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EVALUATION OF A BRIEF QUESTIONNAIRE FOR ASSESSING BARRIERS TO RESEARCH PARTICIPATION

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Racial minority groups are often underrepresented in biobehavioral research. Mistrust stemming from historic abuses of minority research participants is one explanation for this problem. Although mistrust and other variables affect dispositions toward research, brief, quantitative measures of these factors have not been available to researchers in assessing potential recruitment barriers. The present paper is a description and psychometric examination of the Barriers to Research Participation Questionnaire (BRPQ), a new survey designed to assess five factors that affect research participation (religious beliefs, mistrust, health-related fears/beliefs, role overload/time demands, and perceived personal and community benefits). Good model-fit for the proposed five-factor structure and good test-retest reliability were observed among African American undergraduate men and women at an urban, primarily African American university. The BRPQ appears to be a reliable and valid tool for researchers to use in identifying barriers to recruiting African American participants. (*Ethn Dis.* 2006;16:547-550)

Key Words: African American, Assessment, Barriers, Minority, Research Participation

INTRODUCTION

Apprehension about participating in research and unwillingness to participate have been reported among African American adults.¹⁻⁵ Difficulties recruiting adequate samples from minority groups often limit the conclusions of biobehavioral research and the ability of study findings to improve health services for minority populations.^{2,6,7} Despite a growing literature addressing potential barriers and facilitators for research participation, no brief quantitative measures of these factors have been available to researchers in assessing potential recruitment barriers.^{2,5}

Historical abuse of African American participants in government-sponsored research has led to mistrust of the scientific community for African Americans.^{1,2,8} Research with a medical or biological focus reminds many African Americans of the Tuskegee Syphilis Study, which examined untreated syphilis from 1932 to 1972.⁹ In the Tuskegee study, African American men who were fatally ill were not provided appropriate treatment options. An example of the effects of past harms on current trust levels is the finding that a subset of the African American community perceives HIV/AIDS to be a weapon produced as part of a government conspiracy against African Americans,⁹⁻¹¹ a belief that would interfere with participation in HIV prevention research. African Americans are more likely than Caucasians to be concerned that physician researchers will not fully explain research and would expose participants to unnecessary risks.¹ Of the potential barriers to research participation, mistrust has received the

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most attention.^{1-5,8} While level of trust plays a key role in the sentiments of African Americans toward research, a number of other factors likely affect participation.

Health-related fears/beliefs, such as fear of becoming aware of a chronic health problem or fear of experimentation and after-effects, may affect dispositions toward research for African Americans.^{2,4,8} One seemingly understudied factor in research participation is religious beliefs. Some individuals may have difficulty balancing religious beliefs with acceptance of scientific research. Research may be perceived as undermining the power of God. Despite the role religion plays in most African American communities, this factor has not been examined in relation to research participation. Another potential factor in participation is perceived benefits.⁸ Studies often provide incentives to participants, such as free services or a small reward. Older African Americans have identified lack of such tangible benefits as a barrier to participation in clinical research.⁴ Other incentives, however, are not obvious and tangible. For example, some research participants volunteer to help

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gain knowledge that will help others—either at-risk persons or the community as a whole.² Finally, role overload (ie, perception of serving in too many social/occupational roles) could impede participation in research. Schedule conflicts are a commonly cited reason for not being able to participate.^{2,8} Older African Americans have cited caregiver obligations as a barrier to research participation.⁴ Older African American women commonly assume many social roles.¹²

The present study focuses on the psychometric examination of the Barriers to Research Participation Questionnaire (BRPQ), a new brief survey designed to inform researchers about potential obstacles in recruiting research participants from minority groups. The primary objectives of this study were to assess the factor structure and test-retest reliability of the BRPQ within a large sample of African American undergraduates. A secondary objective was to conduct a descriptive analysis of response patterns, examining which potential barriers were endorsed most often.

METHOD

Participants

The participants were 231 African American undergraduates at an urban, primarily African American university (member Historically Black Colleges and Universities) in the southern United States. The mean age was 22.2 years (standard deviation [SD] 6.0 years, range 18–50 years). Although participant sex was not recorded, both men and women were well represented. Participants were primarily selected based on their enrollment in general psychology classes (a course composed of a wide range of nonpsychology majors and generally composed of relatively equal numbers of men and women). Approximately one quarter of the sample was selected based on their

enrollment in other introductory-level psychology classes composed of psychology majors and nonpsychology majors. These classes tended to have a higher female-to-male ratio.

The mean age of a subsample of participants who completed a three-week test-retest reliability assessment was slightly higher (24.8 years, SD 8.3 years) than that of the total sample. Otherwise, participants for the reliability assessment were recruited in the same manner as the total sample from the classes described above.

Measures

Barriers to Research Participation Questionnaire

Based on the literature addressing African Americans' attitudes and beliefs toward research, the 17-item BRPQ was designed to be a brief screen for identifying recruitment obstacles during the development or implementation stages of studies. Five domains are addressed by the BRPQ: items 1–4 pertain to religious beliefs inconsistent with research, items 5–9 to mistrust, items 10–12 to health-related fears/beliefs, items 13–15 to role overload/time demands, and items 16 and 17 to perceived incentives (see Table 1). In developing the BRPQ, we adapted items from previous research assessing barriers to participation as well as constructing items on our own. Four of the mistrust items were generated by Armstrong et al⁸ in the course of their qualitative and survey research of attitudes toward medical research. With the exception of item 14, respondents rate each item on a five-point scale (1=strongly agree, 2=agree, 3=neither agree or disagree, 4=disagree, or 5=strongly disagree). Aside from items 11, 14, and 15, each item is phrased so that agreement is indicative of a barrier to research participation. Items 11 and 15 are reverse-scored. On item 14, respondents identify up to 10 listed social and occupational roles (eg, stu-

dent, full-time employee, child-caregiver) that apply to them, and this item is scored 1 for five or more roles, 2 for four roles, 3 for three roles, 4 for two roles, and 5 for one role or no roles (ie, it is also reverse-scored). The score for each item is then summed for a total BRPQ score that can range from 17 to 85; the lowest scores reflect the most potential barriers.

Procedure

In classroom settings, participants completed a questionnaire packet that included a written informed consent, indication of the participant's age, the BRPQ, and two other questionnaires that are not a focus of the present paper. Participants were informed that anonymity would be preserved by separating the signed consent form from the questionnaire data and assigning an identification number before any examination of the responses.

RESULTS

Psychometric Analyses

Confirmatory factor analysis (CFA) using PROC CALIS in SAS (SAS Institute, Cary, NC) to examine whether the observed data reflected the five proposed latent constructs indicated good model fit (chi-square=5.961, $df=5$, $P>.10$; root mean square error of approximation [RMSEA]=.0289; goodness-of-fit index=.9896). The loadings for each item on its respective factor are depicted in Table 1. Because a negative loading was observed for item 15, and any negative loading is inconsistent with the item's intended contribution to the underlying factor structure, the CFA procedure was repeated without including item 15. The results of the revised CFA using only the remaining 16 items also indicated good model fit (chi-square=8.040, $df=5$, $P>.10$, RMSEA=.0514, goodness-of-fit index=.9855). Therefore, the remaining analyses were conducted by

Table 1. Loadings for each of the 17 BRPQ items on their respective factors

Item	Factor				
	Religious Beliefs	Mistrust	Health Beliefs/ Fears	Role Overload	Perceived Benefits
Illness and death are God's will and are not necessarily affected by research	.75				
God determines wellness, not the results of research	.80				
Researchers sometimes undermine the power of God and prayer	.62				
Science and research harm the reputation of God and make people skeptics of His existence and power	.57				
The government sometimes exposes participants to agents known to be harmful to one's health		.46			
Research is part of a conspiracy to negatively affect the health of ethnic minority groups		.71			
Researchers sometimes hide information from participants prior to research		.68			
Researchers are motivated by their own career goals and not the welfare of human participants		.73			
Being paid to participate in research makes me suspicious of the project		.56			
Research could provide information about my health that I would rather not know about			.52		
I would want to be notified if I had a fatal illness			.76		
I would be better off not knowing about health problems I could have			.81		
It would be difficult to find time to participate in a research study				.69	
These roles sometimes occupy much of people's time. Please indicate which roles apply to you				.43	
I would neglect some of my responsibilities at school, home or work to participate in research				-.68	
There is not anything for me to gain by participating in research					.90
There is not anything for my community to gain by participating in research					.90

BRPQ=Barriers to Research Participation Questionnaire.

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using a revised BRPQ excluding item 15. Eliminating item 15 left only items 13 and 14 to load on the role overload/time demands factor, and their new equal loadings were .72.

The results indicated good three-week test-retest reliability for the subsample of 33 participants ($r=.80$). Internal consistency of the 16-item BRPQ in the total sample was marginal ($\alpha=.63$).

Descriptive Data

Results are presented as mean \pm SD. Examination of the data for each factor revealed that the religious beliefs inconsistent with research factor had the lowest ratings, reflecting potentially greatest barriers ($2.27 \pm .75$), followed by mistrust ($2.85 \pm .57$), role overload

($3.51 \pm .76$), perceived benefits ($3.69 \pm .76$), and then health beliefs ($3.92 \pm .71$). The differences between factor means were all significant ($P<.01$ except difference between role overload and perceived benefits, $P<.05$).

Because of the potential for age/generational effects to affect barriers to research participation, the descriptive analyses were repeated without including the data from a small subsample of participants who were in the 30- to 50-year age range (10.4% of the total sample). Results for the remaining 207 participants were very consistent with the analyses for the total sample, and the ordering of barriers remained unchanged: religious beliefs inconsistent with research ($2.22 \pm .72$), followed by

mistrust ($2.86 \pm .54$), role overload ($3.60 \pm .72$), perceived benefits ($3.66 \pm .75$), and then health beliefs ($3.91 \pm .70$). The only change to the results pertaining to differences between factor means was that the difference between role overload and perceived benefits was no longer significant. All other differences between the factor means were significant ($P<.01$).

DISCUSSION

Based on the results of the present paper, the BRPQ appears to be a reliable and valid tool for identifying barriers to recruiting African American participants. Use of a scale like the BRPQ

may assist researchers in developing better quantitative models for understanding the factors associated with research participation by individuals of ethnic minority groups.

The results suggest that a revised 16-item scale (excluding item 15) provides a more sound and efficient method of assessing the role overload factor. Using the word "neglect" for item 15 may have elicited responses that were not consistent with the originally intended purpose. Participants may have been stigmatized by the negative connotation of neglect and consequently had trouble answering that question objectively.

The present findings also suggest that factors such as religious beliefs, which have not received attention in this literature, may be important in the attitudes of African Americans toward research. Examination of the response distribution for religious beliefs indicated that most respondents agreed with beliefs that appear to be inconsistent with tenets of scientific research. Therefore, whether this variable actually distinguishes research volunteers from nonparticipants who decline, or simply reflects fairly universal sentiments that are inconsequential for willingness to participate, remains to be determined. The data distributions also revealed that a significant minority of respondents agreed with items related to mistrust and role overload. Both findings are consistent with prior research on barriers to participation.^{1,2,8}

Further study is needed to determine the BRPQ's predictive validity (ie, whether the five factors actually predict

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participation in research) and utility for other minority groups and geographic regions. With regard to predictive validity, a respondent could agree with an item or set of items that make up a BRPQ factor score, yet still be willing to participate in a study despite reservations. Conversely, a respondent's concerns could appear to be minor as reflected by a BRPQ factor score, yet be sufficient to result in nonparticipation. Thus, future studies can elaborate on the processes involved in decision-making with regard to research participation.

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