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## Eligibility, Recruitment, and Retention of African Americans with Severe Mental Illness in Community Research

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Abstract: Data that addresses severely mentally ill (SMI) African Americans (AAs) likelihood to participate in clinical research is limited. This study's purpose was to determine if differences exist between races regarding eligibility, recruitment, and retention in a community-based clinical trial. The sample included 293 participants. Data sources included clinical records and interviews. Logistic regression was used for analysis. AAs were as likely to participate and to complete follow-up interviews as Whites. In contrast to studies about non-mentally ill AAs, AAs with SMI appeared to be as willing to consent to and to remain in clinical research studies as Whites.



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## Introduction

Since the National Institutes of Health published guidelines for the inclusion of women and minorities in 1993 (NIH, 2001), there has been not only interest in increasing study participation of underrepresented groups, but also the requirement to do so in order to receive federal research funds. African Americans (AAs) are of particular interest because several studies have reported that AAs might be unwilling to participate in research studies (Connell *et al.*, 2001; Fouad *et al.*, 2000). In studies including subjects diagnosed with mental illness, participation can be further limited by symptoms that make it difficult to engage interpersonally, such as paranoia or suspiciousness. These particular symptoms were attributed to AAs with severe mental illness (SMI) more often than other racial groups in a number of studies (Barrio *et al.*, 2003; Trierweiler *et al.*, 2000) and could potentially reduce their willingness to participate in research. In order to answer any questions about health status and health care delivery in traditionally underrepresented groups in scientific research, it is imperative that adequate numbers of subjects representing diverse racial groups and diagnostic categories can be recruited and retained.

Studies on differential rates of service utilization concluded that AAs were more likely to use inpatient or emergency services (Chow *et al.*, 2003; Lehman *et al.*, 1999; Snowden *et al.*, 1995; Whaley, 2004) and fewer outpatient services (Barrio, 2001; Kuno & Rothbard, 2002; Sullivan & Spritzer, 1997; Thompson *et al.*, 2003) when compared to Whites. It is possible that differential rates of service utilization among participants in these studies might be related to the service setting, inpatient versus outpatient.

In inpatient studies by Chen *et al.* (1998) and Neighbors *et al.* (2003), participant populations consisted of equal or greater proportions of AAs (52% AA vs. 36% White and 81% AA vs. 19% White, respectively). In outpatient studies by Snowden *et al.* (1995) and Zhang & Snowden (1999), proportions of AAs were considerably lower (10% vs. 66% and 19% vs. 70%, respectively). Since recruitment and retention were not the focus of these studies, it is difficult to interpret the meaning of these proportions. It is unknown if they reflect a difference in the demographic make-up of the pool of potential participants, a difference in utilization of services between racial groups, differences in willingness to participate, or differences in the likelihood of those enrolled continuing to study completion.

Studies specifically focusing on recruitment and retention of AAs have largely been conducted on non-mentally ill populations. In these studies, evidence has indicated that AAs might be less likely to participate in clinical research under certain conditions. Consequently, investigators might set recruitment goals for certain racial groups to ensure adequate numbers participate. Durant *et al.* (2007) studied 440 principal investigators that conducted clinical research in 2001 and found that 92% set goals for the recruitment of AAs. Among those who set goals, only 27% failed to meet the standard identified. Among the factors that affected the likelihood of meeting recruitment goals were: the type of study (observation studies were more likely to meet goals vs. Phase III clinical trials that were less likely to meet goals) and identification of barriers to study completion (Durant *et al.*, 2007).

Specific barriers that researchers reported for AAs in studies involving the non-mentally ill population included: fear of exploitation (Gooden *et al.*, 2005), distrust of

experimental treatments in clinical trials (Sengupta *et al.*, 2000), and lack of information about the study (Connell *et al.*, 2001; Fouad *et al.*, 2000; Gooden *et al.*, 2005).

Furthermore, high levels of religiosity (Fouad *et al.*, 2000), difficulty with transportation (Sengupta *et al.*, 2000), and general reluctance to seek medical care (Connell *et al.*, 2001) were also identified as barriers. There is limited information on the research participation of individuals with SMI and even less addressing recruitment and retention of individuals with membership in both underrepresented groups, specifically AAs with SMI. The purpose of this study was to determine if there were significant differences between AAs and Whites with SMI with respect to three aspects of recruitment and retention in a community mental health study: eligibility to be approached, recruitment versus refusal, and retention in the study after consent and enrollment.

## Methods

This study used a cohort design to describe recruitment and retention of subjects in a randomized trial that took place between June 2001 and June 2004. The following sections briefly describe subjects, protocol, and data collection procedures from the randomized trial that are relevant to this study. Detailed methodology and results of the randomized trial have been published elsewhere (Chafetz *et al.*, 2007).

### *Participants*

Participants were recruited for a randomized clinical trial (RCT) from four Crisis Residential Units (CRUs) operated by Progress Foundation that provided short-term residential care as an alternative to hospitalization for voluntary patients. These CRUs are dispersed throughout San Francisco and serve the SMI population. Its residents approximate a treated community sample. Participants were included if they were of age



≥ 18 and able to speak English, and excluded if they had a diagnosis of dementia, other cognitive disorder, or a diagnosis of adjustment disorder with no previous history of SMI.

### *RCT Protocol*

Following informed consent and enrollment, subjects were randomized into one of two groups: usual care in the community (control group) or usual care with Wellness Training (intervention group). The intervention was a 12-month service provided by advanced practice psychiatric nurses to assist community dwelling individuals after they were released from the CRU to identify, prioritize, and manage physical health conditions. Outcomes included improvement in perceived health status, quality of life, physical functioning, and health service utilization, with interviews at baseline, 6, 12, and 18 months. Institutional review board approval was obtained for both the original randomized trial, described elsewhere (Chafetz et al., 2007; Chafetz *et al.*, 2006) and data analysis for this study.

*Recruitment and retention procedures during the RCT.* This study was a collaboration between researchers at the university and Progress Foundation. A mutually beneficial primary care practice run by the faculty and nurse practitioner students provided services to the program clientele while students developed skills in service provision.

Potential participants were asked about interest in the study by CRU staff during routine admission procedures. Research assistants (RAs) made contact with those expressing interest, obtained informed consent, and conducted baseline interviews. Follow-up interviews were conducted in the community at a time and place convenient to the participant. Participants were compensated \$15 for each interview.

An assertive approach was used to locate and retain subjects. Upon enrollment, RAs inquired about contact information including information on address, personal telephone number, and e-mail address. Calls were made and sealed (confidential) letters were sent to these numbers and addresses. Participants also nominated people who could be contacted in efforts to find them; including family members and friends. Mental health service providers were often the best personal contacts for residentially unstable individuals.

Participants were also located through mental health service utilization (MHSU) data including both acute and outpatient services that were billed to the county. RAs contacted participants directly at these sites (e.g. patient telephone) or left messages in care of the program in sealed envelopes. Other follow-up efforts included visits by RAs to treatment programs, homeless shelters, and familiar community congregation sites; sometimes leaving sealed messages at these sites.

Pamphlets and business cards that displayed the study's name and telephone numbers to reach the RAs were also distributed to subjects. RAs carried cellular telephones and could be reached directly by the participants during normal business hours or could leave messages in the evening.

#### *Recruitment and Retention Study Procedures*

*Data.* The dependent variables for this cohort analysis were eligibility to be approached according to the study protocol; recruitment in the study by completion of consent and enrollment procedures; and retention in the study, measured by completion of one, two or three follow-up interviews (at 6, 12, and/or 18 months) as compared to completion of only the baseline interview at enrollment. The primary independent

variable was race, AA versus White, collected by self-report in the baseline interview for those who participated in the study and as recorded in the CRU clinical record for those who refused or were ineligible for the study. Participants of all racial categories other than AA or White were excluded from this sample.

Covariates related to eligibility and recruitment included gender, psychiatric diagnosis (schizophrenia or other), and recruitment site (CRU) and came from admissions data from Progress Foundation. Covariates for the analysis of retention came from self-report during the structured interview at enrollment, and included gender, diagnosis, recruitment site (CRU), housing status (four levels from homelessness to independent living), education (high school diploma, yes or no), income ( $< \$500$  or  $\geq \$500$  per month), partnership status (yes or no), and treatment group (in the RCT). Perceived physical condition and perceived emotional condition were measured by participant responses to 2 items from the Quality of Life Interview where they rated their satisfaction with physical and emotional health according to a 7-point Likert scale (Lehman, 2000). These responses were dichotomized for analysis to reflect satisfied to very satisfied and neutral to dissatisfied. Other variables included having a primary care provider (yes or no), family contact in the last 30 days (yes or no), and substance use as measured by participants' response to two items regarding reported alcohol or drug problems in the last 30 days (yes or no). The items about alcohol and drug problems were taken from the Addiction Severity Index (McLellan, 2000).

*Analysis.* To answer the question about eligibility, variables that were available included race, gender, and CRU site. To answer the question about recruitment, individuals who consented and enrolled in the study were compared to those who refused

to participate. Analyses controlled for sociodemographic and health-related variables. To answer the question about retention, enrolled subjects who completed the baseline interview only were compared to those who completed one, two, or three follow-up interviews. These analyses also controlled for other variables that might explain retention. For each analysis, bivariate categorical variables were analyzed using chi-square tests and continuous variables using t-tests and Mann-Whitney U-tests. Variables that were significant at the  $\alpha=.05$  level were selected for inclusion in a logistic regression. Odds Ratios (OR) and 95% confidence intervals (CI) were generated for each predictor included in final regression models. Analyses were conducted using the Statistical Package for the Social Sciences (SPSS), version 13.

## Results

### *Eligibility*

A total of 527 potential subjects were approached for recruitment. Fifty-six were ineligible. Of those eligible, 193 were White and 100 were AA. In bivariate comparisons by race, those eligible for recruitment differed with regard to psychiatric diagnosis and recruitment site (see Table 1). AAs were nearly twice as likely as Whites to have a diagnosis of a schizophrenia-spectrum disorder (OR 1.82, 95% CI 1.11-2.98,  $p=.02$ ). The mean age of subjects eligible for recruitment was 39.54 (SD=9.71) for AAs and 39.32 (SD=10.30) for Whites. There were no significant gender differences.

### *Recruitment*

Among eligibles, 132 Whites and 73 AAs agreed to participate for a 68% recruitment rate for Whites and a 73% recruitment rate for AAs. Bivariate analyses of predictors of enrollment versus refusal were entered into a logistic regression and results

are presented in Table 2. Males were 1.78 times more likely to enroll (95% CI 1.03-3.10,  $p=.04$ ) and individuals with schizophrenia-spectrum disorders were less likely to enroll than those diagnosed with other disorders (OR .35, 95% CI .20-.58,  $p<.0001$ ). AAs were 1.52 times more likely than Whites to enroll, but this was not statistically significant (95% CI .87-2.68,  $p=.14$ ).

### *Retention*

All participants, 132 Whites and 73 AAs, completed baseline interviews. Twenty-one percent ( $n=15$ ) of AAs completed one follow-up interview, 16% ( $n=12$ ) completed two, and 34% ( $n=25$ ) completed three follow-up interviews. Seventy-one percent ( $n=52$ ) of AA participants were considered retained, compared to 29% ( $n=21$ ) who completed the baseline interview only. The percentage of Whites who completed one, two, or three follow-up interviews was 13% ( $n=17$ ), 17% ( $n=22$ ), and 30% ( $n=39$ ), respectively. Fifty-nine percent ( $n=78$ ) of White participants were retained, compared to 41% ( $n=54$ ) who completed the baseline interview only. There were no significant differences in the number of follow-up interviews by race in bivariate analyses and no differences regarding substance use, income, education, family contact, or satisfaction with physical or emotional health between participants who were retained compared to those who were not retained.

However, participants who completed baseline interviews only versus one or more follow-up interviews differed significantly by diagnosis and perceived physical condition. Participants who perceived their physical condition as neutral to dissatisfied were 2.15 times more likely to complete follow-up interviews than those who were satisfied to very satisfied with their physical condition (95% CI 1.20-3.86,  $p=.01$ ) and

participants diagnosed with schizophrenia were 1.93 times more likely to complete one or more follow-up interviews compared to those with other diagnoses (95% CI 1.01-3.69,  $p=.05$ ). Both variables remained significant in a logistic regression analysis, controlling for ethnicity (Table 3).

## Discussion

In this study of eligibility, recruitment and retention of adults with severe mental illness in a community-based RCT, race was not found to be a significant predictor. While this study replicated racial differences with regard to diagnosis, when controlling for sociodemographic variables, race was not among the variables that significantly predicted willingness to enroll or to complete follow-up interviews. Moreover, recruitment rates were high for both AAs (73%) and Whites (68%), as were retention rates in this vulnerable population of SMI adults (71% AAs, 59% Whites).

Whereas studies of non-mentally ill populations have identified multiple barriers to participation in clinical research among AAs when compared with Whites, this study found participation rates to be equal between the two racial groups. In a study of 379 NIMH-funded clinical trials, Mak *et al.* (2007) found that AAs were actually overrepresented in these clinical trials compared to other ethnic minority groups indicating that the assumption of reluctance to participate in this population may be unfounded.

AA and White participants in this study who were recruited and retained were also comparable on baseline measures of substance use, income, and education. Other studies have reported that AAs with SMI have higher rates of substance use (Montross *et al.*, 2005) and lower socioeconomic status (Chung *et al.*, 1995; McAlpine & Mechanic,

2000). The lack of difference in these areas in this study might indicate that in this sample, participants in both racial groups were equally disadvantaged.

In this study, females were less likely to consent to participate in the study. Similar findings were reported by Robinson *et al.* (1996) in the Treatment Strategies for Schizophrenia study, a RCT that compared three antipsychotic drug treatment conditions combined with psychoeducational family therapy approaches. However in that study, women's higher likelihood of refusal may have been related to the exclusion of pregnant females and the use of medications in the study protocol. Since the data presented here were not obtained in a medication study, this rationale would not apply and no other studies published within the past 10 years were located that explained gender differences in recruitment among the SMI.

Participants with schizophrenia were also less likely to consent than participants diagnosed with other disorders. Our findings are in agreement with those of Thompson *et al.* (1996), who found that a diagnosis of schizophrenia compared to a diagnosis of depression was the most significant predictor of likelihood to refuse to participate in the study. One possible explanation could be found in a study conducted in Germany in which Riedel *et al.* (2005) reported that patients who had a formal thought disorder, were suicidal, or had the negative symptoms of schizophrenia (i.e. flat affect, social withdrawal, amotivation) were less likely to participate. It is possible that individuals with schizophrenia who refused to participate in our study were also experiencing negative symptoms. Aversion to social contact associated with negative symptoms of schizophrenia may have deterred some individuals from participating in the study. This should be explored further.

Conversely, among those who enrolled in the study, participants diagnosed with schizophrenia were more likely than those with other diagnoses to complete one or more follow-up interviews. Furthermore, subjects who were neutral to dissatisfied with their physical condition were also more likely to continue in the study than those who were satisfied to very satisfied. It is possible that individuals who were retained believed that they would receive a benefit from participating, i.e. they possibly viewed their contact with the RAs and intervention providers as a service or a means to obtain services. The results of a study of women at risk for and infected with human immunodeficiency virus support this assertion. Although the study required a heavy burden of frequent physicals, gynecologic exams, and specimen collections, the overall retention rate was 82% (Hessol *et al.*, 2001), suggesting that individuals in need of health services might participate in research as a means to access care. This is an area that requires further inquiry in the SMI population.

This study was relatively successful in recruiting and retaining AAs despite considerable challenges that exist with conducting community-based research among the SMI. The success might be attributed to the use of assertive recruitment and retention methods and the mutually beneficial relationship with the community agency, Progress Foundation. The approach utilized for this study was similar to the “CPR” model described by Spruill (Spruill, 2004). The “C” represents community and the efforts of the researchers to get involved in the community from which the sample was recruited. The “P” represents planning for the provision of benefits tailored to the unique qualities and needs of the community. And the “R” represents rewards, described as tangible benefits to the community that include, but are not limited to financial compensation.



Other studies have reported success using similar methods. Researchers that used a face-to-face approach for recruitment found rates ranging from 48% to 86% for AAs. These rates were similar to or exceeded those for Whites recruited in this way (Arean *et al.*, 2003; Blumenthal *et al.*, 1995; Gilliss *et al.*, 2001). This indicates that the ability of the staff to relate socially to potential subjects by way of personal qualities may be of importance in these populations.

Other studies have also reported similar means of tracking subjects as used in this study as successful means of promoting retention. These methods have included persistent phone calls (Blumenthal *et al.*, 1995; Dilworth-Anderson & Williams, 2004; Hessol *et al.*, 2001), home visits, outreach to neighbors and the community, visits to institutions and shelters, and the use of letters (Blumenthal *et al.*, 1995; Dilworth-Anderson & Williams, 2004; Hessol *et al.*, 2001; Menendez *et al.*, 2001). Flexibility of scheduling and rescheduling missed appointments was also reported as an important means of improving retention (Dilworth-Anderson & Williams, 2004). Several studies have also reported that the use of a community advisory board or gatekeeper in an therapeutic setting (similar to the partnership between the university and community agency) has been reported to be critical in gaining the trust and cooperation of community leaders, facility staff, as well as potential subjects (Arean *et al.*, 2003; Gooden *et al.*, 2005; Julion *et al.*, 2000; Thompson *et al.*, 1996). Strategies used in this study and in other studies may be more important in minimizing the effect of race in study participation, and these strategies warrant further research.

#### Limitations

Because the primary focus of the randomized trial was to test the intervention, there were no controls in place to determine the relative influence of the various methods of recruitment and retention on the rates obtained. As a result, it cannot be determined the extent of influence, if at all, any one particular method might have had on the success of recruitment or retention efforts.

### Conclusions

This study found that among individuals with SMI, African Americans are both eligible for and willing to participate in community research over time. Several methods of recruiting and retaining subjects were implemented in this study; but more is needed to explain if the rates that were achieved were the result of the nature of the study itself, the methods used to recruit and retain, or the conditions being studied. These findings, however, suggest that AAs can be well represented in community-based studies of the SMI.

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Table 1. Comparisons of Eligible Individuals Approached for Recruitment in a Randomized Trial by Race

Variable	Race		$\chi^2$	p
	African American (N=100) %	White (N=193) %		
Gender				
Male	71	66	.77	.38
Female	29	34		
Diagnosis				
Schizophrenia spectrum	48	34	5.70	.02
Other	52	66		
RTP				
Site A	27	24	10.15	.02
Site B	15	29		
Site C	35	22		
Site D	23	25		

Table 2.  
Recruitment of Subjects with Severe Mental Illness in a Randomized trial by Race, by Logistic Regression

Independent Variable	Recruitment		
	Odds Ratio	95% CI	p
Race			
African American	1.52	.87-2.68	.14
White	1.00		
Diagnosis			
Schizophrenia spectrum	.35	.20-.58	<.0001
Other	1.00		
Gender			
Male	1.78	1.03-3.10	.04
Female	1.00		



Table 3. Completion of One or More Follow-Up Interviews Compared to Completion of Only the Baseline Interview, in Subjects with Severe Mental Illness Enrolled In A Randomized Trial, by Logistic Regression

Independent Variable*	<i>Retention</i>		
	Odds Ratio	95% CI	p
Race			
African American	1.64	.87-3.11	.13
White	1.00		
Diagnosis			
Schizophrenia spectrum	2.17	1.10-4.31	.03
Other	1.00		
Perceived physical condition			
Satisfied to very satisfied	.40	.22-.73	.003
Neutral to dissatisfied	1.00		

\*All variables significant at  $\alpha=.05$  were entered into the logistic regression and are presented; race was forced into the model.

June 20, 2008

Editor, Community Mental Health Journal

Dear Dr. Feldman:

We would like to thank you for your review of our manuscript, "Eligibility, Recruitment, and Retention of African Americans with Severe Mental Illness in Community Research (#COMH334)." We have made the revisions suggested by Reviewer #2 (Reviewer #1 requested no changes) and our responses are detailed below.

1. I noted only two minor issues that need a little work, both in the discussion. In the first sentence the authors state that "race did not influence participation." What they mean, of course, is that given their statistical power, they did not see a significant effect of race on participation after controlling for relevant non-race variables that were significantly predictive of participation. That still does not clinch the null hypothesis absolutely, of course. Their overall argument that African Americans were not excluded from the study is very strong, primarily because their raw rates of inclusion and retention were higher among African Americans. I presume that was driven primarily by the large minority population in San Francisco.

*The following sentence was revised removing "race did not influence participation" and replacing it with the following to be more accurate in reporting the findings of the study. "While this study replicated racial differences with regard to diagnosis, when controlling for sociodemographic variables, race was not among the variables that significantly predicted willingness to enroll or to complete follow-up interviews." The minority population of San Francisco was not discussed, however, as the African American population in San Francisco is less than that of the United States overall (9% vs. 13%).*

2. A very minor issue on the following page is that they incorrectly characterized the Treatment Strategies in Schizophrenia study (Robinson et al., 1996) as comparing "antipsychotic drug treatment to psychoeducational family therapy." It was a crossed randomization, in which enrollees were randomized among 3 double-blind drug conditions (full-strength depot fluphenazine, low-dose depot fluphenazine, or placebo) with blinded rapid open medication if worsening occurs) crossed with open randomization to frequent in-home family management treatment versus one baseline multiple-family educational session. One might say that the study "examined the interaction of different depot antipsychotic dosing with different levels of family support." Recruitment of minority patients in that trial was aided by most of the five sites being inner-city hospitals with a large

minority clientele.

*The following sentence was revised to correctly state the methods of the TSS study: "Similar findings were reported by Robinson et al. (1996) in the Treatment Strategies for Schizophrenia study, a RCT that compared three antipsychotic drug treatment conditions combined with psychoeducational family therapy approaches." We wanted to state this as concisely as possible for the purpose of illustrating that this was a medication study and commonly these studies might have difficulty recruiting or retaining African Americans.*

3. I wonder if the choice of sites for cross-cultural studies might be worth mentioning in this context. If one wants to have enough minority participants in a study, they had better do the work in communities with a large minority population. Even that doesn't always work. This reviewer once helped with a cross-cultural (Anglo vs. Vietnamese-American) study of families with a schizophrenic member in a city with a very large Vietnamese population. Many Vietnamese families agreed to participate but then dropped. The unanticipated cultural issue was the strong prohibition of being rude to a person of authority. The family would not refuse the study to the psychiatric social worker or psychologist recruiting them. But participation required transferring their son or daughter to a university psychiatrist, and they would not be so rude to their current community psychiatrist. I don't think this has been published, but if the author is interested, make this known to the editor and I will inquire to see if there is a usable citation.

*While we find this information valuable and appreciate the reviewer's offer, much of the literature supports dramatic differences between minority groups that were born in the United States compared with those who were born in foreign countries. We don't believe that this work would be applicable to this particular sample.*

We appreciate the opportunity to revise and resubmit this manuscript and thank you for your further consideration. We look forward to your final decision. Please contact me with any further questions or comments.