SECTION 20

SPECIAL POPULATIONS CONSIDERATIONS

INTRODUCTION

An important goal of WHI is to recruit and retain a representative sample of postmenopausal women of various ethnic, racial, and socioeconomic backgrounds. This includes women with low literacy levels, visual problems, or other conditions that may challenge their ability to participate. Regardless of whether a Clinical Center (CC) has been designated as a minority site, it is expected that the sample from each CC will include women from a variety of backgrounds. This section on special populations considerations is written as a guide to facilitate CC staff to optimally address the needs of women with a variety of experiences and backgrounds. It recognizes that women will be included in the study who have differences that must be considered as they are recruited and participate in the study.

This section begins with a general discussion of special considerations in cross-cultural counseling and interactions. Information is provided regarding cultural values, beliefs, and behaviors that need to be considered when counseling and interviewing participants as well as suggested approaches for maximizing successful cross-cultural interactions. The special needs of older women are presented, followed by those of women of ethnic minorities. General issues that need to be considered with all minority group women are presented as well as special considerations for women from specific minority groups. The reader is cautioned that these general characterizations may not apply to all minority women. These guidelines are simply meant to offer perspectives that will aid in dealing with these subgroups of women more sensitively, thereby encouraging participation, and adherence, with the study protocols. It should also be noted that some of these issues may be relevant as well for women who are not minorities. This section also considers approaches that should be used with women with special needs.

The final part of this section includes the “Guidelines for Translating Documents into Spanish.” Several CCs have been identified to recruit Hispanic participants and require the Spanish version of WHI documents. This information is included as a matter of record of how WHI documents were translated into Spanish and for reference by CCs in the translation of CC-specific documents.

20.1 Special Considerations in Cross-Cultural Counseling and Interaction

One key to cross-cultural counseling is an understanding of value systems in other cultures and their influence on health and nutrition. Every culture has a value system that directs behavior by setting norms.

20.1.1 Cultural Values

A value is a standard that people use to assess themselves and others. It is a widely held belief about what is important and desirable for well-being. Working with participants from diverse backgrounds requires understanding your own values as well as the values of other groups. Too often we interpret the behavior of others as negative because we don't understand the underlying value system of their culture.

There is a natural tendency for people to be "culture bound," to assume that their values or customs are more sensible and right. Cross-cultural counseling and interaction presents special challenges because they require you to work with participants without making judgments as to the superiority of one set of values over another.

To enhance your understanding of cultural differences in values the following list provides a general comparison of Traditional American values with values commonly found in some other countries.

Traditional American Values	Other Cultures' Values
Personal control over environment	Fate
Change and variety	Tradition
Competition	Cooperation
Individualism	Group welfare
Future orientation	Past orientation
Directness	Indirectness/"Face"
Informality	Formality
Time Importance	Human interaction importance
Duration of life	Quality of life

Examples of Potential Differences in Values

- Participants and health-care staff may differ on the value of time. Most of us are ruled by time schedules. If "being on time" and "not wasting time" are not familiar concepts to the participant, a 9 o'clock appointment may not be kept until 10 or 11 o'clock. This may be considered entirely appropriate behavior.
- Decisions regarding medical screening or food intake might not be decided by the individual, but by group or family agreement. Thus, a woman may not follow the practices suggested because of extended family values and traditions.
- A woman may not believe that her health habits are related to well-being, but rather attribute them to "fate." Thus prevention will be viewed as a "waste of one's time."

20.1.2 Health Beliefs

Cultures vary in their beliefs of the cause, prevention, and treatment of illness. These beliefs dictate the practices used to maintain health. The value of "good health" is also variable. The traditional American culture emphasizes duration of life, whereas some other cultures place greater emphasis on the quality of life.

A woman may follow a specific process in seeking health care. Family is much more important in some cultures. The family supports and is frequently involved in the treatment, unlike Western medicine where the person is dealt with as a separate individual (not a part of a larger family).

20.1.3 Approaches to Dietary Change

Eating is a personal matter and people will change other aspects of their lives such as clothes and language first, and food habits last. Assure participants that traditional American foods are not necessarily better choices than their own culture's food choices.

For some ethnic groups, respect for authority and politeness in public may prevent a woman from raising questions about the study or the dietary change required. You may need to ask several times if there are any questions about the study or diet program.

The degree of compliance may be hard to evaluate and assure. If a woman's values are inconsistent with the underlying rationale for the recommended change, the probability of noncompliance is high. Women may agree to do something out of courtesy or fear, but may have no intention of following through with the study recommendations. Limited understanding of health issues may act as a disincentive for participant compliance, particularly for preventive measures.

20.1.4 Non-Verbal Communication

Your personality and communicating style affect the counseling process. The women may easily detect attitudes you think you are concealing. Genuine interest and concern for the woman are essential qualities for CC staff members during cross-cultural counseling and interaction.

Messages are communicated by facial expressions and body movements which are specific to each culture. You should be aware of variations in nonverbal communication to avoid misunderstandings or inappropriate movements which may unintentionally offend participants. Also, you should use caution in interpreting the woman's facial expressions or body movements. Your interpretation may be quite different from the woman's intent.

- Silence. You may view silence as awkward, however, other cultures are quite comfortable with periods of silence.
- Distance. The most comfortable physical distance between you and another person varies from culture to culture. The typical American generally prefers to be about an arm's length distance away from another person. Hispanics usually prefer closer proximity than most Americans. Giving the woman options for space preference, such as saying "Please have a seat wherever you like," can help you establish the proper distance for that person.
- Eye Contact. The amount of eye contact that is comfortable varies with each culture. Many Americans are brought up to look people straight in the eye. However, older Black Americans may have been taught not to make eye contact with whites. Staring is considered impolite in some groups. However, if you avoid eye contact, or break eye contact too frequently (e.g., as you fill in forms) it may be misinterpreted by the participant as disinterest.

  Observe the participant when listening and speaking. It can offer clues to appropriate eye contact. You can also arrange to sit next to potential participants, rather than directly across from them, to reduce eye contact.

- Facial Expression. Expression of emotion between people of different cultures varies from very expressive, as with Hispanics, to total non-expressiveness, as with Asians. Many Americans have a tendency to regard people who are more expressive as immature and those with less expression as unfeeling.
- Body Language. The position, gestures, and motion of the body can be interpreted differently depending on the culture. The use of hands is a common vehicle for nonverbal expression. A firm handshake may be a positive gesture of goodwill in the Anglo-American culture, but some other cultures prefer only a light touch. Standing with hands on hips may imply anger to some participants. Pointing or beckoning with a finger may appear disrespectful to some cultures.

Conservative use of body language is wise when you are uncertain as to what is appropriate within a cultural group. Observing the woman's actions and interactions with others may give you direction for acceptable body language. Being open with participants and asking general questions about body language can also help if you have doubts about appropriate behavior.

- Verbal Communication. How you speak is as important as what you say in cross-cultural interactions. Your tone of voice should be positive, avoiding condescending, disinterested, or unpleasant tone. The volume should be audible, but not so loud as to make the woman feel uncomfortable. Often we mistakenly assume that a louder voice is clearer and therefore more easily understood by the participant. Articulate each word and adjust your rate of speech, if necessary. Speech that is too rapid might not be understood, while speech that is too slow might actually bore the woman.

  Don't try to imitate an ethnic communication style which is not naturally your own. For example, using Black American language and communication style, when you are not Black American, may be interpreted as ridicule.

- Formality. Anglo-Americans tend to be informal in their verbal communication, but some other cultures prefer to keep a relationship more formal. Don't assume a first-name basis is appropriate for client relationships. Many Black Americans may view being addressed by their first name as too familiar and may infer disrespect. With any participant, terms of endearment such as "honey," etc. should be avoided. Asking the woman how she prefers to be addressed is the easiest solution, or assume formality when in doubt.
- Rapport. It is important to establish rapport with the participant when beginning the visit. Use "small talk" to reflect genuine concern for the woman. However, too much chatting, too many questions, or being "too nice" may cause uneasiness or raise suspicion.

20.1.5 Getting Accurate Information

All staff are concerned with getting accurate information from participants, and this is multiplied when the interaction is cross-cultural. Finding approaches that get better information is easier once you are aware of some additional barriers to communication.

Possible Barriers

There are several reasons why a participant of a different culture may not provide a staff member or counselor with good information.

- Lack of trust;
- Participant feels the information you want is inappropriate;
- Participant is uncomfortable with age, sex, education level, or race of the counselor or staff member; and
- Participant will make an effort to "please" the counselor or staff member.

Suggested Approaches

- Establish rapport and show genuine concern.
- Ask questions in several different ways to double-check information.
- Adjust style of interaction to complement differences in age between you and participant.
- Use open-ended questions.

20.1.6 Preparing for Cross-Cultural Counseling or Interaction

- Understand your own cultural values and biases.

- Acquire basic knowledge of cultural values, health beliefs, and nutrition practices for participant groups you routinely serve.
- Be respectful of, interested in, and understanding of other cultures without being judgmental.

20.1.7 Enhancing Communication

- Ask how the participant prefers to be addressed.
- Allow the participant to choose seating for comfortable personal space and eye contact.
- Avoid body language that may be offensive or misunderstood.
- Choose a speech rate and style that promotes understanding and demonstrates respect for the participant.
- Avoid slang, technical jargon, and complex sentences.
- Use open-ended questions or questions phrased in several ways to obtain information.

20.1.8 Promoting Positive Change

- Build on cultural practices, reinforcing those which are positive, and promoting change only in those which are harmful.
- Check for participant understanding and acceptance of recommendations.
- Remember that not all seeds of knowledge fall into a fertile environment to produce change. Of those that do, some will take years to germinate. Be patient and provide counseling in a culturally appropriate environment to promote positive health behavior.

Information adapted from: "Cross Cultural Counseling: A Guide for Nutrition and Health Counselors." USDA, US Department of HHS, FHN 250, September 1986.

20.2 Working with Older Women, Ethnic Minorities, and Women with Special Needs

20.2.1 Older Women

Recognize the diversity and heterogeneity of older women: They will vary widely on dimensions of health and functional status, educational background, standard of living, and cultural background. The potential for certain health problems increase with advancing age.

20.2.1.1 Health and Functional Impairments

Problems:

- Vision and hearing may be impaired.
- Cognitive impairments such as memory, performance and certain dimensions of intelligence may decline with age. The speed at which information is processed may also be slower. The woman may have difficulty retrieving relevant information.
- May easily fatigue, sometimes become confused.
- May become emotionally distressed (cry) because questions asked evoke sad memories.

Solutions:

- Select a private environment that is free of distractions, extraneous noise, interruptions, etc.
- Appeal to the woman's altruism. Tell her that participation is important for future generations.
- Speak slowly, clearly, provide redundant cues (position yourself so that they can both see and hear you speak). Use the low frequency range of your voice; do not yell.
- Be alert for signs of fatigue. If possible, give the woman a brief rest period. Reschedule, if necessary.
- Strike a balance between compassion and objectivity.
- Repeat questions and response categories.
- Do not overload the woman with information.

20.2.1.2 Personality and Motivational Factors

Problems:

- May be less interested in general in topics of the study and may object to the relevance of certain types of data for the study.
- May be more readily influenced by interviewers and more susceptible to interview bias.
- Ethnic/cultural group differences may be more extreme.

Solutions:

- Clearly identify yourself and don't keep the woman waiting.
- Emphasize the importance of the study and the need for questions and procedures.
- Be sensitive to bias and try not to express opinions.
- Recognize differences in communication styles (language) among different ethnic groups.

20.2.1.3 Cohort Differences (Life Experience Effects)

Problems:

- On average, today's older women have fewer years of formal education than younger women and have encountered fewer tests and standardized interviews.
- May disregard standardized scale formats.
- May sidestep questions and converse "on the side." Information that older women have to report is inherently more complex because they have a lifetime to summarize.
- May misunderstand questions or response options.
- May have different standards about the appropriateness of being asked for certain types of information (e.g., income data; functional status data).
- May be more easily insulted at being asked particular questions (e.g., ability to stand from a chair when answer seems obvious).

Solutions:

- Explain carefully and simplify the procedures to be used and the reasons for using them.
- Give the woman a road map of what will happen, how long it will take.
- Anticipate and address participant fears and anxieties about questions being asked, procedures being used.
- Clarify questions and response options using language more familiar to the woman as needed.
- Explain that sensitive information will not be reported at the individual level; only group data will be reported.
- Emphasize the importance and value of the data to be collected and how it will help current and future generations, etc.
- Emphasize that while some questions may not be appropriate to them, they have to be asked of everyone.
- Promise to provide (and follow through) general information about the study as a whole as it becomes available.

20.2.2 Women from Minority Groups

20.2.2.1 Ethnic/Racial Sensitivity

Problems:

- May have a preference for interacting with individuals who are representative of own minority group.
- May want to participate with a friend but due to randomization scheme they may not be assigned to same group.
- May not have a personal physician or system of regular medical care.
- May be uncomfortable in groups where there are no other individuals from own racial/ethnic group.
- May perceive members of own minority group to be more aware of and sensitive to life circumstances, perspectives and concerns.
- May perceive lack of employment of individuals from minority groups on clinic staff as an indication of prejudice.

- May become offended if it appears that they or others from ethnic/racial minority groups are treated differently or are not respected.
- Published statistics and information on minority community may not be accurate.
- There may be varying perspectives and experiences in ethnic subgroups within African-American, Hispanic, Native American, and Asian minority groups.
- More likely to eat ethnic foods, special spices, seasonings, etc.

Solutions:

- Make sure staff, particularly receptionist, is pleasant, respectful, and positive.
- Do not let a woman wait for an extended period of time in the CC.
- Stress that participation in WHI does not replace the need for regular medical care.
- Select a staff that is representative of the community and that reflects a balance of ethnic/racial groups.
- Have a staff member of the same ethnic/racial background of the women available to explain study protocols, consent forms, and questionnaires.
- Appoint a local advisory committee; include reputable minority community representatives. Ensure that members are clear about their role and level of involvement.
- Become thoroughly familiar with minority community characteristics, information channels, and power structure.
- Recognize the diversity of ethnic viewpoints within minority subgroups that can influence responses to the study protocols.

20.2.2.2 Personality Motivational Factors

Problems:

- May perceive research as a form of exploitation in which non-minority individuals reap the benefits.
- May be concerned about being used as a "guinea pig" in research.
- May believe that only minority scientists should study minority populations.
- May have past history of being exploited by sales people under the guise of a survey or research study.
- May be less prone to self-disclosure in research, particularly to someone from another ethnic or racial group.

Solutions:

- Explain that the study will provide important information for all women of all ethnic and racial backgrounds.
- Note that women from all ethnic and racial groups are included in the study.
- Inform the woman that researchers from all ethnic and racial groups from across the country are involved in conducting the study.
- Have a staff person of the same ethnic and racial background of the woman available to explain information and to assist in completing questionnaires as needed.
- Present study through public forums, such as churches, community associations, fraternal groups, and in ethnically-focus newspapers.
- Obtain sponsorship of various individuals or organizations that have a reputation of showing concern for the welfare of the minority community.

- Use the media to inform and motivate the community about the study.
- Send letter about project on official agency stationery before initial contact. If initial contact is in person, have identification available from official agency.

20.2.2.3 Cohort Differences (Life Experience Effects)

Problems:

- On average, recently immigrated minorities have less experience in completing tests and questionnaires.
- May not be familiar with questionnaires that have items with multiple response options, rating scales, or "skip to" item designations.
- May be reluctant to provide personal information, particularly of a sexual nature.
- May be wary of researchers misusing information.

Solutions:

- Explain why personal and sexual information are asked on questionnaires.
- Explain how to complete forms and how to respond to items and rating scales.
- Tell the woman to ask questions about items that she does not understand. Have someone available to answer questions.
- Explain that information collected during study will only be used for study purposes.

20.2.3 African-American (Black)

Problems:

- May be quite religious. May not readily accept interventions or actions that are perceived to be against God's will or God's plan in nature.
- More likely to believe in destiny.
- May put a high degree of trust in personal physician regarding all health matters.
- May not participate in health research without the perceived support of physician or regular health care provider.

Solutions:

- Explain carefully and simply the procedures and interventions to be used and the reasons for using them.
- Anticipate and address participant questions about the naturalness of replacing hormones after menopause.
- Inform local health care providers about the study and that some of their patients may be involved.

20.2.4 Hispanic

Problems:

- May not feel comfortable speaking English.
- May seek informal approval from husband or older son for decision making.
- May be concerned that personal information (for example, income or immigration information) will place family at risk.

- May be suspicious of government involvement in a research project if family members have lived in oppressive societies with government informers.
- May assume that WHI will replace regular medical care.

Solutions:

- A staff person bilingual in Spanish and English should make initial contacts with potential participants in minority Hispanic CCs. Receptionist and preferably Clinic Practitioners (CPs) should be bilingual.
- If the person answers the telephone in Spanish, the staff person calling should continue the conversation in Spanish.
- Use the formal and respectful form of the pronoun "you" in Spanish, that is, "usted," when talking to Spanish women.
- The husband or older son, if a husband is not available, should be informed about the study to encourage their informal permission.
- Carefully explain the confidentiality of information obtained in the study.
- Assure the woman that personal information will not be provided to other government agencies.
- Explain that personal data will not be reported at the individual level; only group data will be reported.
- Send letter to health care provider about woman's participation in WHI. Stress that the family doctor or health care provider will continue to provide usual care.

20.2.5 Native American

Problems:

- May not be comfortable speaking English.
- May prefer to have a family member present during interview.
- May not accept interventions that are not readily understood or visibly demonstrated to contribute to health problems.
- May not readily accept health care services from non-Indian health service provider or urban Indian health program.
- May associate certain health problem as "normal" part of aging which do not require medical intervention.
- May de-emphasize personal health problems or complaints.

Solutions:

- Provide a trained interpreter or interviewer who speaks the language.
- Where appropriate, accept the presence of other family members during the interview.
- Explain with illustrations how interventions work to prevent disease or improve health.
- Work with local Indian Health Service or Native American health care providers to develop referrals and follow-ups.
- Explain that not all symptoms are caused by aging.
- Explain why it is important to maintain health for the benefit of self and especially for the family unit.

20.2.6 Asian

Problems:

- May be highly concerned about personal social status issues.
- May not readily provide information that could be perceived to shame or reflect poorly on self, or family members.
- May hesitate to respond to questions about income, educational level, living arrangements, and household composition.

Solutions:

- Assure the woman that all information is confidential and that personal information will only be reported as group data.
- Explain why information on income, education, and family background are important to the study.

20.2.7 Women with Special Needs

Problems:

- May not be able to read or write English or Spanish well.
- May not be able to see well enough to read or complete study forms alone.
- Mobility may be compromised.
- May not be able to complete study forms without assistance.
- May require additional time for completion of study forms.
- May become frustrated and discontinue participation.
- May have child care responsibilities for grandchildren or other young children that may interfere with participation.

Solutions:

- Let women know that assistance can be provided in completing forms if they require it, at CC discretion.
- Provide assistance if possible in completing study forms for women who have a low literacy level, visual problems, or physical mobility problems. Ensure that answers recorded are those of the woman, not of the person providing assistance.
- Women who are illiterate are excluded from the study at CC option.
- Exclude volunteers who can not speak in local CC languages or dialect. Only use translators who are part of the bilingual CC staff or volunteer translators for which levels of fluency in both languages are known to be satisfactory.
- Identify women who require assistance in completing study forms during the initial Screening Visit (SV0 or SV1). Check a form that has been completed in the CC by the woman. Incomplete forms, inappropriate responses, or an unusually long period of time completing forms indicate that a woman is likely to need assistance.
- Designate a family member or person in the household to aid women who require assistance in completing study forms at home if one is available. Clearly identify designated person, note on CC forms, and train in approach to providing assistance. Training should emphasize having the designee focus on obtaining and recording the woman's response and <u>not</u> their own. Items on questionnaires that are

sensitive or may be embarrassing to provide answers to family member should be completed in the CC with the assistance of CC staff rather than with assistance of family member.

- Women in the dietary change group who need assistance in completing study forms and participating in DM intervention may remain in this group if they are able to name a family or household member to aid them. Designees should be informed of the commitment required, trained, and encouraged to attend dietary change sessions that are necessary to understand proper completion of forms.
- Assist women with limitations in mobility with arranging transportation to and from the CC.
- Assist women with child care responsibilities; help plan or arrange child care during CC visits.
- If CCs cannot provide assistance for women with inadequate literacy skills and if the woman cannot designate a helper to assist with all aspects of the CTs, she is ineligible.

20.3 Guidelines for Translating Documents into Spanish

These guidelines for Spanish language translation address:

- Translation of documents for which there is no previous Spanish translation;
- Materials used in health promotion projects, with particular focus on multi-center trials; and
- Checking the acceptability of previously translated documents.

Guidelines for Translation:

1. Document is translated by a Native Spanish-language translator, who is skilled in grammatical rules and localized regionalisms. The translation will be entered on a computer with Spanish-language capabilities, including spell-check and thesaurus. All target audiences and their particular regional Spanish will be taken into account, including U.S. Border, Mexican, Central and South American, Caribbean (Cuban, Puerto Rican, Dominican) and Peninsular (Spain). A low literacy audience must be taken into account.
2. The first draft is proofread and reviewed by the translator. The document is to be read word by word, line by line to insure accuracy. During this review, the translator scans for errors, general syntax, and readability.
3. The first draft of the translated document is edited by a fully bilingual English/Spanish editor, who was not involved with the original translation of the document. They will have complete command of Spanish and be skilled in grammatical rules and localized regionalisms. All target audiences, and their particular regional Spanish, will be taken into account, including U.S. Border, Mexican, Central and South American, Caribbean (Cuban, Puerto Rican, Dominican) and Peninsular (Spain).
4. All changes by the editor are incorporated, and a second draft is completed. Closely scrutinized proofreading is now performed to correct any remaining grammatical/typographical errors.
5. The second draft is reviewed by designated Spanish-speaking reviewers who are involved in the use of the translated document and who are expert in the content of the original document. Ideally, these reviewers shall: (a) be expert in representing all of the affected subgroups in the target area; (b) keep in mind the goals of the intended message and the target audience; and (c) avoid re-translating the document, by merely changing the style of the piece or by replacing one correct word with another equally correct word. These reviewers will be provided brief summaries of the target population, including Hispanic subgroups, education, language preference and standards.
6. Only the appropriate reviewers comments are incorporated into the document. Although reviewers are sometimes expert on the content, they may or may not be capable of effectively representing all Hispanic subgroups. In addition, these reviewers, capable experts in their own fields, may not be "communications" experts. What might be appropriate by the reviewers standards may not be appropriate for the target audience.
7. A pilot test with the target audience is done if time and money permit.
8. When differences in opinion occur among the reviewers, broadcast-standards in the Spanish language will prevail. It is recommended that the input of Broadcast experts be considered in settling all differences.
9. A third and final draft is created, incorporating Broadcast input. This draft is submitted to the editor(s) for final proofreading and editing.
10. Another draft is prepared on a compatible computer diskette to produce galleys to reduce typesetting errors.
11. Galleys are carefully proofread by the editor(s).
12. Local Hispanic CCs should determine items or sections on forms with which Hispanic women voice confusion or difficulty.

13. Items or sections of forms with which difficulty is noted should be carefully documented, and specific written recommendations for changes should be sent to the Clinical Coordinating Center (CCC).

14. If applicable, incorporate suggested changes from local CCs into a final draft. The final draft should be reviewed by bilingual editor(s) before typesetting.

15. Final galleys are carefully proofread.

Section 20
Special Populations Considerations

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