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## Attaining Gender and Ethnic Diversity in Health Intervention Research: Cultural Responsiveness versus Resource Provision

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Despite the National Institutes of Health (NIH) mandate to include women and diverse ethnic groups in all NIH-funded research projects, these groups are still excluded as participants in health intervention research. This exclusion has denied them access to state-of-the-art treatments and prevention strategies, making them vulnerable to increased morbidity and mortality and decreased longevity. This article compares two conceptual approaches to inclusion: cultural responsiveness and resource provision. Several issues are raised as to why women and ethnic people of color are not involved in health intervention research. For each of these issues, an appraisal is made as to whether cultural responsiveness or resource provision would more successfully address the problem. It is concluded that cultural responsiveness facilitates participation in research but is not sufficient. An equally important, if not more important, approach may be the provision of resources to empower participants to address problems of access and burden.

In 1994 the National Institutes of Health (NIH) mandated that women and members of diverse ethnic groups be included in all NIH-funded research projects involving human participants unless a clear and compelling rationale justified their exclusion. <sup>1</sup> The population of the United States is made up of 52% women and 28% ethnic groups other than Whites. <sup>2</sup> Prior to 1994, the majority of studies on the health of Americans was conducted in academic medical centers and focused on a limited segment of the US population: middle class, married, White males, or did not report ethnicity or gender at all. <sup>3,4</sup> Since the NIH mandate, there has been a greater effort to involve women and ethnic people of color in research, but that effort still falls far short of its mark. For example, women with life-threatening illnesses who are of reproductive age have been excluded from clinical

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trials by research groups and pharmaceutical companies despite a Food and Drug Administration regulation against these practices. [5,6](#) As another example, AIDS data show that women, African Americans, and Latinos lag behind White men in access to studies of protease inhibitor therapy, clinical trials, medical services, and prevention programs. [7-9](#) The exclusion of women and ethnic people of color from state-of-the-art health intervention research makes them vulnerable to increased morbidity and mortality and decreased longevity. [7,9,10](#)

A plethora of articles on the subject of gender and ethnic diversity since the NIH mandate attests to the efforts made to include women and ethnic people of color in health intervention research and the methodologic problems that investigators are facing in doing so. Many investigators have reported various efforts, methods, problems, and strategies for recruitment, retention, and intervention with women and culturally and ethnically diverse populations. [4,10-17](#) None of these reports has taken a conceptual approach to inclusion strategies or methods. The purpose here is to describe different conceptual perspectives on inclusion of women and ethnic people of color in health intervention research, summarize the various issues and problems surrounding inclusion, and explore which of the different conceptual perspectives would most successfully address the problems and issues raised.

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## CONCEPTUAL APPROACHES TO INCLUSION

Two different conceptual perspectives on the successful inclusion of women and ethnic people of color in health intervention research are explored. The first conceptual perspective is that of cultural responsiveness, and the second is that of resource provision.

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### Cultural responsiveness

The theoretical basis for the cultural responsiveness perspective comes from the theory of social influence proposed by Simons, Berkowitz, and Moyer [18](#); the theory of cultural responsiveness proposed by Sue and colleagues [19](#); and conceptualizations of cultural competence. [20,21](#) This perspective focuses on influencing the attitudes of community members in order to encourage them to participate in health intervention research. The theory of social influence proposes that source (researcher) credibility, attractiveness, and influence are a function of similarity between the source and the receiver (participant). Matching researcher and participant on particular variables such as gender, ethnicity, and language should increase understanding between the two groups and enhance cooperation and positive outcomes. However, social influence theory further proposes that attitude similarity is a more powerful determinant of attraction toward and influence by the source than is group membership. [18](#) From this perspective, matching should go beyond sociodemographic characteristics to include a more important match of values, beliefs, and attitudes between researcher and participant.

In developing their cultural responsiveness theory, Sue and associates [19](#) empirically tested a gender, ethnicity, and language match between researcher and participant and their effects on participation in the use of services. They concluded that these are distal variables and that their effects are less than that of proximal variables. Proximal variables include similar cultural attitudes, values, lifestyles, and ideologies. [19](#) These investigators proposed that even when ethnicity, language, and gender are matched, cultural mismatches can occur if researchers and participants show markedly different cultural values, ideologies, attitudes, and beliefs. The cultural responsiveness hypothesis has been empirically tested and supported. [19,22,23](#) Although distal variables (shared language, ethnicity, gender) have an effect on service use, proximal variables (shared values, ideology) have a significantly greater effect.

Conceptualizations of cultural competence further explain the cultural responsiveness perspective. Concept analysis of cultural competence in the researcher includes attributes of cultural knowledge, cultural sensitivity, and collaboration with participants. [20,21](#) These attributes in the researcher rather than a match on shared ethnic or gender identities between researchers and community members are believed to be persuasive in influencing participation in health intervention research. The cultural responsiveness perspective focuses on the shared knowledge, attitudes and values, and collaborative practice of researchers and participants recognizing that these may be facilitated by shared gender, ethnicity, and language.

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#### Resource provision

The vulnerable populations model provides a contrasting conceptual perspective on the inclusion of women and ethnic people of color in health intervention research. [24](#) This perspective focuses on the provision of economic and social supplies or resources to empower community members to participate in research. Resources include such things as income, education, and health insurance; social integration and status; and political, social, and interpersonal power. In the vulnerable populations model, resource availability is considered fundamental to involvement in prevention, screening and treatment research, and services. Social groups who are impoverished, marginalized, and disenfranchised lack the resources that provide them access to state-of-the-art health care and research. Evidence of their exclusion is seen in increased morbidity and mortality. [7-10,24](#) To increase the participation of women and ethnic people of color in health intervention research, they need resources-income, insurance, knowledge, skills, and power to affect their own lives and health care. This is especially true of low-income, marginalized women, and people of color. Lack of resources rather than contrasting values and attitudes prevent people from participation in health intervention research.

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### ISSUES IN RECRUITMENT, RETENTION, AND INTERVENTION

Among the issues raised as to why women and ethnic people of color are not included in health intervention research are problems with access, availability, and affordability. The burden and perceived lack of benefit of being involved in the research further hamper recruitment and retention efforts. Other issues raised are language and literacy problems. Cultural values, beliefs and attitudes, social priorities, and fear and distrust of health professionals are also factors said to limit inclusion in health intervention research. Finally, insensitive and depersonalizing approaches by health care providers, researchers, and the materials they use discourage participation.

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#### Access, availability, and affordability

Women and ethnic people of color are more likely to live in poverty than are men or Whites. [2](#) They are also more likely to be medically underinsured or uninsured than are men or Whites. [2,9,25,26](#) Lack of health insurance limits or prevents access to health intervention research that involves clinical trials of drugs and technologies, screening programs, and treatment protocols that require third-party payment. Many of these studies occur in academic medical centers that are not readily available because of geographic location, lack of money for transportation, the need for temporary housing and child care, and inability to take time off from work. [11,17,27](#) All of these factors related to access and cost serve to limit the numbers of low-income persons involved in research. In addition to the costs of insurance and the means and opportunity to get to the research site, other aspects of affordability are becoming apparent. A study of participants in Phase I cancer treatment clinical trials revealed that patients were getting much of their information and were enrolling through the Internet. [28](#) Impoverished

people would be limited or excluded in their access to information and participation in clinical trials through these means. Lack of access, availability, and affordability would exclude low-income and marginalized women and ethnic people of color from health intervention research, especially when it is conducted in academic medical centers.

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## Burden and benefits

For most participants in health intervention research, the major motivation is the perceived benefits involved. Benefits may include up-to-date screening techniques, cutting-edge treatment, quality of health facility and providers, financial incentives, and acting on a belief in science and the advancement of knowledge. [27-29](#) For those who are involved in clinical treatment trials, there is the hope of a cure and many are on a quest for treatment and for enrollment in clinical trials. [28](#) Secondly, there may be the motivation to help society or others with the same disease.

Persons not willing to participate may be afraid of side effects, may not want to be in the control group, or may believe that there are many burdens associated with the research. Burdens include cost, wasted time, loss of time at work, traveling long distances, dependence on family members, loss of dignity and energy, and disappointment with outcomes. These are the burdens experienced by White, middle class participants who share the ethos and values of the Western biomedical system (personal communication, J Murray, July 1998). For people who are poor and without insurance, transportation, and child care, the burdens of participation in health intervention research are overwhelming and certainly not a priority. Persons leading a day-to-day existence give priority to shelter, food, and clothing over health care and especially health intervention research. [11](#) Barriers to recruitment for clinical treatment research are great, but barriers to prevention and health promotion research are even greater. [27,30](#) Prevention research requires a longitudinal design and compliance with the protocol for many years. For persons whose priority is meeting daily needs, participation in research for prevention of a future, remote risk of disease is not a consideration. [31](#)

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## Language, literacy, and instruments

Both language and education provide an advantage to some social groups over others in access to state-of-the-art treatments and health care research. Language is important in both English and non-English speaking groups. Language may exclude persons from participation in research for many reasons. First, "medical" English and the medical practice of using acronyms are unintelligible to many lay people, even those who speak English. The use of this language by health care researchers tends to be exclusive. Medical consent forms are especially confusing and often scare people with the language used. [31](#) Attention to language spoken, literacy levels, and preferred medium for communication are also important aspects of encouraging participation in research. [32](#) Population-specific interventions in the forms of comic books, novellas, telenovellas, story telling, and oral traditions may be more persuasive with some groups. [33](#) Newspapers, radio, and television advertising have been recommended for recruitment of some.

The use of one form of a language may exclude participation. For example, all Latino ethnic groups do not speak the same form of Spanish. Translation of consent forms, instruments to be used during research, educational materials, and intervention materials may be particularly difficult when idiomatic equivalence that is based on ethnicity, social class, age, or geographic region is needed. [34](#) The use of idioms and slang may be essential to inclusion of some participants in research.

Ethnocentric biases in language also act to exclude participation. A particular problem is the assumption that concepts from one language can be directly

translated into another. In some languages, certain concepts do not exist. On the other hand, the concept may exist but the idioms for expressing or describing it may differ widely. <sup>33</sup> Response formats of instruments may create additional problems. The use of Likert scale formats may be culturally biased and exclusionary. <sup>35</sup> When language and education are not taken into careful consideration, they may act to exclude persons from participation in research.

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#### Cultural values and beliefs

The Western biomedical ethos is based on individualism, competitiveness, and materialism and is fueled by successes in vaccination and immunization, antibiotic and antiviral therapies, and laboratory and technologic advances in diagnosis and treatment. This approach stands in contrast to the cultural values and social realities of many ethnic groups and people in poverty. For many people, disease and death are thought of as natural occurrences and not something against which to wage a personal war. Putting oneself first, before the family, for costly treatments and time-consuming procedures and appointments, or aggressively pursuing treatment that often fails is considered unseemly, selfish, or even hysterical. <sup>29,36,37</sup> These values would inhibit involvement in clinical trials or experimental procedures and protocols that call for focusing on self without regard to family, costs, or outcomes.

Cultural beliefs or misperceptions about the course of illnesses (eg, cancers, HIV) may also limit participation in screening or prevention programs. <sup>38</sup> Beliefs that breast and cervical cancers are caused by trauma and sexual behaviors, that surgical treatments may cause the cancer to spread, or that HIV can be prevented by cleanliness and antibiotics may keep people from involvement in health screening and promotion research that does not address these issues. <sup>29,38</sup> In addition, cultural modesty and stigma may prevent some ethnic groups from being involved in research involving breast, cervical, or prostate cancer, or HIV. Cultural values and beliefs and social realities that contrast starkly with Western biomedical values play a role in excluding women and ethnic people of color from health care research.

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#### Lack of trust

Fear and distrust are also issues in recruitment and retention in health care research. The Tuskegee syphilis study; research on prisoners and the mentally disabled who are poor and non-White; different forms of genetic research; and racism, discrimination, and hate crimes have made American Indians, African Americans, Asian Americans, and the gay community distrust health professionals and health care researchers. <sup>14,32,39</sup> Many people see health intervention research on serious illnesses as a form of genocide, that is, a method for introducing illness into a community. Furthermore, Latino and Asian immigrants may distrust involvement with health care providers and researchers because they fear that they will be reported to the Immigration and Naturalization Service and may be deported. <sup>40</sup> People who distrust and fear researchers will be reluctant to participate in research.

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#### Insensitivity

Often health intervention is provided in an atmosphere that is depersonalizing, disrespectful, and insensitive to human dignity. Health intervention researchers share with providers these communication patterns that tend to exclude and discourage participation in research. Personalized approaches to recruitment and intervention, face-to-face communication, and a participant-friendly and compassionate system of research have been identified as important factors in encouraging participation in health intervention research. <sup>11,17</sup> Some investigators have found that participation and compliance are enhanced by the personal and visible involvement of the authority figure in the research project

(principal investigator) with the participants. [37](#) If this person is not involved, it demonstrates that she or he does not believe the project is important or that there is a lack of respect for participants. Insensitive communication will have the tendency to exclude participants from health care research.

Problems with access, language and literacy, the burdens associated with research involvement, different cultural values, lack of trust, and insensitivity of health professionals all contribute to low-income persons, women, and ethnic people of color being excluded from research. The question may be asked whether resource provision or cultural responsiveness would more successfully promote inclusion in research.

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## EMPIRICAL SUPPORT FOR INCLUSION APPROACHES

There is a limited amount of research and experiential evidence on the success of either a cultural responsiveness approach or a resource provision approach to the inclusion of women and ethnic people of color in health intervention research. There is less evidence of resource provision as an inclusion strategy than there is of a culturally responsive approach.

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### Resource provision

Most of the literature in this area examines the relationship between health insurance and access to health care, use of services, health status, and enrollment in health intervention research and state-of-the-art treatments. [9,12,25,26](#) The overwhelming evidence from these studies is that persons with the resource of health insurance have better access to care, better health status, better quality of care, greater use of health services, and greater participation in health intervention research than persons without insurance. In addition, people who are adequately insured do better on all of these indicators than people who are underinsured (public coverage only, eg, Medicare or Medicaid). Groups of people who are uninsured or underinsured have been identified as low income, the elderly, Latinos and African Americans, and women, especially those in female-headed households. [2,9,12,25,26](#) Studies of health insurance as a resource tend to be retrospective in their examination of possession of this resource in relation to health status and service use. No prospective studies were found in which health insurance was provided as a resource followed by an examination of whether there was increased inclusion of participants in health intervention research as a result.

Several experiential descriptions of the provision of resources are reported in the research literature. [15,41-45](#) Participants in these studies were often women, ethnic people of color, and people with low income. The resources most commonly provided were financial reimbursement, cab fare, subway tokens, child care, food, and snacks. Resource provision also might be seen in these studies in attempts to make participation in research more readily available to community members. Research was conducted in existing and trusted community agencies, schools, homeless shelters, clinics, drug rehabilitation programs, public housing projects, homes, bars, migrant labor camps, bookstores, and jails. [11,15,33,41-46](#) Although not directly acknowledged by the investigators as a strategy to affect inclusion, it seems clear that these investigators were providing resources in an effort to encourage and make possible participation in health intervention research.

Studies that incorporated resource provision as part of the intervention protocol rarely conducted a formal evaluation of the provision of resources as an inclusion strategy. However, several investigators reported response rates that ranged from moderate (50%) to high (80%) and low attrition rates, [11,15,42,45,46](#) suggesting success with their recruitment approaches. Because most of these studies also employed a culturally responsive approach in the intervention protocol, it is difficult to determine which strategies were more successful in

including women and ethnic people of color in the research.

There was one study that did differentiate between the effects of both resource and cultural responsiveness approaches and the importance of resource provision. In a breast and cervical cancer prevention study conducted by Blumenthal and associates [11](#) in an inner-city African-American community, "lay health workers who were African-American women drawn from the inner-city target population" were employed. All of them had "some college education" and "grass roots community organizing skills" concerning women's health issues. From this description, there was gender and ethnic similarity between research workers and participants and also perhaps similar cultural values. These investigators reported that their initial recruiting activities resulted in a recruitment rate of 20% from a federally funded primary health care center located in the community. Not satisfied with this result, the investigators moved the location of their recruitment to public housing projects and interviewed women in their homes with a consequent 47.6% recruitment rate. In evaluating their recruitment strategies, the investigators concluded that the site of recruitment (public housing project) and the location of data collection (the home) were most important in improving recruitment. [11](#) Availability of the research program is a characteristic of resource provision and, in this case, was a better inclusion strategy than were cultural responsiveness strategies. From the research and experiential evidence provided, it seems apparent that resource provision successfully promotes inclusion in research.

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## Cultural responsiveness

In order to make their research culturally responsive, investigators have employed a variety of methods. These have included matching research workers and participants on language, gender, and ethnicity; employing community members as research workers; and collaborating with the community in conducting the research.

Research on language match between health care researchers and participants demonstrates that language match is crucial to recruitment, assessment, data collection, diagnosis, retention, use of services, data analysis, and outcome. [19,22,23,47](#) Furthermore, the use of interpreters to avoid language confusion results in a new set of problems. Interpreters may distort the questions and the answers in an attempt to condense, substitute, and normalize discussions because of a lack of knowledge of the material or a concept in the language, or to avoid stigma or embarrassment to their group. [48](#)

Matching the ethnicity of researchers and participants is another strategy associated with the cultural responsiveness perspective. Some studies have focused on the preference of clients for an ethnically similar health care provider. These studies have demonstrated a rather consistent preference of African-American, Latino, and Asian clients for ethnically similar health care providers and vice versa. [10,16,29,49](#)

Other investigators have examined whether ethnic similarity increases utilization of services and the number of dropouts from services. [19,22,23](#) In these studies, client-health provider ethnic similarity significantly increased the use of services and decreased the number of dropouts. The results suggested that a researcher-participant ethnic match might have an effect on retention and attrition in health intervention research.

Ethnic matching has been studied from other perspectives as well. One study of recruitment of African-American psychiatric inpatients to clinical research investigated the effects of ethnic matching between researchers and patients. [32](#) In this study, ethnic similarity had no significant effect on response rates, although the inpatient status of the participants might have facilitated recruitment efforts.

A study that examined the effects of ethnic similarity on tutor-tutee interactions also found no advantage to ethnic similarity between tutor and tutee. <sup>50</sup> The investigators noted that other variables such as socioeconomic and power differences between tutors and tutees may have accounted for the lack of statistical effect of ethnic similarity. These variables may be more reflective of the provision of resources rather than of a cultural responsiveness perspective.

Several studies that have employed gender and ethnic matches between research team and participants have reported high recruitment (response) rates and low (10% to 14%) attrition rates. <sup>15,41-44,46</sup> These studies did not specifically examine the effects of gender or ethnicity but they did lend support to the use of matching as a strategy. The studies used and trained lay community workers, which may have added the effects of shared social class and values to the ethnic, language, and gender effects. These studies come closer to the intent of cultural responsiveness and attitude similarity theories than merely matching ethnicity and gender of participants and research workers. One study that investigated the effects of matching on the intervention compared peer mentors and nurses. Peer mentors who shared ethnicity, gender, homelessness, and history of drug taking with participants were more effective in decreasing drug use among the participants than were nurses who shared only gender and ethnicity with participants. <sup>46</sup> However, the nurses were more effective in helping participants with emotional problems. It might be argued that characteristics of homelessness and drug taking in the peer mentors added a sociocultural responsiveness dimension to the study.

The evidence of benefit from a gender match is more equivocal than that of ethnic similarity. Intuitively it would seem that women would be more comfortable with other women when breast or cervical exams or cancer are the focus of research or when sexual practices are being queried. The same would seem true for men and prostate cancer screening or questions about sexual practices. Many studies employ gender matches between the research team and participants for just these reasons. <sup>15,41-46,48</sup> However, gender matching is often confounded by the sociocultural role of men and women in different ethnic cultures. <sup>24,31,41,42</sup> The role of women with regard to power and dominance, the credibility of women as health care educators or providers, and the value placed on feminism all might differ among cultural groups. Power and status of women may be more reflective of a perspective of resource differentials than of a cultural responsiveness approach.

In a series of studies that used a cultural responsiveness conceptual framework and collaboration with the community; ethnicity, language, gender, and social class of research team and participants were matched also. The investigators evaluated their strategies and protocols with the research participants at the conclusion of the project. <sup>41,42</sup> These studies focused on HIV prevention and screening of sexual practices and drug use practices in Latina women with the expectation that the intervention would have a ripple effect on the women's family members. On evaluation, Latina focus group participants related that although gender matching between researcher and participant was acceptable on an individual level, it was not the most effective intervention if family health education was the goal. The women suggested that gender-integrated AIDS education in church groups, school groups, and community groups would be more effective for Latinos from the teenage years through adulthood, and that AIDS education should be delivered by gender-integrated pairs of educators. They believed this strategy would be more culturally responsive, persuasive, and pervasive than all-female groupings with a gender-matched research team.

Many investigators provide anecdotal reports of their attempts to make their research culturally responsive when describing their recruitment, retention, and intervention efforts, although they rarely refer to their approach as cultural responsiveness. Usually these reports do not provide empirical support for similarity between researchers and participants as the key to successful inclusion of women and ethnic people of color, but they do recommend this strategy. For example, McCabe and associates <sup>27</sup> recommend the inclusion of "minority persons in the clinics as professional or support staff" as a strategy to recruit "the



economically disadvantaged" to cancer treatment clinical trials. Lillie-Blanton and Hoffman [14](#) suggest that "community members be involved in as many dimensions of research as possible" and "employing a racially/ethnically diverse research team" will facilitate community-based research because "respondents identify with interviewers." To recruit pregnant Latina participants in a smoking cessation program, Pletsch and colleagues [30](#) concluded that: "Desirable recruiter characteristics were that recruiters be of Latino heritage; bilingual in Spanish and English; and be known, respected and trusted by potential participants and their community members." These recruiter characteristics suggest cultural responsiveness based on ethnic, language, social class, and values similarity. The investigators did report their recruitment (response) rate in their most successful site (25%) and they evaluated reasons for recruitment failure. They concluded "there was no single best approach to successful participant recruitment"; [30](#) however, all of their strategies focused on cultural responsiveness and none on resource provision.

The methods for recruitment and retention reviewed here all attempted a cultural responsiveness approach to include women and ethnic people of color as participants in health intervention research. Many used ethnic, gender, and language matching as a strategy; however, the statistical effects of matching were not examined. Most investigators described their recruitment strategies, but formal evaluation of strategies was limited. [17,32,46](#) Many investigators reported the high financial cost and extended length of the recruitment and retention process. [11,17](#) They recommended methodologic research and rigorous testing of specific strategies to reduce cost and effort and to improve efficiency and effectiveness. [11,17,32,46](#)

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## IMPLICATIONS FOR NURSING RESEARCH

Earlier in this article, several issues were examined that sought to explain why women and ethnic people of color are not included as participants in health care research. Each of these issues is addressed again here with the intent of evaluating whether cultural responsiveness or resource provision best facilitates participation in research. Admittedly, the research evidence on this question is sketchy; however, an initial judgment may be made.

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### Access, availability, and affordability

Cultural responsiveness as an inclusion strategy focuses on influencing the attitudes of community members to participate in research. This approach proposes that participants may change their attitudes toward health care research and may be encouraged to participate by employing research workers who are similar to participants in ethnicity, gender, language, and cultural values and who collaborate with the community in the research effort. However, cultural responsiveness does little to address problems of lack of medical insurance; long distances between home and research site; lack of money for transportation, child care, and temporary housing; and the inability to take time off from work to attend these research trials. It has been noted frequently that low-income persons are least likely to participate in research and most likely to drop out. [11,27,31](#) Income, insurance, location, and affordability are resource variables, and the provision of resources rather than cultural responsiveness is the answer to these problems.

Strategies that nurse researchers can use to meet the problems posed by lack of resources include providing financial incentives for participants as well as transportation, child care, snacks, and temporary housing. [27,30,31,42](#) Assisting participants to obtain medical insurance and disability insurance and drug assistance programs are other resource strategies. Taking the study to the participants by way of mobile units, recruiting in the community, interviewing people in their homes or in shelters, and weekend and evening hours provide a successful alternative to transporting participants or recruiting and interviewing in

clinics and health facilities. [11](#) The provision of resources may be the major and most effective strategy in successful recruitment and retention of low-income participants, many of whom are women and ethnic people of color. The little that cultural responsiveness can add to the provision of resources is that language matching between researchers and participants would enhance communication about resources, and ethnic and cultural similarity may enhance a personal and nonjudgmental approach that encourages disclosure of resource problems and acceptance of resource provision.

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#### Burden and benefits

Decreasing objective burden and increasing the belief in benefits of involvement in research may be addressed by a combination of resource provision and cultural responsiveness. The provision of resources and bringing the research to the community and homes of participants best alleviate the burden of being involved in the research. [11,27,30,44](#) Provision of resources also may be viewed as a benefit of participation by providing benefits such as financial incentives, better health care and access to care, and social and interpersonal involvement with health professionals. Cultural responsiveness may affect both benefit and burden. Employing a research team that shares the cultural values, ethnicity, and language of participants will assist them in understanding the potential benefits of involvement in research. Cultural beliefs and misperceptions that are barriers to involvement in health care research can be clarified by researchers with knowledge and understanding of these beliefs. Information about current treatment and prevention may be more credible when delivered by someone with whom participants can identify. [14,16](#) The burden and benefits of research involvement can best be addressed by the provision of resources and a culturally responsive approach that includes cultural values, ethnicity, and language similarity between researchers and participants.

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#### Language, literacy, and instruments

Language and literacy might be viewed as resources possessed by some in the community; however, matching language of research team and participants might be better viewed as culturally responsive and is essential to the success of the research project for both written and verbal communication. [14,27](#) In addition, close attention to literacy levels for all spoken and written instructions and materials is critical and reflects a culturally responsive approach. [32](#) Language match and appropriate literacy levels are necessary to communication in recruitment, retention, and intervention efforts and present the most compelling case for matching researcher and participant on a particular sociodemographic variable. Providing language classes and literacy skills may be the best solution in the long term to encourage participation in research, but it is a societal solution and probably not realistic for the individual researcher. Cultural responsiveness and shared language address this issue better in the short term. [17,32,50](#)

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#### Cultural values and beliefs

Responsiveness of the research team to participants' cultural values and beliefs promises to be an effective approach to encouraging participation in health intervention research. Tests of the cultural responsiveness theory have shown statistically significant effects of matching cultural values on use of services and retention; furthermore, matching ethnicity and language may provide an additional effect on service use and retention. [19,22,23](#) Research team members who understand and share cultural values will be most effective in recruitment and retention of participants. Knowledge of cultural health beliefs, practices, and forms of prevention and treatment will help recruiters describe the research project in terms, beliefs, and practices that participants are familiar with, trust, and value. Culturally responsive research workers can draw parallels between cultural beliefs and practices and Western biomedical beliefs and practices in order to explain the research protocol and procedures more credibly and

acceptably to participants. <sup>33</sup> A culturally responsive research team will also share knowledge of misperceptions about causes of illness, prevention methods, and treatment and be able to correct these with sensitivity and insight.

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## Insensitivity and distrust

Distrust and fear of health professionals may be decreased by employing a culturally responsive research team that shares values, language, and ethnicity with participants. Trust may be enhanced by having well-known and respected community members and leaders who share cultural background, ethnicity, and language with participants advertise and endorse the project. <sup>11,16,39</sup> However, it should be remembered that the Tuskegee syphilis study was community-based, employed African-American nurses and physicians, and was supported by trusted community leaders such as African-American pastors. Distrust and fear of health care researchers are only partially based on ethnicity, language, and culture. Although these may enhance an initial impression by participants, trust must be earned by research staff who consistently demonstrate dedication to the project and do not violate ethical standards and human dignity. <sup>13,17,31</sup> Overall, however, a culturally responsive perspective encourages the inclusion of women and ethnic people of color as research participants.

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## CONCLUSION

When women and ethnic people of color are excluded from health care research, clinical trials, and state-of-the-art treatments tested in research, they become vulnerable to increased morbidity and mortality. Conceptual approaches to inclusion of women and ethnic people of color include cultural responsiveness and resource provision perspectives.

The original question addressed was whether a cultural responsiveness or research provision perspective would be more effective in increasing ethnic and gender diversity in health care research. From the review of theory and research provided, it may be said that cultural responsiveness to participant cultural values, ethnicity, and language is one very important strategy that researchers must employ and be willing to support through, for example, training, inservice education, and the use of community members in the research process. Cultural responsiveness is, however, only a partial answer. A second equally important, if not more important, strategy is the provision of resources to participants such as financial support, skills, and knowledge. Funds to support these resources must be included in the research budget and study costs. Adequate resources are at the foundation of empowerment for women and ethnic people of color to affect their own lives and health.

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## REFERENCES

1. National Institutes of Health Revitalization Act of 1993. 42 USC Sec 289a-2. [\[Context Link\]](#)
2. *Resident Population of the United States by Race and Hispanic Origin*. US Bureau of the Census, Department of Commerce; September 1997. [\[Context Link\]](#)
3. Graham, S. Most of the subjects were White and middle class. Trends in published research on African Americans in selected APA journals. *Am Psychol*. 1992;47:629-639. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

4. Ness RB, Nelson DB, Kumanyika SK, Grisso JA. Evaluating minority recruitment into clinical studies: How good are the data? *Ann Epidemiol*. 1997;7:472-478. [Full Text](#) | [Bibliographic Links](#) | [Context Link](#)

5. Food and Drug Administration amendment to clinical hold regulations. *Federal Register*. September 24, 1997. [Context Link](#)

6. *Consensus Statement on the Clinical Hold Rule*. New York: HIV Law Project; August 3, 1999. [Context Link](#)

7. Centers for Disease Control and Prevention. *HIV/AIDS surveillance report*. 1999;10(1):1-39. [Context Link](#)

8. AIDS emergency declared among counties' minorities. *Los Angeles Times*. September 29, 1999:A1, A17. [Context Link](#)

9. Shapiro MF, Morton SC, McCaffrey DF, et al. Variations in the care of HIV-infected adults in the United States: results from the HIV cost and services utilization study. *J Am Med Assoc*. 1999;281(24):23-30. [Context Link](#)

10. Millon-Underwood S, Sanders E, Davis M. Determinants of participation in state of the art prevention, early detection/screening, and treatment trials among African-Americans. *Cancer Nurs*. 1993; 16:25-33. [Context Link](#)

11. Blumenthal DS, Sung J, Coates R, Williams J, Liff J. Recruitment and retention of subjects for a longitudinal cancer prevention study in an inner-city black community. *Health Serv Res*. 1995;30:197-205. [Context Link](#)

12. Diaz T, Chu SY, Sorvillo F, et al. Differences in participation in experimental drug trials among persons with AIDS. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1995;10:562-568. [Context Link](#)

13. Hautman MA, Bomar P. Interactional model of recruiting ethnically diverse research participants. *J Multicultural Nur Health*. 1995;1:8-15. [Context Link](#)

14. Lillie-Blanton M, Hoffman SC. Conducting an assessment of health needs and resources in a racial/ethnic minority community. *Health Serv Res*. 1995;30:225-236. [Context Link](#)

15. Nyamathi A, Kington R, Flaskerud, J, Lewis C, Leake B, Gelberg L. Two year follow-up of two AIDS education programs for impoverished women. *West J Nurs Res*. 1999;21(3):405-425. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [Context Link](#)

16. Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health*. 1997;2:31-45. [Full Text](#) | [Bibliographic Links](#) | [Context Link](#)

17. Swanson GM, Ward AJ. Recruiting minorities into clinical trials: Toward a participant-friendly system. *J Natl Cancer Inst*. 1995;87:1747-1759. [Full Text](#) | [Bibliographic Links](#) | [Context Link](#)

18. Simons NW, Berkowitz NM, Moyer RJ. Similarity, credibility, and attitude change: a review and a theory. *Psychol Bull.* 1970;73:1-16 [\[Context Link\]](#)

19. Sue S, Fujino DC, Hu L, Takeuchi DT, Zane NWS. Community mental health services for ethnic minority groups: a test of the cultural responsiveness hypothesis. *J Consult Clin Psychol.* 1991;59:533-540. [Ovid Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

20. Sawyer L, Regev H, Proctor S, et al. Matching versus cultural competence in research: methodological considerations. *Res Nurs Health.* 1995;18:557-567. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

21. Smith LS. Concept analysis: cultural competence. *J Cult Divers.* 1998;5(1):4-10. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

22. Flaskerud JH, Akustu P. Significant influence of participation in ethnic-specific programs on clinical diagnosis for Asian Americans. *Psychol Rep.* 1993;72:1228-1230. [Bibliographic Links](#) | [\[Context Link\]](#)

23. Flaskerud JH, Hu L. Participation in and outcome of treatment of major depression among low income Asian-Americans. *Psychiatr Res.* 1993;53:289-300. [\[Context Link\]](#)

24. Flaskerud JH, Winslow, BJ. Conceptualizing vulnerable populations' health-related research. *Nurs Res.* 1998;47(2):69-78. [Ovid Full Text](#) | [Request Permissions](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

25. Berk ML, Albers LA, Schur CL. The growth in the US uninsured population: trends in Hispanic subgroups, 1977-1992. *Am J Public Health.* 1996;86:572-575. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

26. Vistnes JP, Monheit AC. *Health Insurance Status of the Civilian Noninstitutionalized Population: 1996*. Rockville, MD: Agency for Health Care Policy and Research; 1997. AHCPR publication no. 97-0030. [\[Context Link\]](#)

27. McCabe MS, Varricchio CG, Padberg RM. Efforts to recruit the economically disadvantaged to national clinical trials. *Semin Oncol Nurs.* 1994;10:123-129. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

28. Mack C. *The quest for treatment: cancer patients' experience of phase I clinical trials*. Los Angeles: University of California Los Angeles; 1998. Doctoral dissertation. [\[Context Link\]](#)

29. Robinson SB, Ashley M, Haynes MA. Attitudes of African-Americans regarding prostate cancer clinical trials. *J Community Health.* 1996;21:77-87. [\[Context Link\]](#)

30. Pletsch PK, Howe C, Tenney M. Recruitment of minority subjects for intervention research. *Image J Nurs Sch.* 1995;27:211-215. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

31. Norton IM, Manson SM. Research in American Indian and Alaska Native communities: navigating the cultural universe of values and process. *J Consult Clin Psychol.* 1996;64:856-860. [Ovid Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

32. Thompson EE, Neighbors HW, Munday C, Jackson JS. Recruitment and retention of African American patients for clinical research: an exploration of response rates in an urban psychiatric hospital. *J Consult Clin Psychol*. 1996;64:861-867. [Ovid Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
33. Flaskerud JH. Culture and ethnicity. In: Ungvarski P, Flaskerud JH, eds. *HIV/AIDS: A Guide to Primary Care Management*. 4th ed. Philadelphia: WB Saunders; 1999. [\[Context Link\]](#)
34. Nyamathi A, Flaskerud JH. A community-based inventory of current concerns of impoverished homeless and drug-addicted minority women. *Res Nurs Health*. 1992;15:121-129. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
35. Flaskerud JH. Is the Likert scale format culturally biased? *Nurs Res*. 1988;37(3):185-186. [Ovid Full Text](#) | [Request Permissions](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
36. Naranjo LE, Dirksen SR. The recruitment and participation of Hispanic women in nursing research: a learning process. *Public Health Nurs*. 1998;15:25-29. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
37. Lipton RB, Losey LM, Giachello A, Mendez J, Girotti MH. Attitudes and issues in treating Latino patients with Type 2 diabetes: views of healthcare providers. *Diabetes Educ*. 1998;24:67-71. [\[Context Link\]](#)
38. Martinez RG, Chavez LR, Hubbell FA. Purity and passion: risk and mortality in Latina immigrants' and physicians' beliefs about cervical cancer. *Med Anthropol*. 1997;17:327-362. [\[Context Link\]](#)
39. Dula A. African-American suspicion of the health care system is justified: what do we do about it? *Camb Q Healthc Ethics*. 1994;3:347-357. [\[Context Link\]](#)
40. Chan TC, Krishel SJ, Bramwell KJ, Clark RF. Survey of illegal immigrants seen in an emergency department. *West J Med*. 1996;164:212-216. [Bibliographic Links](#) | [\[Context Link\]](#)
41. Flaskerud JH, Uman G, Lara, R, Romero L, Taka K. Sexual practices, attitudes, and knowledge related to HIV transmission in low income Los Angeles Hispanic women. *J Sex Res*. 1996;33:343-353. [\[Context Link\]](#)
42. Flaskerud JH, Nyamathi AM, Uman GC. Longitudinal effects of an HIV testing and counseling program for low income Latina women. *Ethn Health*. 1997; 2:89-103. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
43. Nyamathi A, Leake B, Flaskerud J, Lewis C, Bennet C. Outcomes of specialized and traditional AIDS counseling programs for impoverished women of color. *Res Nurs Health*. 1993;16:11-21. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)
44. Nyamathi A, Flaskerud J, Keenan C, Leake B. Effectiveness of a specialized vs. traditional AIDS education program attended by homeless and drug-addicted women alone or with supportive persons. *AIDS Educ Prev*. 1998;10:433-446. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

45. Koniak-Griffin D, Mathenge C, Anderson NLR, Verzemnieks I. An early intervention program for adolescent mothers: overview of a nursing demonstration project. *J Obstet Gynecol Neonatal Nurs*. 1999; 28(1):51-59. [Ovid Full Text](#) | [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

46. Nyamathi A. Peer-mentored and nurse case managed AIDS education programs in homeless women. Presented at the American Psychological Association meeting; August 17, 1998; San Francisco, CA. [\[Context Link\]](#)

47. Flaskerud JH. Matching client and therapist ethnicity, language and gender: a review of research. *Issues Ment Health Nurs*. 1990;11:321-336. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

48. Flaskerud JH, Nyamathi A. An AIDS education program for Vietnamese women. *New York State J Med*. 1988;88:632-637. [\[Context Link\]](#)

49. Castro F, Coe K, Harmon M. The effect of ethnic/racial matches between provider and patient on the use of health services by Hispanics and African Americans. *Abstract Book/Assoc Health Serv Res*. 1997;14:41. Abstract. [\[Context Link\]](#)

50. Tom TL, Cronan TA. The effects of ethnic similarity on tutor-tutee interactions. *J Community Psychol*. 1998;26:119-129. [Full Text](#) | [Bibliographic Links](#) | [\[Context Link\]](#)

Key words: cultural responsiveness; ethnicity; gender; health intervention research; inclusion approaches

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