Strategies for Increasing Participation of Ethnic Minorities in Alzheimer’s Disease Diagnostic Centers: A Multifaceted Approach in California

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The overall population of ethnic elders in the United States is growing rapidly, and their needs for health care are growing concomitantly (Morioka-Douglas & Yeo, 1990; Richardson, 1990). Since more ethnic elders are living longer, the numbers affected by Alzheimer’s disease (AD) and related dementias will increase. Currently, the extent to which ethnicity, race, and economic status may be factors in the epidemiology of these disorders is unclear (Rocca, 1994). However, it is probable that these factors exert a complex set of influences upon the way in which these diseases present themselves, as well as the ways in which families respond. Therefore, it is imperative that researchers and clinicians alike understand the unique cultural, biophysiological, and psychological contexts in which these diseases occur (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Gaines, 1988–1989).

California is the most populous and ethnically diverse state in the nation, with an overall population of nearly 31 million (California Department of Finance, 1992). Because of the unique demographics of the California population, health and social service programs have been challenged to extend and provide culturally sensitive services to minority residents, a challenge which is quickly becoming a policy directive. A dementia-specific program of the California Department of Health Services (DHS), one among many programs in the state facing this challenge, has been successful in its attempt to understand the multiple barriers which prevent minority patient access to needed services. This understanding has led, in turn, to the identification of effective outreach strategies, which have resulted in the successful extension of its programs and services to the minority populations in California that DHS is mandated to serve.

Much has been written about the underutilization of health care services and programs by ethnic minorities, particularly the minority elderly (Krause &
Wray, 1991). Reasons for difficulty with access to services have been described by many researchers to include cultural relevance, language, and unique needs (Gallagher-Thompson et al., 1994; Valle, 1989). Cultural values and understanding may include a belief that behaviors related to dementia are part of normal aging, rather than a disease process, and therefore may evoke little concern until symptoms are quite advanced (Valle, 1989; Zhang et al., 1990). For some cultural groups, beliefs about the causes of illnesses like AD include a host of factors, such as the spiritual belief that the illness is a punishment from God; this concept may be unfamiliar to Westernized English-speaking elders to depend on the abilities of English-speaking family members to learn about and make use of services. While the need for community education about AD is great, its delivery will be unsuccessful unless one uses the language and nuances of the particular culture being addressed (Braun et al., 1995; Valle, 1989).

A significant barrier to ethnic elders’ perception that they will receive effective care relates to growing awareness that the diagnostic instruments used in assessing cognitive impairment are strongly affected by culture, education, and literacy. Therefore, validation of the efficacy of existing instruments, as well as the development of improved and alternative techniques for detecting dementia across diverse cultures, is necessary to encourage ethnic elders’ participation (Teng, Chui, & Sapevia, 1990). In addition to "culture-free" test instruments and increased sensitivity and specificity of standardized tests for different ethnic groups (Fillenbaum, 1990), several other factors are likely to facilitate access to services for ethnic populations. These include: (a) locating programs within the target ethnic community; (b) utilizing personnel who are culturally compatible with the target group, as well as conducting sensitivity training when such staff are not available; (c) providing social and health services along with sustained, culturally relevant outreach efforts and education; and (d) conducting research focused on ethnic group dynamics and outcomes in response to specific programs of care (Valle, 1989).

The Centers face the challenge of identifying and reaching specific minority populations. To assist in meeting this challenge, in 1990 DHS established the Outreach Committee, comprising at least one representative from each Center. The Committee met through monthly teleconference calls and two strategic planning meetings during the year. Agendas for all meetings and teleconference calls were set in advance, and small working groups were established to complete special projects identified by the Committee. While a rotating chairpersonship provided leadership, input and active participation were shared by all members.

Geographic distance, as well as the independent organizational nature of each ADDTC, influenced the structure and strategies developed by the Outreach Committee. With the underlying mission of coordinating and developing outreach policies and activities for the ADDTC program, all outreach efforts for the nine individual centers were directed to the Outreach Committee for review, discussion, and recommendations. Given the constraints imposed by physical distance and program diversity, the committee has successfully identified and utilized the expertise of committee members in meeting objectives and completing special projects.

The establishment and activities of the Committee were pivotal in three ways. First, the Committee focused on the issue that the percentage of minorities being served was not consistent with their representation in the population. Second, by actively identifying common problems in developing and conducting outreach, prioritizing issues, and making recommendations to the DHS Policy Committee, the Committee established a legitimized feedback loop on a policy level within the structure of the statewide program. Third, because committee members were in key positions to direct or influence outreach activities at their own Centers, they provided support and motivation to individual program efforts and sensitized the staffs of individual programs on issues of cultural competence.

Outreach Activities Common to All Centers

The Outreach Committee compiled a master list of outreach materials. This pooling of ethnically oriented materials provided informational resources more broadly reflective of the ethnic diversity within the state. The Outreach Resource Directory is now published by DHS in its role as the state repository and clearinghouse for minority materials and information. It contains articles pertinent to outreach in general; translated books, pamphlets, and video/audiotapes ordered by language; and translated neuropsychological tests. By publishing the guide, DHS has successfully taken the efforts of the committee, added to them, and made them available to agencies within and outside California. Copies of the Alzheimer’s Disease Diagnostic and Treatment Centers Outreach Resource Directory can be obtained from the Alzheimer’s Disease Program, Department of Health Services, P.O. Box 942732, Sacramento, CA 94234-7320.

Background

In 1985, DHS, through legislative funding, established six Alzheimer’s Disease Diagnostic and Treatment Centers (ADDTCs); an additional three ADDTCs were founded in 1990. Their mission is to improve the quality of life for all persons affected by Alzheimer’s disease and related disorders through comprehensive assessment, diagnosis, treatment, support, education, and research.
Through the efforts of current staff and without additional support, the Centers actively provided outreach in the form of education, linkage, support, and consultation to varying degrees and in a variety of forms. Workshops and educational events on issues of memory loss and care of dementia patients were targeted to specific minority audiences. Simultaneously, the development of strong linkages with local agencies strengthened the minority outreach effort in at least two ways: (a) it allowed for and facilitated joint sponsorship of educational events; (b) it also allowed the ADDTCs to "piggy-back" onto already established events in various ethnic communities and neighborhoods, such as local health fairs and social events in churches and community centers. Close working relationships with community agencies already serving minority populations also enabled the Centers to strengthen and encourage referrals as well as provide training and education to staff members within these programs.

**Outreach Programs**

In addition to the outreach efforts presented above, which were common throughout the Centers, several Centers within the network were able to establish more extensive outreach programs.

**Center A.** — Through NIA support, which integrated the activities of two state-funded ADDTCs in northern California, satellite clinics were established to improve access to clinical services for low-income, underserved groups. Each satellite provides clinical services including dementia diagnosis, care-planning, resource referral, and participation in research, and is located within the neighborhood health facility where residents are accustomed to receiving primary medical care. One clinic serves inner-city residents with specific outreach to the African American community enhanced through the efforts of an African American clinic coordinator. The other satellite targets Asian and Latino elders through two public health clinics and combines clinical services with educational outreach programs organized in collaboration with local community agencies.

**Center B.** — This center established a clinic in a rural, agricultural community with a majority Latino/Hispanic population at a regional hospital in southern California. Located at some distance from the parent clinic, a local neurologist worked along with the bilingual, bicultural program staff supported by NIA funds to provide the only comprehensive diagnostic dementia program in the county. From its initiation, the entire assessment battery used to evaluate patients was translated culturally and linguistically into Spanish. An additional NIA satellite center has been established for Latinos in the parent county to provide diagnostic services as well as case management and research.

**Center C.** — Given the large Chinese community in the San Francisco area, monolingual Chinese elders were targeted for the development of a collaborative outreach project by Center C. The Center provides the diagnostic team, a social service agency provides coordination and support, and Chinese Hospital provides diagnostic tests and primary medical care for patients. To reduce barriers in seeking services, the team travels monthly to the Chinese community to conduct on-site evaluations, at space donated by the local health center. Bilingual Chinese project assistants provide outreach and translation services. This project was supported in part by an NIA grant.

Other innovative outreach projects were recently implemented in other ADDTCs; data are not yet available to indicate the extent to which their special efforts have resulted in increased participation.

**Impact of the Outreach Committee**

Prior to the establishment of the Outreach Committee, ethnic participants being seen throughout the ADDTCs did not reflect the percentage of these groups within the state population. Figure 1 shows examples of changes in this measure from 1991 to 1993. Specifically, by 1992, the percentage of minority participants had risen to reflect their representation in California. In 1993, the percentages continued to rise in the African American and Asian/Other groups at Centers A and C, respectively, which had targeted these populations. (Center B, which targeted Hispanics, lost their key ethnic staff person. This resulted in lower targeted audience participation at that site, illustrating the pivotal role of bilingual/bicultural staff in ethnic programs.)

The Outreach Committee reflected the need for and provided a continued awareness of ethnic outreach within the state-wide program. It kept minority issues in front of the policy board, and thus fed the goal of including minority participants. By providing expert consultation, its members encouraged and strongly supported the establishment of outreach programs that targeted specific populations and resulted in increased minority participation.

![Figure 1. Impact of targeted outreach on enrollment of minority populations. *White population is above 70% at all centers from 1990–1993. Graph indicates enrollment; a smaller percentage completed the diagnostic evaluation.](https://academic.oup.com/gerontologist/article-abstract/36/2/259/569495)
Conclusions and Recommendations

Several ingredients for successful minority outreach can be identified from the collective experience described above. The first ingredient is the necessity of support from Center leadership; decision makers must be able and willing to get involved, share ideas with staff, and sustain their participation in outreach activities. Although the commitment of time and effort required to initiate minority outreach activities is extensive, it is critical to successful programs.

In addition to this foundation, the models described above have generally utilized specific grants to support outreach staff, develop appropriate informational and diagnostic materials, rent on-site office space, and other costs unique to the goals of each project. In each case these funds augmented the important preliminary groundwork laid by on-line staff using existing funds judiciously.

Thirdly, the hiring of qualified bilingual/bicultural staff for positions within the program is a key element to success in many regards. Clearly, ethnic staff serve as important cultural liaisons to the client population as well as to the host agencies, which are often equal partners in a collaborative effort. Entree to communication channels may remain elusive without the benefit of appropriately selected minority staff. Details ranging from access to parking to schedule coordination are affected by subtle cultural nuances that are often best interpreted by staff from the target culture.

Despite variation in models, the results from the programs described herein suggest that seeking to understand the barriers to minority participation and paying attention to minority recruitment issues can lead to successful outreach. In light of the above, the authors recommend that other communities and states with large minority populations consider adopting similar approaches in order to increase their minority utilization of diagnostic services for AD.

References


Received October 27, 1994
Accepted July 11, 1995

Appendix

The authors wish to thank the members of the Outreach Committee, including: Doris Bass, LCSW, University of Southern California; St. Barnabas Alzheimer’s Disease Diagnosis and Treatment Center; Jean Coleman, RN, University of California, Davis Northern California Alzheimer’s Disease Center; Kimberly Butler, RN, GNP, University of California, San Diego, Alzheimer’s Disease Diagnostic and Treatment Center; Jean Clark, LSCW, University of California, Davis, Alzheimer’s Center; Helen D. Davies, MS, RN, CS, Stanford VA Alzheimer’s Center, Veteran Affairs Palo Alto Health Care System, Palo Alto, CA; Mariann DiMinno, RN, Program for Alzheimer’s Disease Care and Education, University of California, San Francisco; Libby Engebrecth, University of California–Fresno Alzheimer’s Disease Diagnostic and Treatment Center; Dolores Gallagher-Thompson, PhD, Veterans Affairs Palo Alto Health Care System, Palo Alto, CA; Stanford University School of Medicine; Vicki Hart, LCSW, Program for Alzheimer’s Disease Care and Education, University of California, San Francisco, CA; Janice Hauser, University of Southern California, St. Barnabas Alzheimer’s Disease Diagnosis and Treatment Center; Linda Hewett, PhD, University of California–Fresno Alzheimer’s Disease Diagnostic and Treatment Center; Esther Lara, University of California, Davis Alzheimer’s Center; Phyllis J. Lessin, University of California, San Diego Alzheimer’s Disease Diagnostic and Treatment Center; Ruth Mulnard, RN, DNP, University of California, Irvine, Alzheimer’s Disease Diagnostic and Treatment Center; Maryanne Robinson, RN, University of California, Irvine, Alzheimer’s Disease Diagnostic and Treatment Center; Barbara Smith, MA, RN, University of Southern California Geriatric Neurobehavior and Alzheimer Center; Patricia Smith, MA, University of California, Davis, Northern California Alzheimer’s Disease Center.
Handbook on Employment and the Elderly
Edited by William H. Crown
Unique wide-ranging sourcebook about employment policies and programs for older persons—from perspectives of the individual, the employer, and society.
Greenwood Press. 1996. 0-313-28598-5. $75.00 Est.

A Nursing Home and Its Organizational Climate
An Ethnography
By Bonnie Cashin Farmer
A re-examination of organizational issues in a nursing home setting.
Auburn House. 1996. 0-86569-262-9. $49.00 Est.

From First Principles
An Experiment in Ageing
By Haim Hazan
An ethnographic study of an unusual group of elderly persons in Cambridge, England, who call themselves the University of the Third Age.
Bergin & Garvey. 1996. 208 pages. 0-89789-462-6. $55.00

One Day At a Time
How Families Manage the Experience of Dementia
By Carole-Lynne Le Navenec and Tina Vonhod
Foreword by Otto von Mering and Leon Earle
"Given the current trend toward community and home care of older people with cognitive impairments, One Day At a Time makes an important contribution to our understanding of caregiving. The keen attention given to both experiences of elders and caregivers provides relevant coping and management strategies for professional practice. It will be required reading for my gerontology classes."
K. Victor Ujimoto, Ph.D.
Gerontology Research Centre, University of Guelph
Auburn House. 1996. 240 pages. 0-86569-257-2. $55.00

Gerontographics
Life-Stage Segmentation for Marketing Strategy Development
By George P. Moschis
A unique and highly useful model to help marketers segment and successfully target the important mature consumer market.
Quorum Books. 1996. 1-56720-062-1. $55.00 Est.

Men and Aging
A Selected, Annotated Bibliography
Compiled by Edward H. Thompson, Jr.
Bibliographies and Indexes in Gerontology, No. 32
A groundbreaking bibliography that examines the lives of older men.
Greenwood Press. 1996. 256 pages. 0-313-29106-3. $65.00

The Golden Years
A 12-Step Anti-Aging Plan for a Longer, Healthier, and Happier Life
By Lawrence B. Slobody, M.D.
As Edited by David Oliphant
Lawrence Slobody, M.D. prescribes a 12-step plan for making the Golden Years happier, healthier—and longer. In clear, easy-to-understand terms, his new book presents a comprehensive approach to the fight against aging.
Bergin & Garvey Trade. 1996. 192 pages. 0-89789-474-X. $19.95

Alzheimer's Disease
A Guide to Diagnosis, Treatment, and Management
By James Edward Soukup
An invaluable help to the physicians, health care administrators, graduate students, and researchers who are working to understand the diagnostic procedures, treatment, and management factors related to Alzheimer's disease.

Encyclopedia of Relationships Across the Lifespan
By Jeffrey S. Turner
"Turner compiles a comprehensive, nonjudgmental, and readily accessible cross-disciplinary reference to more than 500 terms and concepts (from "Abusive Family Relationships" to "World Views of Lifespan Development") related to the myriad human interaction types from birth to death. This title should be useful in libraries to answer reference questions and to support study in education, human growth and development, nursing, psychology, counseling, social work, and sociology. There does not seem to be a comparable reference tool of this magnitude and completeness."
Library Journal
Greenwood Press. 1996. 512 pages. 0-313-29576-X. $99.50

Encyclopedia of Financial Gerontology
Lois A. Vitt and Jurg K. Siegenthaler, Editors-in-Chief
Consulting Editors: Neal E. Cutler and Stephen M. Golant
Associate Editors: Ann S. Reilly, Linda A. Siegenthaler, Charlotte H. Twombly, Thomas M. Wootten
Introduction by Yung-Ping Chen, Ph.D.
Published under the Auspices of the Institute for Socio-Financial Studies
Comprehensive encyclopedia covering the financial issues significant to the elderly by inter-disciplinary experts for academic, institutional, and public libraries.
Greenwood Press. 1996. 632 pages. 0-313-28549-7. $99.50