Self-Assessment of Cultural Attitudes and Competence of Clinical Investigators to Enhance Recruitment and Participation of Minority Populations in Research

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Reduction of health disparities in the United States is a high priority. One means of effecting such a reduction is to enroll persons of groups that are subject to health disparities in clinical trials.

One barrier to minorities enrolling in clinical research is distrust of the medical establishment based on past abuses and perceived discrimination. We hypothesized that another barrier is a lack of investigators' understanding and skill in effectively communicating with members of minority cultures. We therefore assessed the cultural competency of faculty and staff involved in clinical care and research at Creighton University Medical Center (CUMC).

Thirty-seven faculty and staff members participated. We found that the majority are reasonably culturally competent, but there are areas in which proficiency can be enhanced and recruitment of participants in clinical research can be improved.

Most CUMC faculty and staff respect and have reasonable knowledge of the several cultures of the patients for whom they provide care and with whom they conduct research. But there is a need for continued cultural sensitivity/competency training to enhance understanding of certain aspects of minority cultures, group and interpersonal relationships, perceptions of disease and wellness and to improve their access to minority communities.

Key words: cultural competence ■ health disparities ■ clinical investigation ■ minority populations

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INTRODUCTION

Health disparities in minority populations are well documented.[1-4] Health disparities result from a number of factors, including unequal access to care, unequal treatment of minorities,[1] differential susceptibility to diseases because of lifestyles or biologic factors[3-5] and differential responses to therapeutic agents.[6,7]

The goal of eliminating or reducing disparities has become a research priority for the nation,[3] and Creighton University Medical Center (CUMC) has made health disparities research an institutional priority. The state of Nebraska has allocated a portion of the Tobacco Settlement Fund to improving minority health, and some of these funds have been directed to the study of health disparities in Nebraska minorities. In order to diminish disparities that result from lifestyle (e.g., smoking, overeating, etc.), it is necessary to enroll members of the communities susceptible to disparities in studies of interventions designed to work in the contexts of specific cultures. To test therapeutic interventions designed to reduce risk factors for differential susceptibilities to disease or test for differential responses to pharmaceuticals, it is necessary to enroll members of minority groups in controlled trials. Congress and the National Institutes of Health (NIH) have recognized this: Congress enacted a mandate for the inclusions of minorities (and women) in clinical research,[8] and the NIH have developed policy and guidelines addressing this mandate.[9]

Clinical investigators have found it difficult to enroll minorities in clinical research.[10-14] One can conceive of several barriers to enrollment of minority populations into clinical research protocols, including mistrust of the medical establishment, language differences, different cultural values, different cultural perceptions of health and disease, different styles of relationship and investigator access to these populations. These barriers have all been observed and documented in health professional–patient interactions in the provision of care.[1] Mistrust has been determined to play a large role in the relative lack of enrollment of African Americans in clinical research protocols.[10-12] We have undertaken a study to determine whether the difficulty CUMC investigators have encountered in enrolling minorities in clinical research results from a lack of investigators' knowledge of or sensitivity to other cultures so that measures can be taken to increase their ability to engage minorities in clinical research.

In the year 2000, 10% of Nebraska residents, 22% of Omaha residents and 63% of the population of the CUMC primary service area comprised minority populations.[15] Our medical center's primary service area has substantial numbers of African Americans, Native Americans and immigrant populations from Latin America, Africa (including an estimated 8,000–10,000 Sudanese refugees) and Asia. And there is cultural and linguistic diversity within these groups. These minority populations are subject to health disparities similar to those experienced by U.S. minority populations.[5]

We previously assessed and reported the attitudes and knowledge of health disparities and clinical research in a study that included African Americans, Native Americans, Vietnamese, Hispanics and Sudanese.[16] We assessed the satisfaction of members of minority populations with the healthcare and cultural competence of healthcare providers in Omaha, NE and the willingness of members of minority populations to participate in clinical research. We found that most members of minority communities who participated in our study were satisfied with their healthcare and healthcare providers. However, there were some expressions of distrust and of dissatisfaction relating to communication, language barriers, knowledge of cultural differences in perceptions of and reactions to disease and perceived unequal treatment. Many of those in our study expressed a preference for providers of similar ethnic and cultural background and some groups prefer providers of the same gender. We also found that, with the exception of African Americans, a majority of members of minority populations in our study group are willing to participate in clinical research if they believe it may be of value to members of their community.

In this study, we addressed the ability of investigators and research staff members to relate to and communicate effectively about health and clinical research with members of minority communities. We have attempted to assess attitudes, knowledge, communication and social skills of clinical investigators with respect to minority populations. These factors are important in the contexts of clinical research, subject recruitment and patient care. We developed and pilot-tested a self-assessment tool consisting of more than 20 items, the Cultural Competency instrument (CCI).[17] It was designed to assess provider and investigator knowledge, attitudes and sensitivity to other cultures and to assess areas of patient/provider interactions and environments that may be improved. We followed the administration of the CCI by focus group discussions with the investigators and research staff members to elicit more information about their perceptions and cultural competence.

Cultural competency is defined as "… a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations."[18] We interpret this to mean awareness of unique and defining characteristics of the populations for which health professionals provide care and from which they wish to enroll clinical research participants. Culturally competent investigators should utilize this knowledge when interacting with these populations.

Information derived from the CCI and focus groups should enable us to develop programs of provider/investigator education intended to improve quality of care to minority and/or ethnically and/or racially diverse populations to encourage these populations to participate in healthcare research and to facilitate investigators' recruitment of clinical research participants.

Table 1. Departments

Anesthesiology	1
Cancer center	1
Dental school	3
Family medicine	3
Institute for Latin-American concern	3
Medicine, pediatrics, family medicine	1
Medicine/allergy	1
Medicine/cardiology	1
Medicine	7
Neurology	3
Nursing	2
Ophthalmology	2
Pathology	1
Pediatrics	1
Psychiatry	3
Pharmacy	1
Surgery	3
Total	37

METHODOLOGY

The CCI was developed, piloted with a small group of clinical investigators and revised to produce the final instrument used in this study.[17] It is intended as a self-assessment of: 1) knowledge of cultural differences, 2) attitudes toward cultural differences, 3) effects of cultural differences on professional relationships with members of other cultures and 4) accommodation of different cultural and ethnic groups encountered in research and clinical care.

In order to recruit participants in this study, all department heads at CUMC were contacted via letter, e-mail and/or telephone, and asked to participate or nominate members of their staff to participate in one of three focus groups. The criterion for participation was that nominees be engaged in healthcare and/or clinical research involving racially and/or ethnically diverse patients. Persons who participated in the pilot study utilized to develop the CCI were ineligible to participate in the three focus groups.

At each CCI study session, respondents were given an overview regarding the purpose of the cultural proficiency study. They were asked to sign a consent form. When consent forms had been signed and collected, the instrument was distributed. Respondents were given approximately 30 minutes to complete the form. Respondents were asked to answer the questions to the best of their knowledge and ability and to hold questions and comments until the focus group was conducted. A focus group discussion was conducted after the questionnaire had been collected. The facilitator who conducted the focus group for the pilot study and the community assessments[16] also conducted the CCI focus groups. Participants were paid $50 for their time and effort. Transcripts were made for two of the three focus groups.

Demographic Data

Thirty-seven individuals affiliated with CUMC completed the CCI. They included principal investigators, research nurses, interviewers, health educators, counselors and other personnel involved in clinical research and patient care. Twenty-six of thirty-seven, a majority, were faculty members with professorial titles; six were nurses; and all interacted in various ways with research subjects and/or patients. Twenty-six of the participants hold doctoral degrees, of which several hold more than one, eight have bachelor's and/or master's degrees and three did not respond to the question. Slightly more than half, 19, of the participants identified themselves as of European descent; nearly half, 16, identified themselves as belonging to minority groups, including five African-American, five Hispanic and three Asian-Indian; and two declined to respond. The mean age was 47 (range 28–75) and the mean time employed at CUMC was nine years (range ≤1–47).

Thirty-three participants are involved in clinical care; 20 spend more than 50% of their time in patient care (mean time in clinical care for all =51.2%). All save two are engaged in clinical research and 17 spend more than 50% of their time in research (mean time in research for all=33%). Table 1 indicates the departments of those who participated in the study.

Findings

Knowledge of cultural differences. A number of the questions of the CCI are intended to elicit perceptions of the level of cultural competence, attitudes and practices of healthcare providers and clinical investigators with members of other cultures. It is widely recognized that culture and language dif-

Table 2. Knowledge of cultural differences

Query	Agree # (%)	Disagree # (%)	Don't Know # (%)	NA or Missing # (%)	Total # (%)
A. My department or clinic, consistent with the needs of the community, has specialist on staff who is familiar with minority/ethnic folk illnesses and/or practitioners	17 (45.9)	13 (35.1)	5 (13.5)	2 (5.4)	37 (100)
B. My department or clinic is not equipped to treat minority/ethnic folk illnesses	10 (27.0)	20 (54.1)	5 (13.5)	2 (5.4)	37 (100)
C. This department or clinic has utilized ethnic/minority therapeutic approaches in its treatment of ethnic/minority patients	11 (29.7)	11 (29.7)	11 (29.7)	4 (10.8)	37 (100)
D. My department or clinic refers patients to facilities that are equipped to treat folk illnesses	7 (18.9)	15 (40.5)	12 (32.4)	3 (8.1)	37 (100)

ferences present important challenges to health professionals' provision of care and minorities' participation in research.[13,14,19,20] Most of the participants of our study believe that the departments and clinics in which they work provide competent care to those of other cultures and patients who speak languages other than English. Eighteen said that providers in their departments or clinics are competent to treat all patients regardless of their language and culture, nine said only English or Spanish speakers and five said only English speakers. Several qualified their responses with comments reporting perceived limitations, noting the need for interpreters and comments, acknowledging that not all providers are competent to treat patients of diverse cultures.

Many also reported that their departments and clinics have providers who are familiar with folk illnesses (e.g., *bilis* or *empacho* in Latinos, imbalance of *Am* and *Duong* in Vietnamese or windigo in native Americans) defined by ethnic groups[21,22] and with ethnic health practitioners and practices (*curanderos*, medicine men, shamans, faith healers, etc.) (Table 2A). Most believe that their clinics are capable of treating ethnic- or folk-defined illnesses (Table 2B). However, only about 30% reported that their clinics use ethnic/minority therapeutic approaches (Table 2C) and a small minority said that their department or clinic refers patients to facilities that are equipped to treat folk illness (Table 2D). This may reflect lack of knowledge of where such competencies may be found, which may also reflect inadequacies in cultural sensitivity training. Written comments indicate that several of the respondents understand that there are conditions from which people suffer that are not readily defined by western medicine.

When asked what happens with patients without recognizable medical problems, the answers were not reassuring. Twenty said such patients are assured that they are healthy and released. Eleven said that a battery of diagnostic tests is done to determine whether anything has been missed. Four each said that they are reassessed using culturally specific diagnostic instruments or referred to a facility or institution that is better equipped to deal with this culture and one said that they are referred to mental health providers. There were more responses than respondents. It is possible, but not certain, that participants who answered by saying they reassured patients also responded positively to the battery of tests question. It is also possible that those who responded by saying that patients were reassured understood the word symptoms to include objective findings as well. Five of the 20 who said that patients were reassured also said they would give a battery of tests; three of the 20 said they would refer the patient to a facility better equipped to deal with this segment of the population; and one of those three also said they would refer the patient to a mental institution.

Most respondents also report little or no direct experience with certain cultural practices, e.g., female genital cutting, child marriage and scarification. This does not necessarily mean that they are ignorant of those cultural practices but may indicate that they rarely encounter problems resulting from them.

Attitudes toward cultural differences. In the expectation that attitudes toward cultural differences may reflect and affect cultural competence, we queried our respondents about assimilation, practice style and clinical decision-making. Attitudes expressed by the participants clearly show that a significant majority believe that assimilation of immigrant and minority groups to American norms and values is good (Table 3A). This could be interpreted

Table 3. Attitudes toward cultural differences

Query	Agree # (%)	Disagree # (%)	Don't Know # (%)	NA or Missing # (%)	Total # (%)
A. Based on my experiences and knowledge, assimilation (being defined as learning American norms and values) is good	27 (73.0)	6 (16.0)	3 (8.0)	1 (2.7)	37 (100)
B. My department or clinic assumes that all patients have assimilated or are in the process of assimilating*	8 (21.6)	24 (64.9)	4 (10.8)	1 (2.7)	37 (100)
C. My department or clinic supports or encourages assimilation	10 (27.0)	11 (29.7)	11 (29.7)	4 (10.8)	37 (100)
D. Assimilation prevents children from learning harmful indigenous or cultural practices	4 (10.8)	29 (78.4)	4 (10.8)	0 (0)	37 (100)

* Assimilation is defined as accepting the dominant norms and values as demonstrated by dress, language, education, etc. It does not necessarily include religion.

as a lack of respect for other cultures or alternatively, as recognition that assimilation of American norms and values is a pragmatic approach to enabling people to get along and succeed in a large, complex and diverse society.

Whatever the interpretation, the belief that assimilation is good does not much affect practice. When asked whether providers assume that immigrants have assimilated, a majority responded negatively and only slightly more than one-fifth responded positively (Table 3B). Further, approximately 60% of respondents reported that their departments do not encourage assimilation or they are unaware of any effort to encourage assimilation (Table 3C). These findings may reflect that although the respondents believe assimilation is good, they do not necessarily believe that retaining ethnic cultural norms and values is bad. When asked whether assimilation prevents harmful effects of indigenous or ethnic cultures on children, they overwhelmingly disagreed (Table 3D), apparently reflecting respect and nonjudgmental attitudes toward the practices of other cultures.

Effect of cultural differences on relationships with those of other cultures. One would reasonably expect that recognition of cultural differences may affect the way health professionals approach and relate to their patients and research subjects. We assessed this by asking questions about professional style and clinical decision-making.

It would be easy for professionals to assume that cultural differences make it difficult for patients or research subjects to understand or appreciate the circumstances of their illnesses, complaints or the nature and need for clinical research. This could easily give rise to a paternalistic approach to subjects and patients. When queried about the value of paternalism in dealing with ethnic minorities and immigrants, the great majority rejected it (Table 4A) Group participants also generally recognized that in many cultures, decisions are made collectively or in consultation with family members and that others "have to be consulted" (Table 4B).

Accommodation of different cultural and ethnic groups. When faced with significant numbers of persons from ethnic, minority and immigrant groups, it is desirable that conscious efforts be made to ensure that staff members are competent and well trained to deal with these groups, that effective translation/interpretation is provided for those with native tongues other than English and that an environment in which these groups feel comfortable is provided. We asked our respondents to address several questions relating to these matters.

In our medical center, we have substantial numbers of patients who speak Spanish, Nuer, Dinka, Arabic, Vietnamese, Thai and French as native tongues, either exclusively or with English as a second or later language. This presents important challenges with respect to accurate communication between health professionals and those of other cultures. CUMC has in-house Spanish interpreters at all times; interpreters of the other languages mentioned above are on-call. If interpreters are not readily available or an undesirable delay is likely, professionals are authorized to utilize the AT&T Language Line for interpretation. The policy also explicitly states that family members are not to be used as interpreters. However, when we asked our study groups what they did if an interpreter is needed, they indicated that they use a variety of approaches (Table 5), including asking other patients or relatives; they recognize that neither is desirable but at times they deem it unavoidable. It is clear from the multiple responses and the comments that most recognize the need for competent interpretation and are sensitive to patient privacy and family relationships. We also inquired about the availability of skilled translation services (Table 6A). Most agreed that they are available but two respondents noted limitations of the availability of interpreters in languages other than Spanish, sometimes necessitating long waits for a professional interpreter. These findings

Table 4. Effects of cultural differences on professional relationships

Query	Agree # (%)	Disagree # (%)	Don't Know # (%)	NA or Missing # (%)	Total # (%)
A. It is for the good of the ethnic/minority patient that healthcare providers take a paternalistic attitude with him/her when discussing their illness and treatment	5 (13.5)	30 (81.1)	2 (5.3)	0 (0)	37 (100)
B. This department or clinic recognizes that other adults in the household, besides spouses and parents, may have to be consulted before any medical decision can be made regarding a patient	28 (75.7)	5 (13.5)	3 (8.1)	1 (2.7)	37 (100)

indicate to us a need to educate investigators and providers more effectively about the policy, the services available and how to access them.

When asked whether cultural sensitivity training is provided, only about a quarter signified that their departments have such training and another quarter simply didn't know (Table 6B). The fact is that there are numerous opportunities for cultural sensitivity training provided by departments and it is included in the orientation training for all hospital employees. The finding that half of those queried said that such training is not offered indicates an institutional failure to promote adequately and to emphasize the importance of that which is offered.

Creation of a clinical environment in which ethnic groups and minorities feel comfortable is another indicator of cultural sensitivity and competence. In order to assess this, we asked about staffing and the content of educational and promotional materials. We posed the leading statement:

My department or clinic has no minorities on staff because: it is difficult to find minority providers; there are no funds for additional personnel; it is difficult and there are no funds; this statement does not apply.

Thirty-three responded that the statement does not apply. We also ascertained that a majority of respondents work in departments or clinics that attempt aggressively to increase the number of ethnic minority providers (Table 6C).

We also determined that most of our group participants are aware of educational and promotional materials used in their departments or clinics that are published in a variety of languages (Table 6D) and picture people of color (Table 6E). (Most promotional documents utilized by the hospital and departments picture persons of different ethnic groups and a number are translated into Spanish and Nuer; only a few are translated into other languages.)

Focus group findings. Several themes emerged in the focused discussions that followed the completion of the questionnaires.

There were strong expressions of respect for different cultures, including a clear recognition of diversity among groups, e.g., diversity of immigrants from Sudan and of Hispanic groups from different parts of Latin America and Puerto Rico.

There were expressions of frustrations about the effects of culture on compliance or understanding of disease states or understanding and compliance with schedules, particularly appointment times. Once these are recognized, effective attempts to improve communication to ensure better understanding have been devised. For example, instead of requesting that a Sudanese patient return for an appointment in a week (a concept of time not utilized by many recent Sudanese immigrants), the patient may be instructed to return after seven sleeps.

There was also clear recognition that providers bear responsibility for educating, in a culturally effective way, those of other cultures with respect to experimental goals, research design, patients' and research subjects' rights, risk factors, preventive measures, appropriate surveillance and compliance with experimental and therapeutic measures. There is also recognition that providers bear the burden of effective communication with members of other cultures. Recognizing that cultural differences result in different perceptions and different relationships, some of the providers questioned whether some from other cultures can make truly informed decisions or grant truly informed consent when confronted with advice, information and recommendations from those they perceive to be authority figures, either the investigator, provider or someone from their own culture.

In discussing the value and importance of good interpretation, there were expressions that interpreters should be not only technically and linguistically accurate but also culturally aware. Preferred interpreters are either professional interpreters or

Table 5. Accommodation of different cultural and ethnic groups—language

In my department or clinic, if we need an interpreter for a patient…	Number*
A. A relative will be used, regardless of age, e.g., children	10
B. We will ask another patient to translate for us	4
C. We will use healthcare personnel who know the language	20
D. We will use a professional interpreter or a native-speaking health professional	25
E. Other and/or comments:	
• If subject matter is not worrisome for a child, and parents are present, e.g., only good news	
• Spanish-speaking student or hired Spanish speaker	
• Any of the above based on availability and clinical scenario	
• We ask social services for advice, help	5

* Respondents checked more than one answer

healthcare practitioners who are bilingual and of the culture for which they are interpreting. On occasion, providers have felt they have no choice and must use family members or acquaintances as translators. This sometimes makes health professionals reticent to ask patients questions that the professional believes may be embarrassing for a patient to answer through a family member or acquaintance.

Though generally respectful of other cultures, professionals expressed concern that some folk remedies to which their patients resort may be harmful rather than helpful. They recognize that many groups use alternative or folk medicine. They try to understand them so that they can help patients avoid potentially harmful treatments. Health professionals sometimes admit that they violate cultural mores because they perceive it to be in the best interest of a patient. They acknowledge that many folk remedies may be efficacious but they have not been tested to determine whether they are good, innocuous or harmful. A small number are less tolerant of cultural differences and they recognize that this creates some difficulties in communication.

During the focus groups, there was a strong expression of desire and a need for more thorough education in cultural content, practices, beliefs and sensitivity to differences among cultures.

CONCLUSION

The intent of our study was to determine what deficits in cultural competence exist among CUMC clinical investigators and health professionals and what challenges they face in enrolling subjects in clinical research protocols so that we might design measures to overcome the deficits and challenges.

In general, we found that healthcare providers and clinical investigators at CUMC express respect for other cultures and the attitudes, expectations and values they bring to patient care encounters and clinical research protocols. Further, there was a strong expression of provider responsibility to provide culturally sensitive care in the context of different beliefs and value systems. However, one must interpret these expressions of respect and responsibility in light of the existence of unconscious bias and stereotyping that lead to differences in communication and treatment.[23] CUMC clinical investigators expressed a felt need for more thorough and effective cultural sensitivity training and a desire to communicate more effectively with other cultural communities. The challenge of communicating with patients through interpreters is well understood; there were expressions of frustration and uncertainty about whether interpreted communication is adequate or effective. There was special concern about the quality and medical accuracy of translation, par-

Table 6. Accommodation of different cultural and ethnic groups

Query	Agree # (%)	Disagree # (%)	Don't Know # (%)	NA or Missing # (%)	Total # (%)
A. My department or clinic, consistent with the needs of the community, has qualified paid or volunteer interpreters on staff, i.e., individuals who are native or proficient speakers of Spanish and/or Sudanese and/or French and/or etc.	20 (54.1)	12 (32.4)	3 (8.1)	2 (5.4)	37 (100)
B. This department or clinic provides cultural sensitivity training to its entire staff	10 (27.0)	18 (48.6)	9 (24.3)	0 (0)	37 (100)
C. This department or clinic is making an aggressive attempt to increase the number of ethnic/minority healthcare providers	21 (56.8)	8 (21.6)	7 (18.9)	1 (2.7)	37 (100)
D. My department or clinic's posters, booklets and pamphlets are published in a variety of languages to meet the needs of our ethnic and racially diverse patient clientele	23 (62.2)	12 (32.4)	1 (2.7)	1 (2.7)	37 (100)
E. My department or clinic's posters, booklets and pamphlets include pictures of people of color as well as whites to indicate the diversity of our clientele and providers	27 (73.0)	2 (5.4)	7 (18.9)	1 (2.7)	37 (100)

ticularly when someone other than a health professional is used as the interpreter.

The fact that clinical investigators have stated that they have difficulty in enrolling minorities and immigrants, while simultaneously expressing significant respect for other cultures and making real efforts to be culturally aware suggests that the problem arises in inadequate communication, in spite of efforts to improve communication. It suggests that investigators may be concerned that their ability to explain protocols in another language to another culture is not adequate to obtain truly informed consent. The university IRB requires written translations of protocols if nonnative English speakers are to be enrolled. But it is well known that information and understanding regarding protocols is most effectively communicated by a combination of written and oral descriptions and discussion.[24]

Another barrier to enrollment may be that our investigators do not have good knowledge of how to access members of minority and immigrant communities. Most of the community groups that we studied expressed willingness to participate in clinical research if they believe it will be of value to their community,[16] though African Americans were significantly divided about this. Thus we should provide investigators with information and services that enable them to reach out to community groups and organizations to inform them about research opportunities.

We conclude that there are several subjects that can and should be more heavily emphasized in cultural sensitivity training. These include:

- more information about ethnically or folk-defined diseases;
- more information about folk practitioners and folk remedies;
- more information about interpersonal and group relationships within different cultures; and
- more opportunities to interact with members of other cultures in environments other than the medical center.

We also concluded that there should be greater promotion of specific cultural sensitivity training programs: a significant minority of our participants was unaware of cultural sensitivity training offered at our medical center. There is also a need to disseminate more widely the policy and information about the availability of interpreter or interpretation services.

We have designed a program to educate minority communities about the intent and value of clinical research in respect to health disparities, what their expectations about clinical research should be, what their rights are with respect to information and continued participation, what questions they should ask if they are requested to enroll in clinical research protocols and to keep participants and communities informed of the results of specific research projects. Culturally specific approaches to each of the minority communities will be utilized. The intent is to enable our investigators to access minority communities more readily and to ensure that the communities know what to expect of investigators and what the rights of research subjects are. We will report this and an evaluation of its outcomes in a future communication.

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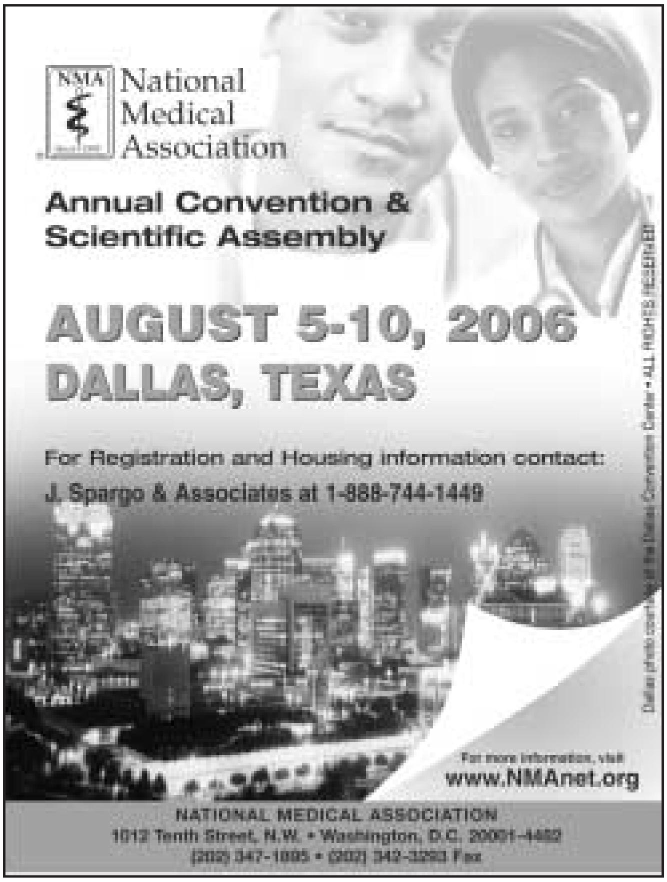

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