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Promoting cultural proficiency in researchers to enhance the recruitment and participation of minority populations in research: Development and refinement of survey instruments

Omofolasade Kosoko-Lasaki[a,*], Cynthia T. Cook[b], Richard O'Brien[c], Judith Kissell[c], Ruth Purtilo[c], Frank Peak[a]

[a]*Health Sciences Division and Medical School, Creighton University, 2500 California Plaza, Omaha, NE 68178, USA*
[b]*Department of Sociology, Creighton University, USA*
[c]*Center for Health Policy and Ethics, Creighton University, Ethics Initiative at the MGH Institute of Health Profession in Boston, MA, USA*

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Abstract

A community assessment instrument (CAI), to assess community attitudes and beliefs about research and services of the local medical establishment, and a cultural competency instrument (CCI), to assess the cultural knowledge and competence of clinical investigators, were developed to address the need for culturally competent researchers by the minority community that the Omaha health care system (especially Creighton University) serves. The instruments also investigated the minority community's knowledge of medical research and benefits. The CAI and CCI questionnaires were administered by trained interviewers to members of ethnically and racially diverse groups in Omaha and to a group of researchers and clinicians at Creighton University. Respondents identified questions that were difficult, not clear and/or controversial. Modifications to the CAI and CCI were made for use in subsequent focus group studies. This publication reports a pilot study intended to develop and refine the instruments.

Keywords: Cultural proficiency; Researchers; Community; Minority populations

1. Introduction

Despite the overall improvement of health in the American population, studies have shown that there are disparities in the health and health care of certain racial and ethnic groups (Blue, 2003; Brach & Fraser, 2000; Brant, Ishita, et al., 1999) and disparities in the delivery of culturally and linguistically competent care (Cross, Bazron, Dennis, & Isaacs, 1993; Edgar, Patton, & Day-Vines, 2002).

Because many of the determinants of well-being span the boundaries of healthcare and medicine, eliminating health disparities calls for new and non-traditional partnerships with diverse sectors of the community. This requires a new approach to research, especially if the subjects are of a diverse groups and/or cultures that experience health-care disparities. The effort also calls for a fundamental change in how research is designed, conducted and disseminated in collaboration with diverse racial and ethnic communities (Francis, 2001; Glenn-Vega, 2002; Hanley, 1999; Jackson, 2002; Mason, 1995a, b). We believe it also calls for the engagement of communities in the development of clinical research protocols that address health disparities.

2. Background

The Creighton University Medical Center (CUMC) has undertaken a program of research that addresses health disparities in minority populations of Omaha, Nebraska. It is well known that some, maybe most, minority populations harbor a distrust of the health care establishment and are reluctant to participate as subjects in clinical research projects (Dominick & Wimmer, 2003; Freimuth, Quinn, &

*Corresponding author. Tel.: +1 402 280 2332; fax: +1 402 280 4030.
E-mail address: skosoko@creighton.edu (O. Kosoko-Lasaki).

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Thomas, 2001; Madriz, 2001; Shavers, Lynch, & Burmeister, 2000; Talone, 1998; White, 2000, 2002). In order for CUMC clinical scientists to conduct research in this area, it is essential that they develop trusting relationships with minority communities. This requires that CUMC investigators understand the cultures they study and that minority populations understand and appreciate the value of participating in research.

With the intent to develop educational programs addressed to clinical investigators and community members, we developed two assessment instruments: a community assessment instrument (CAI) (Online Appendices 1–4) and a cultural competency instrument (CCI) (Online Appendices 5 and 6). The CAI is intended to assess the knowledge, perceptions and attitudes of the minority communities that Creighton University serves and the minority communities' knowledge of medical research and its benefits. The CCI is intended to assess the level of cultural proficiency among CUMC medical researchers, clinicians, and other healthcare providers.

This report details the pilot study and the modifications made to both the CAI and CCI before administering the instruments to the focus groups selected for the larger studies. Pilot study and the main study were approved by the Creighton University Institutional Review Board.

3. Materials and methods

3.1. CAI pilot study methodology

The CAI was developed to answer five research questions that were formulated to assess the need for culturally proficient health-care providers and three research questions formulated to assess the minority community knowledge of health care issues. The research questions are:

3.1.1. Need for culturally proficient providers and researchers

Research question 1: To what extent are people of color satisfied with health care in the Omaha community?

Research question 2: To what extent are people of color able to communicate with health care providers in the Omaha community?

Research question 3: To what extent do people of color prefer to be treated by health care providers who are of the same ethnic, racial, and/or cultural background?

Research question 4: To what extent do people of color practice folk medicine?

Research question 5: To what extent do people of color feel pressured to assimilate?

3.1.2. Knowledge of health-care issues

Research question 6: To what extent have people of color participated in a health care study or/and do not want to?

Research question 7: To what extent do people of color know the benefits of participating in health-care study?

Research question 8: To what extent do people of color know the leading cause of death for people in their ethnic/racial group?

Fifty-one survey items were developed to test these 8 research questions.

Research question 1—**dissatisfaction with health care in the Omaha community** was measured by: rating of health care providers, visiting another health-care provider for the same condition that was not a referral, not wanting to see the same health-care provider on returning to the health facility for another illness episode, and whether respondent received medication or an injection during the visit.

Research question 2—**not able to communicate with health-care providers**—was tested using: not being able to complete paper work or forms at health care facility, doctor not asking patients what s/he thought caused illness, no discussion with patient about treatment, not asking about alternative medical providers, not asking about family and friends perception of illness, need for an interpreter, health-care providers use of language, gestures, and visual aids to communicate, whether the health care providers communicated at the client's level, and whether health-care provider communicated effectively.

Research question 3—**people of color preferred to be treated by health care providers of the same ethnic, racial, or cultural background**—was rephrased in question format and asked of respondents along with the question of whether certain illnesses or conditions are better treated by someone of the same ethnic, racial, or cultural background.

Research question 4—**people of color practice folk medicine**—Respondents were asked if there were cultural practices that they performed before going to a health care provider. Research question 5—**feeling pressured to assimilate**—was tested with feeling uncomfortable because they talk, dress, or look different; are pressured to accept treatment or therapy that may go against their cultural beliefs or practices; and being pressured to change gender role behavior.

Research question 6—people of color have never participated in a health care study and do not want to, Research question 7—people of color do not know the benefits of participating in a health care study and do not know anyone who has participated in a health-care study, and Research question 8—people of color do not know the leading cause of death for people in their ethnic/racial group—were rephrased in question format and asked of respondents.

A pilot study was conducted to measure the efficacy of these items and to clarify and refine the draft CAI before administering it to the larger community. Twelve persons, a cross-section of the Omaha minority community, were recruited from organizations representing members of the African American, Hispanic American, Native American, and Sudanese refugee populations. Community organizations were contacted by telephone or visited by a study representative. The only requirement for participation was that the participant be a person of color, proficient in

English (no interpreters were available for the pilot study), and have had contact with a health care provider within the Omaha community within the last year (see Online Appendix 7 for additional information on guidelines for recruiting participants).

Respondents were given an overview of the cultural proficiency study by the study coordinator. They were then asked to sign a consent form. When all consent forms had been collected, the Pre-CAI instrument (Online Appendix 1) was distributed. Respondents were given approximately 30 min to complete the form. Respondents were then asked to answer the questions to the best of their knowledge and ability. They were told that all questions would be answered after the focus group discussion was conducted. After the questionnaire was collected from all respondents, the facilitator, a person of color not affiliated with Creighton University, conducted the focus group discussions, which was transcribed by a paid recorder. After the focus group discussion, respondents were asked to complete the Post-CAI instrument (see Online Appendix 2). Respondents were paid $50 for travel and time.

3.2. CCI pilot study methodology

The CCI (Online Appendix 5) was developed to provide possible answers to the research question that health-care providers at CUMC were culturally proficient when delivering health care to people of color. Twenty-six survey items were developed to answer this research question. These items were based on the six levels of cultural competency as discussed by Blue (2000), Cross and et al. (1989), Edgar et al. (2002), Glenn-Vega (2002), Mason (1995), and National Center for Cultural Competence (2002). The research survey items were pilot tested with six providers and clinical investigators from CUMC.

The CCI instrument sought to measure how well the survey items/levels were integrated into the delivery of health care that serves an ethnically and racially diverse population.

After participants were given an overview of the purpose of the cultural proficiency study, they were then asked to sign a consent form. When all consent forms had been signed and collected the survey instrument was distributed. Respondents were given approximately 30 min to complete the form. As with the CAI pilot group, there were many questions and comments about the instrument. Respondents were asked to answer the questions to the best of their knowledge and ability and to hold their questions and comments until the focus group was conducted. Respondents kept their questionnaire during the focus group discussion. Suggestions and comments articulated during the focus group were also written on the questionnaire and handed in at the end of the meeting. The facilitator that conducted the focus group for the CAI pilot study also conducted the CCI focus group. Respondents were paid $50 for travel and time.

4. Results

4.1. CAI pilot study

The pilot study provided preliminary answers to our research questions and identified flaws in the design of the instrument. Table 1a–f provide demographic information on the twelve participants. Five of the 9 female participants were African Americans. Only two of the respondents were married: the Sudanese male and the Hispanic female. Two individuals had no children. The Hispanic representatives were both female and indicated that English was not their first language. Two of the four Native Americans were male and one indicated that English was not his first language. The Sudanese male spoke Nuer as his first language. Only the Sudanese and one Native American were college graduates, but two of the African Americans, one Native American, and one Hispanic American had some college education. Respondents were not asked for their income or age. Their occupation is detailed in Table 1f. Three people indicated that they were retired (two African American females and one Native American male). Two women, one African American and one Hispanic indicated they were homemakers/housewives (both women were either separated or divorced), and one African American female said she was disabled. All the other participants were employed.

4.2. CAI pilot study revision

The first revision to the CAI instrument based on the pilot study had to do with age, number of children, and children under 19. The original instrument neglected to ask

Table 1a
Race/ethnicity-marital status and gender demographics of focus group participants

Race/ethnicity and gender	Male	Female	Total
African American	0	5	5
Native American	2	2	4
Hispanic American	0	2	2
Sudanese-American	1	0	1
Total	3	9	12

Table 1b
Race/ethnicity and English demographics of focus group participants

	Yes	No	Total
African American	5	0	5
Native American	3	1	4
Hispanic American	0	2	2
Sudanese	0	1	1
Total	8	4	12

Table 1c
Race/ethnicity and education demographics of focus group participants

	High school	HS grade	College	College graduate	Master	Total
African American	1	2	2	0	0	5
Native American	2	0	1	1	0	4
Hispanic American	1	0	1	0	0	2
Sudanese	0	0	0	0	1	1
Total	4	2	4	1	1	12

Table 1d
Race/ethnicity and number of children demographics of focus group participants

# Children and race/ethnic	0	1	2	3	4	5	11	Total
African American	1	0	2	0	1	0	1	5
Native American	1	0	1	0	1	1	0	4
Hispanic American	0	0	1	1	0	0	0	2
Sudanese	0	0	0	0	0	1	0	1
Total	2	0	4	1	2	2	1	12

Table 1e
Race/ethnicity and marital status demographics of focus group participants

	Single	Married	Divorced	Separated	Widowed	Total
African American	3	0	1	0	1	5
Native American	1	0	3	0	0	4
Hispanic American	0	1	0	1	0	2
Sudanese	0	1	0	0	0	1
Total	4	2	4	1	1	12

Table 1f
Race/ethnicity and occupation demographics of focus group participants

Occupation	Frequency
Housewife/homemaker	2
Interpreter	1
Day care teacher	1
Supervisor	1
Administrative assistant	1
Human services worker	1
Event exercise	1
Disabled	1
Retired	3
Total	12

the respondent's age. Although we had asked if the respondents had children and their ages, many of our respondents said they did not remember the age of their adult children. Thus, we revised the instrument to obtain the respondents age and the number and age of children under 19. In Nebraska, children are still considered minors until they reach the age of 19. The assumption was that

Pilot Study CAI	**Main Study CAI**
Age not asked.	What is your age?
Question not asked.	How many children do you have? a. 0 b. 1 c. 2 d. 3 e. 4 f. 5 or more (specify)
	How many children are under age 19? a. 0 b. 1 c. 2 d. 3 e. 4 or more
Question not asked.	What are their ages?

Fig. 1. Demographics: age.

children under 19 may still be dependent on their parents for health-care (see Fig. 1). It was important to ascertain that the respondent's contact with health-care providers were primarily for him- or herself or for children who still lived in the home. As indicated earlier, all of the respondents had children except two, however, we did not get their ages.

The second revision was to education, race, and religion. The pilot study asked: what is your education. Some respondents did not know how to interpret this, others wanted us to know that they had an associate degree. This question was revised to ask for the highest grade or degree completed. We also added associate degree to the list of choices. Race also created a problem. Race and ethnic

group were originally two questions. Race was a closed-ended question: Black, White, other; and ethnic group was open-ended. However, none of our respondents in the pilot study chose the white category, they all wrote in their ethnic group. For these respondents ethnic group and race was one and the same. Since we were able to identify the groups that we wanted in the study, we developed one closed-ended question. There were no Vietnamese or whites in the pilot study, and we needed to distinguish between the Sudanese and the African Americans (the Sudanese considered himself an African American because he had citizenship). Thus, the revised question that was used in the main study (Cook, Kosoko-Lasaki, & O'Brien, 2005) had representation from all of the ethnic groups in the pilot study in addition to the Vietnamese and White groups.

Religion was an optional open-ended item in the pilot study and remained optional, but closed-ended in the main study. Attempts were made to cover all possible religions in the Omaha community. However, all of the respondents in pilot study identified themselves as protestants with the exception of one Native American who wrote Native American church (see Fig. 2 for revisions to education, race, and religion).

The next revision was when we asked our respondents where they get their health care. The question asked: "When you and a family member are ill, you go to _____" (see choice of answer in Online Appendix 1). Most of our respondents went to the emergency or the doctor's office. One respondent said she went to the clinic and treated herself. Some respondents wanted us to define what we meant by ill: "how ill?" However, one respondent said, "it was hard to just take that one specific time I went to the doctor and then answer all the questions… so my answers are kind of…" Another respondent said, "…it's hard for me during this questionnaire to take a specific example when I went to the doctor. I was picking and choosing the different times because I've had different experiences…It wasn't all for the same thing." We also didn't know if the emergency room they were using was Creighton University or another health care facility. The "other" category was added in the hopes that respondents would inform us if they used a folk, traditional, or herbal healer. The revised question asked what provider they used the last time they were ill and if that provider was affiliated with CUMC (see Fig. 3).

The fourth revision had to do with written communication. The question was rephrased so that "last time" appeared in the beginning of the sentence and we added a "don't know choice". Only three respondents in our pilot study said they did not have to complete forms the last time they went to the ER, clinic, or doctor's office. All three were African Americans (see Fig. 4).

The fifth revision was the most significant for our main study. The pilot study assumed that "satisfaction" was associated with physicians only and not other health professionals; however, a couple of our respondents indicated dissatisfaction with a nurse and a lab technician.

Pilot Study	**Main Study**
What is your education?	What is the highest grade or degree that you have Completed?
a. Some high school	a. Some high school
b. High school/GED graduate	b. High school/GED graduate
c. Some college	c. Some college
d. Bachelor degree	d. Associate degree
e. Some graduate work	e. Bachelor degree
f. Master s degree	f. some graduate work
g. Ph.D, J.D., M.D.	g. Master s degree
h. Other (specify)	h. Ph.D., J.D., M.D.
	i. Other (specify)
What is your race?	What is your race and/or ethnic group?
a. Black	a. African-American/Black
b. White	b. Caucasian/White
c. Other (specify)	c. Hispanic/Latin
	d. Native American
	e. Sudanese
	f. Vietnamese
	g. Other (specify)
What is your religion (optional)?	What is your religion (optional)?
	a. Protestant
	b. Catholic
	c. Native American
	d. Buddhist
	e. Muslim
	f. Judaism
	g. Other (please specify)

Fig. 2. Demographics: education, race/ethnicity, and religion.

This question, therefore was changed: respondents were asked to rate doctors, nurses, and other health-care personnel that they had contact with during their health care visit (see Fig. 5). The majority of our pilot study respondents were satisfied with the care they received, but wanted to distinguish between nursing care and medical care.

The sixth revision created the most challenge. The pilot study question wanted to ascertain if the respondents were dissatisfied with their health-care provider and therefore sought a second opinion or another provider for the same illness. There was no time period specified, and the wording of the question was very confusing to the respondents (see comments in Pilot Study Transcript in Online Appendix 8). This question was reworded to query about health utilization within a 2-month interval of their last visit to a health provider (see Fig. 6). The results of the pilot study

Pilot Study	Main Study
When you or a family member is ill, you go to _____?	I would like for you to think about the last time you or a family member was sick or ill. Did you or the family member go to_____?
a. Emergency room (ER)	a. Emergency room (ER)
b. Clinic or HMO	b. Clinic or HMO
c. Doctor s office/private physician	c. Doctor office/private physician
d. Treat yourself or family member at home	d. Treat yourself or family member at home
	e. Other (specify)

If you chose letter a, b, or c in the previous question, was the health care facility or health care provider affiliated with Creighton University Medical Center (CUMC)?

a. yes
b. no
c. don' t know

Fig. 3. Health care.

Pilot Study	Main Study
I would like for you to think about the last time you went to the ER, clinic, doctor' s office. Were their forms or papers that you had to complete?	The last time you went to the ER, clinic, or doctor s office, were their forms or papers that you had to complete?
a. yes	a. yes
b. no	b. no
	c. don' t know

Fig. 4. Health care.

Pilot Study	Main Study
How would you rate the care you received at that visit?	How would you rate the care you received from the nurses at your last visit to the ER, Clinic or doctors office?
a. excellent	a. excellent
b. good	b. good
c. adequate/satisfactory	c. adequate/satisfactory
d. below adequate	d. below adequate
e. unsatisfactory	e. unsatisfactory
	How would you rate the care you received from the doctor at your last visit?
	a. excellent
	b. good
	c. adequate/satisfactory
	d. below adequate
	e. unsatisfactory

Fig. 5. Health care.

Pilot Study	Main Study
Did you go to another health care provider after leaving the ER, clinic, or doctor s office?	Did you go to another health care provider within two months before your last doctor s visit for the same condition or illness?
a. yes	a. yes (if yes, go to question 26)
b. no	b. no (if no, skip to question 30)
	c. don t know

Fig. 6. Health care.

indicated that two respondents had visited another provider after having seen their last health-care provider but did not know which provider they should reference in our survey.

The seventh and last revision had to do with oral communication. In our study, we were concerned with satisfaction of health care services; therefore, we assumed that if clients could not communicate with their health care providers they would not be satisfied with the care given. The pilot study respondents spoke English, but we knew our main study participants would not. The pilot study question asked about the use of ''visual aids'' for communication. Many of the respondents did not know what we meant by ''visual aids'' so this question was expanded to provide examples. Also, we added the choices: do not know and not applicable.

Most of our respondents said the provider did not use visual aids, but they all spoke English so perhaps the provider did not think it was necessary. Even though one of the requirements for participating in the pilot study was that the respondent be proficient in English, we asked the question, ''Did you need an interpreter when you visited the ER, clinic, or doctor's office.'' The respondents in the pilot study indicated that ''some clinics don't ask if you need an interpreter'' and that ''sometimes even if you speak

Pilot Study	Main Study
Did the health care provider use visual aids to communicate? a. yes b. no	Did the health care provider use visual aids to communicate? For example, show you a picture of the heart, lungs, digestive system, etc when explaining your condition or illness? a. yes b. no c. dont know d. not applicable
Did the health care provider speak to you (physician) at your level during your visit? a. at my level b. spoke down to me c. don t know	The health care provider a. spoke to me at my level b. used too many big words that didn t understand c. spoke down to me d. b and c e. don t know

Fig. 7. Communication.

English there are problems of understanding…Perhaps there should be a question, did you understand the language of the health care provider.'' Another suggestion was ''were you offered an interpreter?'' No revisions were made to the pilot study question on interpreter usage, since several other questions had been developed to measure communication as shown in Figs. 7 and 8.

The pilot study respondents were also asked about their perception of how the provider spoke to them. Most said they were spoken to at their level; one person, a Hispanic female, said she ''didn't know''. However, the choices for this question were expanded to include ''used too many big words'' (see Fig. 7).

The final revision was to a general question regarding effective communication. This was developed into 3 new questions in the main study as shown in Fig. 8 (see also Online Appendix 3).

4.3. CCI pilot study results

Six health- care providers affiliated with CUMC participated in our pilot study. Table 2 gives the demographics by race and gender.

Pilot Study	Main Study
Did you feel that you were able to effectively or ineffectively communicate with the health care provider? a. effectively b. ineffectively	Were you able to talk to the nurse about your illness? a. yes b. no c. yes, but s/he _____ d. don t know e. not applicable

Fig. 8. Communication.

Table 2
Demographics of the participants in the CCI pilot study

Race	Number	Sex	Number
Black	1		
White	3	Male	3
Chinese	1	Female	3
Filipino	1		
		Total	6
Total	6		

The health-care providers, who were the respondents to the CCI pilot questions objected to the true/false format. Many said the multiple-choice format would be more appropriate and that we should add a ''not-applicable'' category or a ''don't know''. For the limited number of multiple-choice questions that were on the pilot instrument, many respondents said they would have to choose more than one answer. Terms like ''assimilation,'' ''bizarre'' and ''folk illnesses'' should be defined. The respondents commented that some of the cultural practices (like scarification, female genital cutting, and child marriages) that we were enquiring about were illegal in the USA but should be included anyway. The comments by the health care providers resulted in a complete revision of the CCI instrument to a multiple-choice format for the main study. In addition, questions like ''length of time at CUMC,'' ''percentage of time spent in clinic,'' ''percentage of time doing research,'' and ''department affiliated with'' were added to the identifying data section because they were more comprehensible to the individuals. See Online Appendix 5,6 and 9 for the CCI pilot study questionnaire, the revised questionnaire, and the transcript from the CCI focus group discussion.

5. Discussion

The terms and definitions used in the content of the CAI and CCI instruments were adapted from studies and publications well detailed in the literature (Cross et al., 1989; Goode, 2003; Hanley, 1999; Mason, 1995a, b). There

was no attempt to prove the statistical validity of the survey items. The research questions were designed to measure individual perception of the cultural proficiency of their health-care providers. Specifically, the CAI questionnaire was developed to assess the strengths and the weaknesses of the medical community in Omaha in providing culturally competent health care and conducting clinical research for a diverse client/patient population. The instrument identified the strong areas that can be used as models for developing, improving, and maintaining, cultural competency and/or proficiency within the Creighton medical community. The CAI also identified areas in which people of color perceive the need for improvement by the medical community through self-awareness and/or cultural sensitivity training. In addition, the instrument is intended to assess how well people of color in Omaha communities are informed about their particular group's health-care needs and their willingness to participate in health care or clinical research studies.

The CCI instrument was designed to measure how well cultural competency behavior is integrated into the delivery of health care to an ethnically and racially diverse Omaha population. This instrument will allow administrators and healthcare providers to identify areas of, and levels of, cultural competency that may need improvement. Knowing the level of competence allows facilities and providers to begin the discussion on how to improve services to a racially and ethnically diverse population or to recognize their limitations; that is, the medical facility may be competent to provide services to a mono-cultural or bicultural population only.

The CCI was designed to identify six levels of cultural competency in the medical providers (researchers, physicians, nurses, and other health-care personnel) at Creighton University. We believe that the instrument will also help the researchers in the development of clinical research protocols that address health disparities. The definitions and/or characteristics describing each level have been well documented in the literature (Blue, 2000; Cross, et al., 1989; Edgar, et al., 2002; Glenn-Vega, 2002; Mason, 1995a, b; National Center for Cultural Competence, 2002).

The limitation of this study is the sample size. The small representation of specific racial and/or ethnic groups is insufficient for making inference to the larger Omaha community and may impact the validity of the instruments.

6. Conclusions

The CAI and CCI instruments have been developed, revised and modified after the initial interview with the focus groups. Since their development, the modified CAI and CCI instruments have been used in further focus group studies at Creighton University and in the Omaha community that we serve. The results from these studies are documented in recent publications (Cook et al., 2005; O'Brien et al., 2006).

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Appendix A. Supplementary data

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.evalprogplan.2005.12.003.

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