Issues and Recommendations for the Recruitment and Retention of Older Ethnic Minority Adults Into Clinical Research

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A burgeoning literature indicates that treatment of mental disorders offsets mortality, morbidity, and poor quality of life in senior citizens. Unfortunately, ethnic minority senior citizens, who are in most need of mental health services, have not been well represented in psychosocial research. This lack of attention is due, in large part, to difficulties that may arise in recruitment and retention of older ethnic minority adults in research studies. The purpose of this article is to discuss successful methods for recruiting older ethnic minority adults into psychosocial research and to offer specific suggestions for keeping this population involved in longitudinal studies. Also included is a discussion of past research and present data from treatment studies that used the methods discussed in this article.

According to the National Center for Health Statistics, older ethnic-minority adults are in most need for psychosocial services because of the many social and financial stressors that this group encounters. During the past 20 years, geropsychologists have documented the effectiveness of psychosocial interventions for treating mental disorders in late life (for reviews, see Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993; Scogin, Jamison, & Davis, 1990). However, in our own review of this literature, only 22% of these studies included ethnic minority samples (i.e., Areán et al., 1993; Cohen, Teresi, & Blum, 1994; Gallagher-Thompson & DeVries, 1994; Ganzini, Lee, Heintz, Bloom, et al., 1994; Morin, Kowatch, Barry, & Walton, 1993; Reynolds, Frank, Perel, Miller, et al., 1994; Reynolds, Frank, Perel, Imber, et al., 1992; Scogin, Jamison, & Davis, 1990). Because of the paucity of research on older ethnic minority adults and the need for services in this populations, many organizations, including the National Institutes of Health (1992) and the Human Capital Initiative (1993), have asked researchers to include more older ethnic minority adults in their research endeavors. This is no easy task. The underrepresentation of ethnic minorities in geriatric mental health research is due, in large part, to the difficulties that many researchers encounter when trying to use traditional methods to recruit and retain older ethnic minority adults in research projects (Minkel & Kail, 1989; Thompson, Heller, & Rody, 1994). However, it has been our experience that recruiting and retaining older ethnic minority adults is made easier when methods to recruit and retain older ethnic minority adults are tailored to address the issues that prevent potential participants from engaging in research. The purpose of this article is to provide background information on recommendations for recruiting and retaining older ethnic minority adults and to describe effective recruitment and retention methods that we have used in our own research. Our discussion covers the usual difficulties encountered in recruiting and retaining any geriatric sample and highlights the additional difficulties specific to conducting research with an older ethnic minority population.

Problems Recruiting and Retaining Older Adults

Recruiting any sample of older adults into clinical research is difficult, time consuming, and expensive (Ballard, Nash, Rainford, & Harrell, 1993). In most geropsychiatric studies, between 70% and 80% of older adults who are approached to participate in a study actually agree to be research participants. This is significantly lower than the standard 90% to 95% response rate seen in younger samples (Carter, Elward, Malmgren, Martin, & Larson, 1991; Thompson, Heller, & Rody, 1994). Keeping older adults into research is a different matter. Most researchers find that once they have recruited older adults into a research protocol, the participants are less likely to drop out of the research project. In fact, the average dropout rate for geriatric studies is only 10% (Carter et al., 1991).

Studies investigating the factors related to participation in research have found that older adults who refuse to participate in research tend to be male, to be older, and belong to a lower income group (Wilson & Weber, 1976). The few studies that have been conducted to understand attrition in older samples found that common characteristics among older participants who failed to continue in a research project included factors such as advancing age, increased disability, and participants seeing themselves as older and reporting themselves to be less active than those who remained in the project (Carter et al., 1991; Markides, Dickson, & Pappas, 1982; Norris, 1985). Interestingly, these studies consistently found that belonging to an ethnic group was not significantly related to responding to or dropping out of research. Although these studies have not found a
difference in the rates of participation in research among ethnic
groups, the reasons for not participating, and therefore the re-
cruitment and retention strategies, do differ considerably be-
tween ethnic-minority and Anglo older adults.

A number of articles have discussed the issues related to re-
cruiting and retaining older ethnic minority adults into re-
search (Ballard et al., 1993; Carter et al., 1991; Kushman &
Freeman, 1986; Lasoski, 1986; Leander & Neuwirth, 1978;
Mindel & Kail, 1989; Souder, 1992; Steinmetz-Brekenridge,
Thompson, Brekenridge, & Gallagher, 1985; Vinales Cun-
ningham, 1991; Wallen, 1992; Williams, Vitello, Ries, Bokan,
& Prinz, 1988; Yeatts, Crow, & Folts, 1992). Research with
older Anglo adults has found that the major issues in recruiting
and retaining these older adults into research has to do with not
knowing about the research study and trouble with transporta-
tion to the research center (Souder, 1992). Recruitment and
retention strategies that are successful with older Anglo adults
are designed to address these problems (e.g., advertisements in
newspapers, providing transportation; Thompson et al., 1994).
The issues involved in recruiting and retaining older ethnic mi-
nority adults into research are more complex. According to
Valle (1989), the overarching issues to consider when trying to
recruit older ethnic minority adults into research projects are
their ethnocultural beliefs about mental illness and help-seek-
ing behavior and the socioeconomic constraints present in being
both older and belonging to a ethnic-minority group. These is-
ues manifest themselves in the following ways: (a) distrust of
the goals and processes of research by older ethnic minority
adults and their families; (b) difficulties in transportation to re-
search and clinic centers (Ballard et al., 1993; Mindel & Kail,
1989); (c) lack of information about the disorder that is being
investigated (Ballard et al., 1993) and negative cultural atti-
dudes toward mental illness (Landrine & Klonoff, 1994); (d)
lack of information about the kind of help that the participant
or family can receive by participating (Souder, 1992); and (e)
lack of culturally or racially compatible professional staff
(Ballard et al., 1993; Mindel & Kail, 1989; Takeuchi, Sue, &
Yeh, 1995). The literature is replete with useful suggestions for
recruiting and retaining older ethnic minority adults. Many
methods involve overcoming the access barriers just described.
We detail here the methods, rationale for the methods, and data
on the effectiveness of these various approaches from research
studies that we have conducted with older ethnic minority
adults.

Successful Techniques for Recruiting and Retaining
Older Ethnic Minority Research Participants

Overcoming Fear and Distrust

The primary way that researchers have dealt with this partic-
ular problem has been to establish a strong, positive relation-
ship with the community, family members, and potential re-
feral sources (Mindel & Kail, 1989; Williams et al., 1988).
According to Dilworth-Anderson and Anderson (1994), at-
ttempting to recruit an older ethnic minority person without in-
volving the family may result in alienating the family and fuel-
ing distrust about research. This issue holds true for other social
supports who are close to the older ethnic minority adult. In

a study by Carter et al. (1991), as many as 32% of potential
participants refused to participate in research because their
families and physicians discouraged them.

Henderson, Gutierrez-Mayka, Garcia, and Boyd (1993) have
successfully overcome fear and distrust in recruiting older Afri-

can-American and Hispanic participants into caregiver inter-
vention studies. Their method involves a number of strategies
aimed at establishing a link to the specific communities targeted
for the research. Their method first involved developing a pro-
file of the community that listed the major organizations and
key community members who would be most helpful in recruit-
ing potential research participants. After this community pro-
file was constructed and the key centers and members were con-
tacted, the researchers continued to work closely with these cen-
ters and members throughout the course of the study. They did
this in several specific ways. First, information was provided
about the resources available to potential participants if they
decided to be involved in the project. Then the leaders' advice
and help were enlisted around recruitment issues. Finally, fol-
low-up information was provided to the community once the
project was finished. Any concerns or fears about research were,
therefore, dissuaded by working directly with key community
leaders and members.

A randomized trial that was conducted by Patricia A. Areán
is an example of how successful this model can be for recruiting
older ethnic minority adults into research (for details, see Ar-
én et al., 1993). In this study, we randomized 75 people over
the age of 55, and approximately 25% of the sample belonged
to an ethnic minority group. In our first attempts to recruit
community participants, we initially used advertisements in lo-
cal newspapers and the radio, a method that has been found to
be highly useful in recruiting White geriatric samples (e.g.,
Steinmetz-Brekenridge Thompson, Brekenridge, & Gal-
lagher, 1985). Although this method was quite useful in recruit-
ing White participants, only 1% of those who responded to ad-
vertisements belonged to a minority group. To recruit older mi-
nority adults, we first contacted the leaders and organizers of
New Jersey community senior centers and the Area Agency on
Aging, providing them with a brief description of the project.
Once these community and organizational leaders had a chance
to meet and discuss the project, the principal investigators met
with the leaders of each organization to answer any questions
about the project. These meetings also provided an opportunity
for the investigators to ask questions about how best to recruit
from the organizations and to ask advice about any barriers to
participation that we could anticipate. After concerns were ad-
dressed, the principal investigator met with the target popula-
tion to discuss the project with the organization leaders present.
This provided an opportunity to educate potential participants
about depression and the project services while allowing the
community an opportunity to voice their concerns and ques-
tions. Throughout the course of the study, investigators period-
cally met with the organization leaders to update them on the
study progress and preliminary results. The investigators also
used these periodic meetings to obtain advice about recruit-
ment strategies. By working with community churches, syna-
gogues, and senior centers, the number of older minority adults
calling for information about participation increased from 2 in
the first 6 months of the project to 39 in the subsequent 6
months. We were able to recruit significantly more ethnic minority adults through this method than through traditional methods (e.g., posting flyers and newspaper advertisements).

In another study by Dolores Gallagher-Thompson, under the auspices of the Geriatric Research, Education, and Clinical Center of the Veterans Affairs Health Care System, Palo Alto, California, the investigators compared a number of methods for recruiting older Hispanic adults into research projects assessing the efficacy of different interventions to reduce caregiver distress. Gallagher-Thompson et al. (1994) found that, by far, the most effective method of recruitment was collaborating closely with local service agencies for Hispanics. In this study, the investigators contacted, in person and by phone, 350 community centers serving the Hispanic communities in Northern California. As reported in their study, 61 of the 64 Hispanic participants in the initial phase of the research were referred by these community agencies, whereas the remainder were referred by others who had participated in the project or responded to notices in the media.

Overcoming Transportation Barriers and Outreach

As discussed previously, another major barrier to recruiting and retaining participants is the fact that many research projects are held in communities in which ethnic minorities do not live. Most older adults, in general, have trouble getting around because of very real limitations such as disability, health concerns, and living in neighborhoods that are dangerous. These issues are particularly salient in older minority people. There is considerable research to show that older minority adults tend to have more health problems and to be more disabled (Haney & Gear, 1991; Hildreath & Saunders, 1991) than older White adults. Additionally, cultural and racial barriers may dampen an older minority person's interest in traveling to a nonethnic neighborhood for fear of the potential for becoming a victim of racially motivated crime. Therefore, many older ethnic minority adults may be less motivated to come to a center that is not in their neighborhood. There are a number of ways to address this problem. One immediate solution is to provide free transportation to and from the research site (Ballard et al., 1993). This can often be costly for projects with small budgets, as transportation is often expensive, particularly when frail or disabled older adults are involved. Moreover, this method does not address the concerns an older and minority person may have about being in a foreign neighborhood. A superior method is to conduct the study in the target community. This method substantially increases the likelihood that older minority adults will come to the study site for two reasons: First, the site should be more conveniently located and should result in less travel time and expense; second, if the study site is in the community or provided in a community center, then potential participants may be less distrustful of the research. Arcán et al. (1993), Ballard et al. (1993) Gallagher-Thompson et al. (1994), and Henderson et al. (1993) have used this approach successfully. For instance, Ballard et al. (1993), in recruiting older African-American adults into their Alzheimer's Disease support project, were able to double the number of people in their study by providing services in the community. Some settings may not be feasible because the location is not a place the older minority adult would normally go. Henderson et al. (1993) found that providing services in a community church actually restricted the number of participants in their project because some participants had affiliations with different churches in the community and felt uncomfortable going to a church to which they did not belong. Once Henderson et al. (1993) changed the location of their services to a community center, participation increased significantly. On the other hand, some settings may not be appropriate because older minority research participants may not want friends and families to know they are in a research study. In the Areán et al. (1993), we were able to obtain referrals from senior centers, but because many of the participants' friends also attend the senior center and knew of the project, these older adults preferred to be seen at the university. In fact, 99% of all the ethnic minority participants recruited through senior centers preferred to participate at the university setting because they were afraid that their friends would find out they were participating in a study for the treatment of depression.

Often transportation or inability to travel to a setting for either treatment or follow-up evaluations may result in subsequent attrition from the research project. Many older people have time demands that impede their ability to come to treatment or to research interviews. For instance, they may be physically ill and have numerous medical appointments during the day. As stated previously, older ethnic minority adults tend to have more chronic illnesses that older Anglo adults and, therefore, may have even more time constraints because of illness. Some older adults are caring for their own aging parents or spouses and often do not have the financial resources to hire home care staff to watch the spouse or parent (Ballard et al., 1994; Henderson et al., 1993). For example, many African American women have custody of their grandchildren and, therefore, have to meet the needs for these children as well as care for their own needs (Dilworth-Anderson & Anderson, 1994).

In the Areán et al. (1993) study, we found that these issues often resulted in participants' having difficulty in coming to treatment and coming for follow-up interviews. To retain participants through out the follow-up phase of the study, we often met them in their homes at their convenience to conduct the assessments. Also, we were able to assist many of these older adults with coming to treatment by using the transportation services that the senior centers employed. We often called participants on a regular basis to remind them of appointments and to help them solve any of the problems they had in coming to treatment while remaining flexible if participants could not come to treatment on a given day. By using these methods, we were able to retain 94% of the minority participants throughout the course of the study.

Similar methods (e.g., using home visits to obtain follow-up data) were used by Gallagher-Thompson et al. (1994). Using these methods resulted in retention of about 95% of the family caregivers in the intervention study for a period of up to 6 months after conclusion of the active portion of the study.

Education About the Disorder Under Study and the Benefits of Participating

Many researchers consider this to be a crucial element in recruiting older ethnic minority adults into research. As Carter et
al. (1991) found, many older adults are willing to participate in research studies but do not do so because they know little about the disorder under investigation and of the possible benefits to participating in research. Ethnic minorities are also more likely to have stereotyped ideas about mental health problems that could be dispelled through education. With these issues in mind, Souder (1992) proposed a consumer-oriented model of recruiting all older adults into research projects. Among Soud-
er’s suggestions is to appeal to potential participants’ curiosity about their health and describe in detail through news an-
ouncements, community, and radio talk shows symptoms of the disorder under investigation and the benefits of participat-
ing. Souder pointed out that many older adults are curious about their health and welcome opportunities to obtain free opinions and recommendations to improve their quality of life. This may be particularly true of ethnic minority and poor older adults who do not have access to extra health services but have many health problems. Therefore, one method to recruit older ethnic minority adults would be to recruit through other research projects that involve health screenings by adding a psych-
ological component to the “parent” project. Not only would older ethnic minority adults receive important information about their health but they have an opportunity to learn about the facts of psychological problems.

This particular method was used by Dolores Gallagher-
Thompson in collaboration with a group of associates from the Stanford University School of Medicine. The investigators for the first study wanted to recruit 150 Mexican-American women over the age of 60 to participate in a study of biomedical risk factors for osteoporosis. This ongoing study involves longitudinal measurement of bone density, nutritional and exercise habits, and other concurrent medical conditions (e.g., diabetes). Participants were seen annually for 4 years. Because of Gallagher-Thompson’s interest in the interactions of biomi-
dical and psychosocial factors (e.g., presence of depressive symp-
toms, degree of acculturation), a psychosocial component was included in the baseline (first) assessment for 119 of the partic-
ipants. Thus, recruitment for the “parent” project, which relied heavily on advertising of free comprehensive medical evaluation over 4 years, resulted in recruiting 80% of these older women from the parent study into the psychosocial component. Of those who agreed to participate in the psychosocial screening component, 20% were depressed and were invited to participate in other clinical research studies for treatment of late-life de-
pression (Gallagher-Thompson et al., submitted for pub-
lication). To Dolores Gallagher-Thompson’s knowledge, this is one of the first studies to use this particular method with older Mexican-American women.

Understanding Cultural Barriers

The issue of cultural competence is the most important issue to consider when researching an ethnic minority population. Attempting to recruit a group of older ethnic minority adults without considering cultural factors can result in a failed re-
search project. In research that provides services that are cul-
turally sensitive, a study must meet the following prerequisites: (a) The setting must be embedded in the cultural community, (b) staff administering the research protocols and intervention packages must be bilingual–bicultural, and (c) the staff must be sensitive to the cultural nuances within the ethnic group so that information about the subgroups that make up a culture can be fed back to the researchers and service staff to improve recruit-
ment and retention (LeVine & Padilla, 1980).

As stated in other articles in this special section, using re-
search and clinical staff drawn from ethnic groups from which one wants to recruit may help overcome the fear and distrust that the population may have of research. According to Valle
(1989), the use of bilingual and bicultural staff is imperative for any outreach methods to be successful. In the Gallagher-
Thompson et al. (1994) study mentioned earlier, recruiting older Mexican Americans was highly successful because of the use of Spanish-speaking staff who were also bicultural. This staff not only conducted research interviews and treatments but also acted as the research representatives to the community. In the Areán et al. (1993) study, the research and clinical staff were also multietnic. Having culturally diverse staff not only helped to make ethnic minority research participants to feel more connected to the research project but also helped in clarifying diagnostic issues in the assessment phase. For instance, one Hindu participant reported among his depressive symptoms a decrease in appetite and sexual desire. This participant claimed that he did not see these symptoms as a problem because, in his religion, letting go of these “desires” would bring him closer to a spiritual state. Fortunately, one of the research staff member’s family was from India. This staff member was able to interview the man and helped to clarify whether this decrease in appetite and sexual drive was related to his culture or caused by depression.

For another study conducted by the first author Patricia A. Areán (Areán & Miranda, 1995), we recruited Chinese, His-
panic, and African-American older adults. Our staff included at least 3 people from each of these ethnic groups who were bicultural and bilingual. Because participants were interviewed twice over a period of 2 weeks, retention was an important issue. Be-
cause we used research staff from these different backgrounds, retention rates for the monolingual samples in this study were 100%. The retention rates for those participants who were bili-
ingu and for the African American samples increased from 60% to 98%.

Feedback to the Community

This issue is a vital part of the entire process of conducting research with an aging ethnic minority population, particularly if researchers expect to continue conducting research in the community. For example, in Gallagher-Thompson’s work with Hispanic family caregivers, doing radio and television shows in Spanish about results from the studies that we have conducted has actually increased the number of phone calls to our center inquiring about our services by about 15% over calls received during previous months when the media contacts were not available. In the Areán & Miranda (1995) study, providing feedback to the medical clinics who referred patients about the preliminary findings increased the referral rates by 50%. How-
ever, to maintain the flow of referrals from the physicians, re-
peated presentations and collaboration with the medical clinic is crucial, so that physicians do not forget that the study is in
place. We have found that, by using this method, the referral agents often provide useful insights into our findings and consistently report that they are made to feel part of the research process.

**Dealing With Perceived and Actual Poor Health**

Little work has been done to understand how this particular barrier might be addressed in clinical research. What we do know is that perceived level of health and disability significantly influence whether older adults continue to participate in research (Markides et al., 1982; Norris, 1985) and that older ethnic minority adults tend to view themselves as sicker than older White adults do (Johnson & Wolinsky, 1994). As Norris (1985) pointed out, a researcher should not bring pressure on an ill participant to continue in a research project. However, it may be possible to amend traditional methods of data collection and treatment delivery. A key concept to consider is feasibility in scheduling of data collection and in methods of treatment delivery. For example, meeting on two or three different occasions (where each meeting is relatively brief and occurs at a location of maximal convenience to the older ethnic minority adult) will increase the likelihood of their being able to complete the assessment process. Encouraging breaks when the individual needs to take a rest and providing some nourishment if the interview spans the participant’s usual lunch or dinner hour are simple methods that indicate the researcher’s willingness to respect and work within participant limitations of the participants.

In terms of treatment studies, modifications can often be made in the pace of the work, in how homework and other between-session assignments are made, and in what is expected of the frail older adult. This allows ethnic minority participants to feel that they are fully participating in the intervention protocol. For example, with monolingual and low-literacy Mexican-American family caregivers, Dolores Gallagher-Thompson has found that the psychosocial educational program requires greater reliance on spoken (rather than written) information (compared with Anglo caregivers), as well as greater use of symbols and art to communicate treatment-specific information. In addition, modifying homework so that it is more behavioral in nature (rather than focusing on written reports or exercises) and involving family members in the intervention itself are most helpful in the monolingual and illiterate samples. In the bilingual and the monolingual and highly educated samples, these methods are not necessary.

**Providing Incentives**

As discussed earlier, many older adults may not participate in research because they are unaware of the benefits of participating. This is also an issue for retaining older ethnic minority adults in longitudinal studies. The biggest challenge in longitudinal research with older adults is having participants return to the research project after receiving the intervention under investigation (Carter et al., 1991; Norris, 1985). In most circumstances, returning to a study site to engage in a lengthy interview has no apparent benefit to an older adult. Therefore, providing incentives to return is a useful way of ensuring retention.

Retention rates for older Mexican-American caregivers in intervention research have been excellent. In Gallagher-Thompson’s work, two factors influence the dropout rate in these studies. The first is the location of the study. We have found it imperative to conduct the interventions in communities with high concentrations of older Hispanics (e.g., Salinas, King City, San Jose) rather than expecting participants to travel to Palo Alto, where the investigators are. Second, provision of monetary incentive (on completion of the project) to help defray the cost of transportation or finding a caregiver to care for the Alzheimer’s Disease patients enhances participants’ motivation to complete posttests and follow-up interviews. In the studies that we have conducted with this population, providing incentives decreased dropout rates from 25% in the initial pilot phase, when less was known about these issues, to under 10% in the actual research project. Although these incentives are useful for any older adult, providing financial incentives to older ethnic minority adults not only offsets the cost of participating but may make the older ethnic minority person feel that his or her family situation, which often involves financial stress and burden, is understood and is being respected as well.

**Conclusions**

Recruiting older ethnic minority adults into psychosocial studies involves much effort on the part of the investigators conducting research. The overarching theme that unifies all of the recruitment and retention methods mentioned here is establishing a close and collaborative liaison with the target community and understanding the cultural issues that may impede research recruitment, as well as being sensitive to the health and financial constraints this population faces. Recruiting and retaining older ethnic minority adults into research requires much flexibility, creativity, and effort to assimilate to the ethnic minority community. This effort involves direct work with key community leaders and family; dissemination of information to the community; and significant outreach efforts for those older adults who have time, health, and financial constraints. Researchers should not be discouraged by the amount of effort required to conduct research with an older and ethnic minority population. It has been our experience that once we have been integrated into the community, recruiting from the older ethnic minority population becomes much easier over time. As an example, Gallagher-Thompson has found that interacting with the Mexican-American community and providing information about results from our studies in Spanish by bicultural staff stimulates interest in services and fosters a greater willingness to participate in future research projects. In addition, Areán has found that, through continuous work with county health centers, the Area Agency on Aging, and community senior centers and groups, other key leaders hear about our research efforts and reach out to us to discuss our findings with their community and to create programs in their centers based on these findings.

In conclusion, this population is one in great need of mental health services and evaluation of those services. Working with this population is difficult but rewarding in the end.
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