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Obtaining family consent for participation in Alzheimer's research in a Cuban-American population: Strategies to overcome the barriers

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Abstract

Cultural values and beliefs affect family attitudes toward participation in research. Significant resistance to allowing their elders with dementia to participate in clinical research was encountered in Cuban-American families. These families expressed concern about disturbing the elder's comfort (*tranquilidad*) and solitude (*soledad*) Furthermore, most believed that intervention would be futile. Feelings of guilt associated with nursing home placement may have been exacerbated by the suggestion that active intervention could be effective.

Strategies to overcome these barriers included reduced emphasis on the potential superiority of the intervention to be tested, reassurance that contact with research staff was usually appreciated by participants, arrangements to talk with the family as a group about the study, and increased use of Spanish-language consent forms.

Keywords

Alzheimer's disease; Cuban-Americans; diversity; exercise; intervention studies; multicultural issues; research study participation and recruitment

Introduction

When older individuals are unable to make legal decisions due to Alzheimer's disease, a family member must provide consent if they are to participate in research. Cultural values and beliefs can affect the attitudes of family members toward consenting to research participation. In the conduct of a study of nursing home residents with Alzheimer's disease (AD), the authors encountered significant resistance to providing consent from family members in the Cuban-American community of south Florida. The purpose of this paper is to describe the concerns expressed by these families in regard to providing consent to participate in research for an elder with dementia and the strategies that were successful in allaying their concerns.

Since few intervention studies include minority elders,¹ we were anxious to have adequate minority representation from the diverse population of south Florida in our study of exercise in nursing home residents with Alzheimer's disease. Two nursing homes used in the study had a primarily Hispanic resident population; a large number of these residents were Cuban-American. However, after receiving numerous refusals from families in the Cuban-American community, we began to question our customary approach and to examine the barriers to recruitment in this population.

Other researchers have described barriers to recruitment of minority elders, Gauthier and Clarke² reported suspicion and fear among those in the African-American community. Past unethical research has resulted in fear about being victimized as research subjects. Strategies to overcome this barrier for the African-American community included: (1) providing adequate information about the research, (2) emphasizing the contribution to society, and (3) demonstrating that the researcher was a highly competent expert in the field.²

Other barriers to participation, identified by Wrobel and Shapiro³ with poor urban elders, included inconveniences such as lack of transportation and long waits. Families' lack of understanding of Alzheimer's disease was another problem. Families frequently mischaracterize symptoms of AD as normal aging changes. Additionally, because AD cannot be cured, families may see research as having no benefit for their loved one.

Flauskerud and Nyamathi⁴ described similar factors, such as lack of access to research centers due to distance or lack of transportation, as barriers to recruitment of culturally diverse populations in research. In addition, families may not share the researcher's values regarding the benefits of participation. Benefits such as the advancement of science may be a low priority when meeting day-to-day needs is a critical concern.

Methods

We were recruiting participants for a study of the effects of exercise in nursing home residents with AD. If included in the study, participants would be assigned at random to one of three groups: walking, comprehensive exercise, or social conversation. The primary aim of this four-year study was to examine the effects of an exercise intervention on function, mobility, mood, depressive symptoms, and self-care ability in institutionalized elders with AD. This study is significant because nursing home residents, particularly the cognitively impaired, have a sedentary lifestyle, spending most of their day either sitting or lying in bed.⁵ In addition, depressed residents with AD are far more likely to become lethargic, sedentary, and increasingly dependent on others for care.⁶

Families were first contacted by the facility in the form of a letter from the director of nursing, written in Spanish when indicated, describing the study and expressing the support of the nursing home's administration for the project. Next, research assistants contacted families. Because cultural incompatibility between researchers and families may be a barrier to success,³ recruiters who were Cuban-American and bilingual made the initial contact. The study was thoroughly explained, either in person or over the phone, and questions were answered. Families were assured that their loved one would be asked for assent each time they were approached by a member of the research team and participation would not be forced. Further, they were informed that the resident would not be taken away from appointments or other preferred activities to participate in study activities. Safety precautions were also described. If the family members refused, they usually stated their reasons and the research assistant recorded them in the notes with direct quotes. If no reason was given, family members were offered an opportunity to elaborate so that we could better understand their concerns and, perhaps, allay them.

Results

Despite these efforts, the refusal rate in Cuban-American families was initially quite high compared to participants from nursing homes with primarily non-Hispanic residents (63 to 69 percent refusal rate among Hispanics versus 37 percent among non-Hispanics). From reasons recorded in the research assistants' notes, several patterns and themes began to emerge from conversations with family members. The themes were *tranquilidad*, *soledad*, and *futilidad*. Misconceptions about the loved one's condition and abilities were frequently encountered as well.

Comfort (*Tranquilidad*)

The most frequent reason given for refusal involved the concept of individual comfort and restfulness. Resistance to any attempt to interfere with their loved one's rest was a primary concern expressed by family members. Many objected to any disturbance of the peace their loved one had established with his or her environment. Any change in routine could be construed as a threat to that state of being. One family member stated, "We want our mother to be [*tranquila*] in a tranquil state." Other statements made by family members of potential participants included: "She needs to rest"; "We just want her to be comfortable for her final days here on earth"; and "This person is at [nursing home name] to convalesce. I can't give permission for participation in the study."

Tranquilidad is viewed in a positive light among Cuban-Americans as well as other Latin populations. It is especially applied to young children and elders within these cultures. Interestingly, this concept of *tranquilidad* is not limited to the physical condition of the individual. There is a large psychosocial component involved. It can be equated with being at peace with one's self and the environment.

With regard to elders, the concept of *tranquilidad* includes the elder's right to rest after a long and busy life. As one advances in years, it is a personal right, perhaps even a reward, to attain such tranquility. This concept also includes a measure of responsibility placed on family members to establish or preserve this perceived state of comfort. Purnell and Paulanka¹⁵ note that, among Cuban-Americans, dependency is encouraged as part of the sick role. The ill individual is showered with gifts and relieved of his or her responsibilities. Family members become actively involved in decision-making for the ill person. *Tranquilidad* may be seen as an extension of this attitude toward the sick role.

Solitude (*Soledad*)

A related belief was that it would be best for the elder to be "left alone." Some families were quite direct ("we want her to be left alone"). The assumption seemed to be that the resident would be less distressed if left alone. The idea that their loved one could be lonely or depressed and hence might welcome regular contact with the research team was dismissed by some. The belief that those with AD are unable to experience emotions is a commonly held belief among professionals as well as family caregivers and may influence this perception.⁷

Futility (*Futilidad*)

A somewhat different theme was that there was nothing that could or should be done to improve the quality of life for this individual with AD. Families made such statements as "her mind is gone" and "there really isn't anything that can be done to change his condition" or "she's at the point right now where I'd rather have things stay the way they are." Their statements also seemed to imply that to improve functioning would prolong life and therefore prolong suffering, which related back to the themes of *tranquilidad* and *soledad*. In contrast to current thinking within Western biomedicine, Hispanics generally view memory loss and disability as

natural processes leading to death.⁴ An acceptance of fate and religious faith (*i.e.*, the will of God) support this view. Aggressive intervention would be viewed as a contradiction to these beliefs.

Misperceptions

Family members were sometimes unaware of the older person's remaining abilities. Gallagher-Thompson and associates⁸ noted that lack of knowledge about dementia was common among Hispanic caregivers. Statements such as "she doesn't even walk anymore" were made to support the notion that the residents were not able to participate in the study, yet all of them had been screened for ability to walk. One woman, who was the daughter of a prospective participant, told me that her mother "didn't speak a word." The nursing assistant, who was making a bed nearby, volunteered that, in fact, the resident had spoken about her family that morning.

Culture, values, and traditions

The role of extended family is vital in Hispanic culture.⁹ On the basis of the underlying value of respect and support for one another, Hispanic families place a strong emphasis on establishing intergenerational kinships, which include elders as esteemed members (*familism*). More specifically, Cuban-Americans feel a responsibility for caring for older relatives and consider it a duty to keep elders in the home until they die. The idea of placing a loved one in a nursing home is to most Cuban-Americans taboo, a sign of not caring. One is considered *un mal hijo o hija* (bad son or daughter) for placing an elder in a nursing home.

When faced with the complex care of a family member with dementia, Cuban-Americans, like other Hispanic families, are fraught with conflict. Values such as families, spirituality, and the acceptance of fate dictate that adult children and grandchildren will provide care for elders at home.⁹ Extensive physical care and problematic behaviors associated with Alzheimer's disease create a tremendous caregiver burden and the need to seek formal assistance. As a result, the decision to obtain care outside the family leads to feelings of guilt. Since this difficult decision may be justified with the belief that nothing more could be done by the family (or anyone) to help their loved one, family members may not be receptive to the idea of a study designed to improve quality of life. The researchers' enthusiasm about the purpose of the study and the possibility of improving the elder's functional abilities may have reawakened doubts as to whether family members have done enough for their relative.

The duty to care for an elder at home at any cost is further supported by traditional gender roles. Hispanic families are generally patriarchal, and the woman is expected to stay home and care for the parent or grandparent. Offspring are expected to live near their elders so that they can also provide care. Sisters or cousins help by relieving the primary caregiver's duties or by bringing food or other help.⁹

Stigma associated with psychiatric illness may also be a barrier to participation in research. Nurses that worked on the dementia units pointed out to us that residents with dementia had few visitors compared to cognitively intact residents. Although not expressed by our participants' relatives, Gallagher-Thompson and associates⁸ found that Mexican-American caregivers felt embarrassed about their relative's dementia and blamed the evil eye (*el mal de ojo*), "bad blood," or nerves (*nervios*) as the cause.

Guilt plays an important role in shaping behavior. According to Hernandez,¹⁰ the decision to place an elder in a nursing home may also be influenced by the his or her past behavior. If the older individual left parents in Cuba when he or she migrated to this country, the elder may perceive placement in a nursing home by his or her children as punishment for past neglect.

Even the acceptance of outside help within the home can result in guilt and emotional distress. In a study of African-American and Hispanic caregivers of family members with dementia, more Hispanics thought that the use of home attendants meant that the caregiver was avoiding responsibility.⁹ Hispanic caregivers also had much higher rates of depression as compared to African-American caregivers born in the United States. Kane¹¹ notes that, among Hispanics, reliance on family is more important than reliance on the church, physicians, or mental health professionals.

As more Cuban-Americans acculturate, one may speculate that the distress related to placing an elder in a nursing home will decrease. At present, changing gender roles have left some families without an individual at home to provide care, but the belief in the duty to provide care remains the same. Changes in employment have challenged the maintenance of the extended family. Nevertheless, cultural traditions and values create pressure on middle-aged individuals to provide their older relatives with optimal care at a time when many elders are living longer and may need specialized care in the home or outside the home.

Strategies for success

Discussions of attitudes and beliefs among the members of the research team prior to approaching families for consent was crucial to improving the acceptance rate. Reasons for refusals were reviewed and scripts were developed for use when approaching families. Team members focused on acceptance of traditions and values and support for families' decisions regarding participation in the study.

The use of language was important in gaining support of family members. We were careful to avoid the implication that the research protocol would mean care superior to that which was provided at the nursing home. We noted that the contact with members of the research team was generally appreciated by previous participants. Since the word "exercise" seemed to conflict with the perceived need for *tranquilidad*, we found it necessary to assure them that the elder would not be asked to engage in strenuous activities. Families were assured that the activities were actually movements that would ordinarily be used in normal daily activities.

From past experience in obtaining consents, researchers had been accustomed to contacting the individual designated on the resident record as the "next of kin" and discussing consent with him or her. In the Cuban-American community, where familism is an important value, a shift in the process was needed. As became evident, the individual designated as next of kin was often the resident's daughter and she deferred to other family members to make the final decision. A verbal assent by the next of kin was often only the first step in a series of discussions with other family members. Typically, family members discussed the possibility of the elder's participation with each other at length. If a key decision-maker objected, despite the support of other family members, the next of kin would decline on behalf of the family. To deal with this, research assistants came to expect a lengthier process and offered to speak to other family members by making an appointment either to meet at the nursing home or to make a home visit.

To reach families by telephone was frequently challenging. To leave messages was rarely helpful and the researchers soon learned to call in the evening or on Sunday afternoon. We began by being physically present at the nursing home on Sundays, hoping to meet families that came to visit. We were surprised to find very few visitors on the dementia units. The nursing administration confirmed that residents with dementia often did not have visitors.

Henderson and Gutierrez-Mayka¹² reported that Hispanics viewed dementia as a stigma shared by all members of the family. Although this underlying belief may have been operable, we have no anecdotal evidence to support this. Communication with the individual with advanced

AD can be frustrating and stressful, and so family members may visit less often due to deterioration of communication abilities. Conversely, some relatives wanted to be apprised of the progress their loved ones were making in the study, and we agreed to communicate on an ongoing basis. A few family members visited frequently and were readily available to discuss the study or their loved one's progress.

For families that were more comfortable communicating in Spanish, a Spanish-language version of the consent form was used. A Spanish-speaking research assistant would explain the forms and be available in person to answer questions. We found that family members who met with research assistants in person were more likely to sign the consent forms.

Results following changes in approach

For the total sample, the average age of participants was 87; the range was 73 to 100. The average Mini-Mental State Exam (MMSE) score was 10.57 out of a possible score of 30. Participants had an average length of stay of 769 days with a range of 32 to 5,354, and each had an average of six to seven diagnoses. No differences in these socio-demographic characteristics were noted between Hispanic and non-Hispanic participants.

In one nursing home, where 75 to 80 percent of the residents were Hispanic, 19 potential participants (all Cuban-American) met the criteria for the study in the development of the first panel and seven families consented (37 percent). For the second panel at the same nursing home, 16 individuals qualified (all but one were Cuban-American) for the study and five consented (31 percent). Strategies to obtain consents were changed before beginning the process at the second nursing home that had a high proportion of Hispanic residents (80 to 85 percent Hispanic). Twenty-two potential participants (all but one were Cuban-American) were identified and 14 consents were received (63.6 percent). In comparison, another nursing home, where residents were all non-Hispanic whites, yielded 49 potential participants and 31 consents (63 percent). These results were similar to those achieved with Hispanic families in the second nursing home where the revised approaches were used.

Conclusion

Ethnic diversity is increasing at a rapid rate among older Americans. The proportion of Hispanic elders in the US population will triple by 2050.¹³ The *Healthy People 2010* objectives call for elimination of racial or ethnic disparities in health care¹⁴ and the inclusion of minorities in all federally funded research. Recruitment of specific groups of minority elders presents challenges to researchers that have not been fully explored in the literature. This paper describes the difficulties encountered in recruiting Cuban-American elders for a study of exercise in Alzheimer's disease and strategies that were successful in gaining consents and increasing participation of minority individuals.

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