. There are new genetic findings that show the rate of deposition of the toxic protein varies among people and is governed by a few genes. Some people who have genes that cause a fast rate of deposition will develop symptoms of AD in their sixties or seventies while others will not show symptoms until much later and possibly not at all (Corder, et al. 1993; Hardy 1994).<sup>5</sup>

The second most common form of dementia in the United States is a group of diseases called vascular dementia which constitute about 20 percent of all cases. An additional 20 percent of persons have a mixed case of AD and vascular dementia. The vascular dementias cause brain cell death due to blood flow interruption in the brain. Blood flow interruption is caused by a stroke in which blood is blocked in its flow by a clot or is lost into tissues due to a blood vessel which literally breaks. Either way, brain cells die (O’Brien 1994). The cognitive result is confusion that is similar to, but not exactly like, AD.

There is not known to be a genetic effect associated with causing vascular dementia, as there is with AD. However, there are diseases which are risk factors for vascular problems. These include diabetes, obesity, hypertension and alcoholism (Main 1994). Such conditions are problems in most populations, but among American Indians they are extremely common and serious. As Weibel-Orlando notes in Chapter 13 of the print book, within Native American communities there are numerous cases of diabetes of such severity that it is very common to see those who have had amputations of fingers and lower legs (Young 1994). Also, hypertension is extremely common. In an effort to control these problems, intensive educational campaigns are maintained through the tribes and the Indian Health Service Community Health Representative program. One result may be that American Indians are more likely to suffer from vascular dementia

even though they are genetically “protected” from AD (Hendrie et al. 1993; Rosenberg 1996).

The increased risk of dementing diseases with concomitant intellectual loss is associated with advancing age. The older a person is, the greater the risk of dementia. This is one of two epidemiologic facts known about the most common type of dementia: Alzheimer’s disease. The second known epidemiologic fact is that dementia has a worldwide distribution. No social, racial or ethnic group appears to have total immunity from dementing disease.<sup>6</sup> However, some societies or ethnic groups may have a significant variation in the amount of certain types of dementia. Studies of elders’ thinking and memory abilities have shown variance in the prevalence rates of dementia (Jorm 1990). For example, Alzheimer’s disease may be more common in Western Europe and North America, with the exception of American Indians (Jorm 1990:72–3). However, Russia, Japan and China may have less Alzheimer’s disease and more vascular dementia compared to Western Europe and North America. These studies suffer from comparison problems in research design as well as diagnostic variability.<sup>7</sup>

### **SOCIOCULTURAL ASPECTS OF DEMENTIA**

Sickness episodes have been examined from a sociocultural perspective in two categories: (1) disease as a biologically objectifiable condition; and (2) illness, which is subject to sociocultural influence. For example, Alzheimer’s disease can be described in terms of pathological changes in the brain and symptomatic changes over time. However, this does not address the sociocultural context such as that in the Estrada case. The “folk” definition of the disease, interpretation of the symptoms, beliefs about etiology, beliefs about appropriate therapies and social values placed on given disease conditions are all parts of the illness experience. Such aspects of disease are subject to organization and structuring in accordance with prevailing sociocultural systems (Herskovits 1995; Stafford 1991; Gubrium 1986). For complete analysis, the examination of human sickness demands a biocultural perspective incorporating the disease/ illness dimensions.

Given the worldwide increase in length of life and the geographic distribution of dementia, many intriguing questions arise regarding the sociocultural response to dementia as it occurs in cross-cultural perspective. To date, little is known about dementia. There is no known etiology, no cure, little accurate mapping of epidemiologic patterns, no ability to predict the length of the disease and little information about differential sociocultural responses to the symptoms of dementia. It is this last issue which will be examined here, using examples from an ethnic population in Florida who are derived from Cuban, Puerto Rican and Spanish ancestors.

Widespread American values such as independence, domination over the environment and high status of youth all operate against the caregiver when dealing with an elderly dementia victim. More specifically, the Alzheimer’s-type patient is not only old, therefore losing the status of youth, but also suffers multiple losses of function resulting in the inability to negotiate even the simplest aspects of life unaided. The loss of youth, intelligence and independence produces a social stigma akin to those with severe psychiatric afflictions such as schizophrenia.

Other sociocultural correlates impinging on Alzheimer’s disease and care of the patient and caregiver include the American kinship structure, migration patterns and

division of labor based on gender. Typical nuclear family organization, dispersed post-marital residence patterns and geographic mobility in the pursuit of occupation and finances all act in concert to create a home caregiving environment in which burdens are placed on only one or two individuals (Henderson 1987). Enormous emotional and physical burdens devolve on an individual caregiver. A popular guide for the home caregiver is titled *The 36-Hour Day* (Mace and Rabins 1981), reflecting the caregiver's perception of his or her job.

### **SELF-HELP GROUPS AND SOCIAL NETWORKS**

The special difficulties imposed by the sociocultural environment on those families coping with Alzheimer's disease have given rise to the spontaneous emergence of mutual aid societies specifically designed for Alzheimer's disease patients and family members. Such mutual aid societies typically go under the rubric of a "support group" and are a specialized part of one's wider social network. Alzheimer's disease support groups can be seen as cultural products that emerged in response to the deficits of an acute care medical system unable to meet the needs of a population experiencing a chronic debilitating brain disease. In fact, the informally organized Alzheimer's support groups developed by Bobbie Glaze in the early 1970s have led to a nationally incorporated network: The Alzheimer's Association, formerly the Alzheimer's Disease and Related Disorders Association.

Alzheimer's disease support groups function socially as fictive kinship groups. They arise in a culture in which fragmented kinship networks are typical; thus, they supplement the immediate, face-to-face interactions and assistance that become more difficult when family members become geographically dispersed. Support groups also fill gaps created by the acute-care medical system in the long-term management of the disease. One of the discrete internal functions of support groups is to provide knowledge as well as the sharing of techniques for in-home management of the demented patient (Yale 1995). The in-home caregiver can also look to guidebooks to better develop the role of the caregiver (Andresen 1995; Feil 1993), while professionals evaluate the impact of caregiving on the caregiver (Young and Kahana 1995). Ultimately, Alzheimer's disease support groups are types of social networks which create a facsimile of a healing community. Social networks develop through contacts with relatives, friends and neighbors, through which individuals maintain a social identity and receive emotional support, material aid, services and information, and develop new social contacts (Berkman 1985; Penrod et al. 1995). Here the population is brought together by a common experience related to brain failure, in an effort to better cope with this drastic and unpredicted change in the latter years of their lives (Henderson 1987; Henderson et al. 1993).

### **ETHNIC-SPECIFIC ALZHEIMER'S SUPPORT GROUPS**

In the mid-1980s, I observed that the Tampa, Florida, Alzheimer's support group showed a virtually all-"white" user profile. Since Tampa is largely a tri-ethnic community (Euro-American, African-American, and Latin) the support group did not match its predominant population base. Nationally, Hispanic elderly people are 3.7 percent of all elderly (Older Americans Almanac 1994). In Florida, the 65\_ age group of

Hispanics is 12.2 percent of all elderly (*The Tampa Tribune* 1992). Under the auspices of the University of South Florida Suncoast Gerontology Center I developed a plan for the implementation of an Alzheimer's disease support group intervention in ethnic communities that generally do not use existing support group services (Henderson et al. 1993; Gutierrez-Mayka and Henderson 1993). In 1986, an Alzheimer's disease support group in the Latino community of Tampa, Florida, was initiated by taking into consideration ethnic-specific local history and patterns of illness experiences. However, after two years the support group floundered after the stimulus of the funded project stopped. The complex operational needs of volunteer groups overcame the intent and desire to keep the group viable.

The century-old local Latin history is multifaceted and resulted in participants from various Latin cultures. Most were of Cuban origins arising from needed labor pools for Tampa's hand-rolled cigar industry begun in the late 1800s. Also, political migrations starting around the early 1960s produced additional waves of Cuban immigrants, from which some participants were derived. Second in numbers were Puerto Ricans. Next in participant frequency were the Spanish descendants who came to Tampa in the early part of the twentieth century. Last in numbers were the Afro-Cubans. These people were immigrants from Cuba with genetic and cultural origins from West Africa and Cuba. Their native language is Spanish. There were no Mexican Americans, South Americans, or other Latin Americans in the support group.

The development of Alzheimer's disease support groups in ethnic populations is designed to strengthen the coping capacities of the elderly minority caregiver by extending state-of-the-art information and fostering peer support. As Jay Sokolovsky showed (Chapter 12, 2<sup>nd</sup> Edition, 1997), ethnicity-based informal supports may be attenuated to the point of dysfunction, due to changing urban conditions and overburden linked to the inherent difficulty of caring for an Alzheimer's disease patient. Therefore, extrafamilial help is commonly needed.

The proliferation of Alzheimer's disease support groups nationwide is direct evidence of the vigor of the informal health care sector in coping with dementing disorders. However, the AD support group system on a national basis is used primarily by a specific and limited population: white, middle-class caregivers. This user pattern constitutes an undesirable and unnecessary bottleneck to ethnic caregivers in need of help. This is particularly true in view of epidemiologic research which indicates that dementing disorders are present in all racial and ethnic populations.

In the last decade, there has been a modest increase in efforts to develop ethnic-specific AD support groups. In the early 1980s, no major city in the United States could boast such a group except fledgling ones for Spanish speakers in San Diego and Tampa (the group described here).<sup>8</sup> Today, there are ethnic-specific support groups for Chinese Americans in Boston (Levkoff, personal communication) and San Francisco (Elliott 1995; Elliott et al. 1996), as well as one for Mexican Americans in San Antonio (Gallagher-Thompson, Talamantes, Ramirez, and Valverde 1996) and very likely others.

A need for cultural specificity in Hispanic health interventions is well documented. For example, the importance of family image in health and disease (as with Case #1 and #2 below), intrafamilial expectations of caregiving (as with Case #1 below), changes in extended family networks (as with Case #3 below), language differences and intraethnic

diversity must be understood for effective intervention (Valle 1981, 1989; Henderson and Gutierrez-Mayka 1992).

### **IMPLEMENTING THE LATIN SUPPORT GROUP**

The efforts of this project constituted a model for the implementation of support groups in ethnic minority populations (Henderson 1996; Henderson et al. 1993; Gutierrez-Mayka and Henderson 1993). The basic steps of this model for ethnic AD support group development are: (1) reliance on members of the target communities to coach project staff in the development of community-compatible support groups; (2) understanding of the network of personal, familial and community resources already used in coping with AD relative to the formal and informal health care systems; (3) training of support group leaders from the community; and (4) locating AD support groups in the Hispanic community. In initiating these plans, the Latin Alzheimer's disease support group received a boost from the Department of Aging Services in Hillsborough County (Tampa is the county seat). Staff in this agency directed project implementers to a senior day care center located in the historic Latin district of Tampa called Ybor City. A bilingual Latin day care center aide who had family experience with dementia was interested in serving as a support group leader. Her supervisor would allow her to have compensatory time for the hours that she would use in conducting a support group, estimated at four to five per month.

The decision was made to train the leader at conferences on dementing disorders conducted by the University of South Florida's Suncoast Gerontology Center and to conduct a series of three small group discussions with her. In addition, it was decided that support group meetings would be jointly led by the project staff so that the local support group leader could observe how to conduct meetings. On a gradual basis, she could exert more influence on group dynamics.

The meetings were scheduled monthly and led by two professionals from the Suncoast Gerontology Center as well as the local support group leader. The location suggested by the local group leader was a Hispanic hospital in Tampa, Centro Español Hospital. Announcements were made via Spanish-language newspapers and radio stations in the community. The leader's work at the day care center provided her several potential support group participants. These activities led to the initiation of a support group meeting that was considered attractive to Latinos, due to the participation of a Hispanic support group leader and the use of Centro Español Hospital, a culturally potent symbol in their health care domain.

As David Jacobson states, "The meaning of 'social support' is intelligible within its cultural context" (1987:58). Therefore, one of the assumptions tested by this project was the appropriateness and utility of support group intervention as a proper means of intervention in "Hispanic culture." Some investigators suggest that group psychotherapy, which is akin to family support group intervention, is prone to failure among Hispanics due to members' concerns about privacy (del Valle and Usher 1982). Reflecting on this issue, one of our support group members referred to the reluctance to discuss Alzheimer's disease in public:

You know what I think happens in a lot of Latin people who have family members with this disease, they feel like they don't want other people to know about it. It is not that they are ashamed of it but I think they like to keep it to themselves. . . . A lot of them feel that way. A lot of Latin people keep their things to themselves. They don't let everybody know their problems, their medical problems. I don't know why but I have noticed that . . . maybe they don't want people to know they are suffering.

Del Valle and Usher do note that with proper empathy from group leaders such concerns can be overcome (1982). Other specialists agree that there are positive benefits of Hispanic group meetings. Acosta reports that although group psychotherapy among Hispanic people is not currently common, it "can be a powerful modality in treating the Spanish speaking Hispanic patients" (1982).

The experience of this model project is consistent with the predictions that the support group will represent a fictive kinship network unit in itself. According to Escobar and Randolph, the extended kinship network is a primary social resource among Hispanics, and the strong reliance on the *concepto de la familia* is a key element in Hispanic culture (1982). Within six months after the start of the support group, members had developed car pooling schedules, phone calling to check on members during nonmeeting weeks and a repeated pattern of conversation in Spanish at the beginning and end of meetings while members arrive and depart. One of the earliest examples of mutual ethnic identity came from members detailing historical events surrounding life in Ybor City, where most of them used to live. Also, they talked about acquaintances they have in common. The number of these acquaintances and the fact that many turned out to be distant relatives came as no surprise to the group. As the support group meeting was started in earnest, conversations spontaneously developed which tapped members for information on the current status of their patients.

The prominence of the Latin dynamics of family structure is very clear in issues related to burden-bearing and responsibility. The foremost of these is the sex-biased pattern of familial transmission of responsibility for care of the demented patient. Members commonly report that women are expected to provide care to the demented person, whether it be the woman's spouse, a parent or a parent-in-law. When the family has both males and females "available" for bearing the major responsibility, it is still the female who is expected to provide that type of care. One respondent reported that during the life of the patient (her father), her mother and she would be expected to provide the bed and body care for the patient; when death occurred, her brothers would take charge of the father because it then entered a business dimension, namely, the cost of the funeral and a matter of public display.

If the family does not have a close "blood-relative" female to provide bed and body care for the patient, these duties will typically be assigned to a nearby daughter-in-law. This provides a source for a variety of intrafamilial irritations. For example, many Hispanic parents are concerned that their adult children may disengage from family responsibilities with the parents. In fact, a daughter-in-law is often the target of great hostility. By marrying the son, she becomes the recipient of his attention and help, thereby reducing the amount of assistance available to the other family members (del Valle and Usher 1982). Nonetheless, the daughter-in-law may be pressed into service to her in-laws. Although a new household has been established, the expectation of direct

caregiving support is placed on women. Therefore, selection of a helper from the new couple is strongly biased toward the bride.

### **Case 1: Vascular Dementia in a Tampa Latin Family**

The following case incorporates dimensions of cultural influence in terms of gender roles in a case of vascular dementia in a Latino family.

Sixty-eight-year-old Mr. Perez was hospitalized at Centro Español Hospital with a diagnosis of vascular dementia. The prognosis was not favorable and included complete bed care for the remainder of his life. Consideration of nursing home placement was unthinkable to Mrs. Perez, who elected to care for him at their home.

The Perez local family consisted of Mrs. Perez's able-bodied eighty-eight year-old mother, who lived with Mrs. and Mr. Perez. The Perez adult children consisted of a married son with two small children and a divorced daughter with three older children and one grandchild for whom she was the babysitter.

Having learned of her husband's diagnosis and prognosis at his bedside, Mrs. Perez led her daughter into the hallway of the hospital and told her that it was up to them (meaning her daughter and her) to provide the ultimate in care for the husband and father at home. The adult daughter recoiled and began to list the nearby family members who could have likewise given direct support and assistance but on whom her mother was not calling. Mrs. Perez was unable to understand her daughter's reaction, in that she was the expected helper of the primary caregiver.

When a support group for the caregivers of dementia patients was formed at Centro Español Hospital, the daughter was actively involved. However, Mrs. Perez attended only one meeting because of her sense of public humiliation due to the nature of her husband's disease. Nonetheless, the adult daughter, who gave occasional "hands-on" care, attended the meetings regularly and served as a broker of information and support from the meeting to her mother. The mother responded by initiating use of community services and reevaluating her role as caregiver.

The patient remained at home (with brief episodes of hospitalization) for three and a half years before dying there.

*Case Comment.* The expectation for female caregivers was brought out very clearly in the case of Mrs. Perez and her adult daughter. This type of expectation of caregiving by women has been observed in this project and reflected in the fact that out of the 36 actual caregivers, 29, or 81 percent, are women. Based on data of caregiving frequencies and types, the ranked preference of Latino caregivers by sex and kinship relation in this study was as follows: (1) wife, (2) sister, daughter or other adult blood-kin, (3) female nonkin, (4) male blood relatives, and (5) male in-laws. Note that even before switching to kin-related male caregivers, nonkin females were relied upon.

### **Case 2: The Garcia Family**

Many Latino caregivers are worried that the community will interpret the sometimes bizarre behavior of the dementia victim as evidence of "craziness in the family." The following case is such an example.

Mr. Garcia suffered from dementia for several years. He was cared for at home with a minimum of fanfare or help from kinsmen and neighborhood friends. Mrs. Garcia discussed the early stages of her husband's dementia. As she began to tell of specific

circumstances, she began to explain a Latin ethic. “I tell you one thing about the Spanish, they will get very upset about someone who is crazy or does crazy things.” She hastened to add that this is due to lack of education and not that they happen to be of Spanish descent.

Even during a time when her husband was so confused that he was urinating on the living room floor, Mrs. Garcia tried to put up a front that everything was okay, to her neighbors certainly, but also even to her children. Mrs. Garcia said, “How could I tell my family not to bring a girlfriend or boyfriend in here because the house smells of urine?” Mrs. Garcia said that former friends avoided her because they “fear the disease” or just felt uncomfortable about being there. This bothered Mrs. Garcia to the point of wondering if she was being penalized for some past sin.

An event that prompted Mrs. Garcia to put deadbolts without keys on doors of the house involved her husband wandering away from the house at night. She awoke at 5:00 A.M. to find that Mr. Garcia was not in bed. She immediately checked the house but could not find him. Her first response was to get in the car alone and scout the neighborhood for him. Only after this proved futile did she return to the house to call neighbors for assistance. They first checked their backyard pool and then decided to drive in separate cars around the neighborhood while Mrs. Garcia waited at home. A neighbor found Mr. Garcia about two miles from home, “just in his briefs,” with blisters on his bare feet. His safety as well as the public nature of his “crazy behavior” mortified Mrs. Garcia.

*Case Comment.* Alzheimer’s disease presents symptoms that the general public interprets as characteristic of someone who is “crazy.” The stigma attached to mental disorders is well-known within this culture and many others. Escobar and Randolph (1982) report that, for many Hispanics, mental illness is still seen as a dreaded affliction akin to *mal de sangre* or “bad blood.” The issue of a family member being “crazy” was a common one in the Latin Alzheimer’s support group meetings. There was often a personal crusade launched to be sure that friends and family understood that Alzheimer’s disease is an organic disease and, therefore, not under the control of the individual, thus relieving the patient and family of social liability.

The Latin support group members extended their concern about social stigma and mental disorders into financial arenas like insurance coverage. They complained, as do other families of Alzheimer’s patients, that insurance categories place all psychiatric afflictions in mental health domains. Because mental health problems often are not covered by policies, families found themselves negotiating with physicians to enter the diagnosis as an organic brain disease.

### **Case 3: The Lopez Family**

The families in this sample strongly valued the image of being strong, tightly knit and reliant on family resources to succeed in life. However, over time, a “generation gap” has developed. Older Latins are less likely to use social services and community resources than their adult offspring. Attendance at a support group meeting communicates publicly that help is needed; self-reliance has failed. The following case shows the adaptation made to bridge the gap.

Maria Lopez attended her first support group meeting in the company of her oldest son. Her stepdaughter had been summoned to go with her, but her work schedule

prevented her attendance. During the two-and-one-half-hour meeting, Mrs. Lopez's son, Roberto, introduced her and provided some details of his father's condition. Mrs. Lopez sat quietly during this discourse, which included commentary and questions from others in the support group which her son answered. During the support group meeting, Mrs. Lopez herself commented only about her love for Cuban coffee and, due to its strength, the "lift" that it produces from the caffeine.

One month later Mrs. Lopez was again accompanied by her son to the support group meeting because the stepdaughter was unable to arrange her job in order to bring the stepmother. This time, Roberto Lopez talked mainly about their former upbringing in the Latino quarters of Tampa known as Ybor City. As discussion turned more toward caregiver issues, his mother began to comment in response to her son's status report of the father's condition. Roberto reported that the father had been very hostile and aggressive for the past few days, to which Mrs. Lopez had said to the group by quoting her own statement to her husband, "I'm tired of this. If you don't straighten up, I'm going out this door." Roberto followed this comment by saying that when his mother responds sharply to his father this "brings him back to reality."

Eight weeks later, Mrs. Lopez is accompanied by her stepdaughter Marcela. Marcela began by saying her stepmother's problem is "lack of sleep." Mrs. Lopez said, "I'm very nervous," and then demonstrated with her hands by shaking them and saying, "Just like this." Maria Lopez now became outspoken and discussed a history of being physically abused by her husband and occasions of running into the street to solicit help from other Latin neighbors. In reference to her husband's condition, Mrs. Lopez became so bold as to demonstrate his stooped gait and short steps while shuffling his feet. Her stepdaughter interjected that, "It's the Haldol" (a tranquilizing medication). It was clear that Mrs. Lopez was willing at last to express her anger through her raised voice, rapid speech and physical mimicry of her husband's condition.

Mrs. Lopez referred to her state of "nerves," which is affirmed by Marcela. Mrs. Lopez said that she didn't take any *medicatinos* (medicines) for herself because she couldn't afford them. But, she did take honey to ward off heart problems. Mrs. Lopez also said that she kept her husband fully medicated with prescription medications in order to "keep him cool."

One month later Mrs. Lopez attended the meeting by herself, having been "car pooled" by other members of the group. As a result of encouragement from the group, an aide came to the home to give Mr. Lopez a bath twice a week. It became clear that Mrs. Lopez spoke openly and freely over time within the group setting, having phased herself into the support group family.

*Case Comment.* David Maldonado (1985) suggests that Hispanic populations variably respond by age cohorts to available helping services such as Alzheimer's family support groups. This age cohort effect was very clearly observed in the Latin Alzheimer's support group. The most active members were adult daughters and sons of parents who were coping with Alzheimer's disease. The older-generation Hispanics seldom attended the group except when specifically brought by their daughters or sons. Furthermore, when knowledge of additional community resources was made known to the parent generation, arrangements for such resources were negotiated through the adult daughters or sons in the group.

It was common to see the older generation Latin person attending the group with an adult daughter or son. The older person sat quietly and occasionally added an affirmation in response to a monologue delivered by the adult offspring. Usually, however, within a few meetings the older person spoke up, and the role of the adult offspring became less important.

### **THE FATE OF THE SUPPORT GROUP**

The Latin support group no longer exists. After 24 months of testing a model process for implementation of ethnic-specific support groups, the group could not sustain itself after project funding ended. Seven months after funding ended, the group stopped meeting. In spite of its effectiveness and efforts to continue its operation after funding, the support group slowly declined in attendance. The dynamics of this decline are related to lack of finances, the volunteer nature of the group, overburdened caregivers, lack of sustenance by other organizations whether private or governmental, and failure to sustain the infrastructure of organizational vitality.

From its inception, the project had considered its longevity to be a critical factor. Because there are costs associated with group operation, the project staff had tried to get the county aging service unit to incorporate the group into the senior adult day care programs. Local politics prevented such an alliance. Consequently, there was no permanent place to conduct the meetings and no money to pay for utilities of a meeting place.

The efforts to keep the group going included the training of laypeople to operate the group after the funded professionals left. These people were caregivers who expressed an interest in continuing the group as leaders. A six-hour training session was developed for them and presented in a casual, non-“school” fashion. The intent was to make them comfortable with the training and defuse images of school and tests. Five caregivers from the group participated. This training was done five months prior to the end of funding so that trainees could practice their skills under the supervision of professional project staff.

The volunteer caregivers/group leaders were motivated to continue the group because of their reaction to a relative’s devastation by dementia. They adopted a “warrior” stance against this terrible disease and “fought the disease” by being leaders of the support group. However, the enormous energy required to provide care for a dementia patient left them exhausted. They could not add the role of support group leader to their overburdened life. To conduct the weekly phone calls to group members, write a short newsletter and otherwise get the meeting organized was simply too much.

Most of all, the support group’s organizational infrastructure was starved for attention. The roles played by participants were clear when the professionals and the lay caregivers were in the group. However, when the combined “lay caregiver and group leader” role emerged, the division of authority and labor was blurred. Also, other needs were present. There was the need to bear the costs of the newsletter. Someone would need to be given the authority to levy dues or assign a rotational cost-sharing system to maintain the newsletter. The newsletter obviously required a typewriter or word processing capability. Someone needed to buy snacks for the meeting. During the funded years, these problems were not problems. Yet, a multitude of small but significant

elements of organizational operation became barriers to survival of a volunteer group of Latin people trying their best to cope with dementia.

The professional project staff had offered to be available as consultants for any and all questions to assist the new leaders with operating the group. The new group leaders made some use of this offer. For awhile, the newsletter was copied and mailed from the project offices. However, even the task of getting the copy to the office was a barrier to caregivers and this assistance fell into disuse.

It may seem that a solution would be to get non-caregiver volunteers to be the group leaders. However, recruitment is a labor-intensive project. As always, there is a need to meet direct and indirect costs of operation, even if there were non-caregiver leaders. However, the strongest barrier to lay non-caregiver leaders is the caregiver perspective that no one can really understand their trauma except those who have experienced it. A layperson with some training in the disease symptoms and what it must be like to be a caregiver will have very low credibility. For “real” caregivers, intellectualized experience only is no experience at all.

Another option for institutionalizing the Latin Alzheimer’s disease support group could have been the local Latin social and health clubs. Unfortunately, these were in financial decline at the time of this project and the health care components no longer exist today. Moreover, the Latin clubs were home to specific segments of the Spanish-speaking population and not universally compatible with all Latins.

While this project showed that there is a need and a way to provide support group help to Latin caregivers of Alzheimer’s disease patients, its longevity was severely compromised. The reason for the support group’s demise is multifactorial. It may seem that the obvious explanation is financial. However, this singular explanation neglects the local politics, caregiver attitudes, the wish to be a leader in the absence of sufficient energy to do so, and, certainly, flaws in the project design and staff actions.

## **SUMMARY**

The effectiveness of the Latin Alzheimer’s disease support group was high, as judged by sustained participation of members, development of interpersonal linkages between members, recruitment of new members by long-standing members, and direct reports of the comfort received from participants in support group meetings. However, no instruments were used to measure effectiveness in terms of improved mental health or caregiver functioning. Nonetheless, this support group of Latins shows that certain cultural patterns such as extreme reliance on female caregivers, generational effects and “low service user” patterns can be overcome when culturally compatible approaches are used.

Certain unique characteristics of these support group members contributed to the configuration of this ethnographic profile. For example, most participants were middle class and high school educated. All were bilingual and were at least second-generation residents of Tampa. Still, elements of ethnic culture remained very strong in the minds and behaviors of people considered to be highly acculturated. This definitely applied to the members of the Latin support group.

There were vast numbers of poor, monolingual Latinos in Tampa who apparently were not attracted to this type of intervention. Other local factors were revealed by

examining another Latin-specific Alzheimer's disease support group operating in the country. Dr. Ramon Valle worked with such a group primarily composed of Mexican Americans in San Diego. Those meetings were characterized by multiple generations of participants, including young children (Valle, personal communication). In Tampa, however, the young children of the adult caregivers in the sample were seldom present. Valle attributes the difference to intraethnic variation. The San Diego group participants were Mexican Americans who came to California 30 to 40 years ago. They exhibited the "Mexican heritage interactional pattern." The interdependence of family members produced a "group" approach to resolving family problems (Ho 1987).

Most older people do not get dementia. For those who do, the devastation and impact on a patient and family members is enormous. The overwhelming impact of this disease on families is being perceived by the American government in terms of programs specifically for dementia victims in adult day care, respite care and nursing home care. However, policies made for the majority population can neglect specific needs of ethnic and minority groups. This appears to be the case on a national basis with lay-developed Alzheimer's disease support groups. Yet, this project shows that, with proper community involvement and sensitivity to sociocultural issues, a helpful intervention can be put in place.

At the time this project was conceptualized and implemented, there was great doubt that support groups, as developed in mainstream society, would work in ethnic minority communities. That notion was proven wrong. As noted earlier, ethnic-specific Alzheimer's disease support groups are now being developed elsewhere in the United States. In fact, the concept of disease-related support groups among elders has proven useful in societies outside the United States, as shown by the development of hypertension support groups in Croatia (Sokolovsky, Sosic and Pavlekovic 1991). However, the fact that the Latin support group in Florida lasted only a few months after funding ended shows that too little attention was given to what ethnic minority caregivers would need to keep the group operating effectively by themselves.

Today, developing a similar intervention could include a relentless effort to integrate the group into the general or ethnic community social service system. Fund-raisers could be undertaken by volunteers from other social service organizations. Whatever the specific mechanism needed to keep the ethnic support groups operating, more creative thought can now be given to the issue of longevity, since there is evidence that the prerequisite questions of developmental feasibility have been answered.

## NOTES

This project was supported, in part, by a grant, 90AM0724, from the Administration on Aging, Office of Human Development Services, Department of Health and Human Services, Washington, D.C. 20201, and the State of Florida, Department of Health and Rehabilitative Services; Aging and Adult Services; and the University of South Florida Suncoast Gerontology Center. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

1. Alzheimer's disease results from progressive brain cell death. The early symptoms include short-term memory loss of slow onset. Later, more general and severe cognitive deficits ensue. Ultimately, the person dies from a severely damaged brain (Friedland 1994).

2. The actual number of cases of Alzheimer's disease is difficult to determine. The difficulty relates to the very gradual worsening of symptoms, which makes it impossible to state when a case "begins" and, consequently, can be counted. Also, there are different ways to count cases, such as AD specifically and only, all dementias of any kind, possible cases, probable cases and cases of confusion of unknown etiology. The vagueness in determining the number of cases allows for variation in listed prevalence rates. There may be some exaggeration in rates when, for example, an organization perceives the need to gain attention for its cause. By using various definitions of a case, literature may report rates for AD as high as four million cases while other reports specify only two million cases (Blume, Persily and Mintzer 1992).

3. In a living person, the only absolute diagnosis requires a brain biopsy, but because this is such an invasive procedure, a clinical diagnosis is made by ruling out every other possible medical cause of symptoms relating to memory loss and confusion. If the patient's history shows a slow and progressive onset of dysfunction and no other medical cause can be found, a diagnosis of dementia of the Alzheimer's type is made. At autopsy, confirmation can be obtained by examining brain tissue microscopically.

4. The protein is beta-amyloid.

5. These genetic findings imply that populations will show variance in the amount of AD present in older age cohorts. The gene responsible for the variance of the toxic protein is known to be variable across populations. The gene is known to play a role in fat metabolism. However, it is theorized that its complex chemistry also has a "side effect" of chemically assisting or inhibiting the deposition of the toxic protein in the brain depending on which genetic combination is present (Hardy 1994). In terms of population prevalence variability, it is hypothesized that the indigenous people of the Western Hemisphere have a low frequency of the genetic combination causing fast deposition of the toxic protein (Henderson 1994a). This implies that American Indians would have low rates of AD. Conversely, Euro-Americans would have higher rates than American Indians because this group has more people with the gene causing fast rates of deposition.

6. Due to variations in diagnostic criteria and methodological designs, comparison of cross-national epidemiological studies is limited to meta-analysis of data (Mortimer 1995).

7. Recent genetic studies which identify specific genes related to the causation of Alzheimer's disease seem to support the variation between Western European/American rates and Asian rates. The genetic profile of Western Europeans and North Americans (not including American Indians) suggests more genes related to Alzheimer's disease whereas the genetic profile of Asians suggests less Alzheimer's disease and more vascular dementia (Corder et al. 1995; White et al. 1996). Extrapolating from these data, American Indians may have an "Asian dementia profile." The characterization of American Indians as having an "Asian dementia profile" is consistent with the prevailing archaeological view of an East Asian source for the peopling of the New World.

8. This project also involved the development of an African-American support group. This chapter on Latin caregivers was stimulated by and expanded from an invited article in a special issue on Hispanic aging in *The Clinical Gerontologist* (Henderson and Gutierrez- Mayka 1992). For other publications on the African-American support group see Henderson et al. 1993; Henderson 1992; Henderson 1994b; Henderson 1994c).