USE OF FOCUS GROUPS IN MULTI-SITE, MULTI-ETHNIC RESEARCH PROJECTS FOR WOMEN'S HEALTH: A STUDY OF WOMEN ACROSS THE NATION (SWAN) EXAMPLE

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Objective: To outline the lessons learned about the use of focus groups for the multi-site, multi-ethnic longitudinal Study of Women Across the Nation (SWAN). Focus groups were designed to identify potential cultural differences in the incidence of symptoms and the meaning of transmenopause among women of diverse cultures, and to identify effective recruitment and retention strategies.

Design: Inductive and deductive focus groups for a multi-ethnic study.

Setting: Seven community research sites across the United States conducted focus groups with six ethnic populations: African American, Chinese American, Japanese American, Mexican American, non-Hispanic white, and Puerto Rican.

Patients or Participants: Community women from each ethnic group of color.

Interventions: A set of four/five focus groups in each ethnic group as the formative stage of the deductive, quantitative SWAN survey.

Main Outcome Measures: Identification of methodological advantages and challenges to the successful implementation of formative focus groups in a multi-ethnic, multi-site population-based epidemiologic study.

Results: We provide recommendations from our lessons learned to improve the use of focus groups in future studies with multi-ethnic populations.

Conclusions: Mixed methods using inductive and deductive approaches require the scientific integrity of both research paradigms. Adequate resources and time must be budgeted as essential parts of the overall strategy from the outset of study. Inductive cross-cultural researchers should be key team members, beginning with inception through each subsequent design phase to increase the scientific validity, generalizability, and comparability of the results across diverse ethnic groups, to assure the relevance, validity and applicability of the findings to the multicultural population of focus. (*Ethn Dis.* 2009;19:352-358)

Key Words: Focus Groups, Multi-ethnic, Menopause Transition, SWAN Study

INTRODUCTION

During the last 25 years, recognition of the importance of the social, emotional, and physical changes of the mid-life stage to women's long-term health and well-being has emerged.[1] The majority of the research on transmenopause, however, has been conducted in Western countries predominantly with clinical samples of women from European backgrounds.[2,3] Thus, this population has shaped the emergent clinical picture of the mid-life menopausal transition. Yet studies of non-European women, both in the United States and internationally, indicate significant variations in the experiences during this transition, but these cultural differences have not broadened the understanding of the meaning of this universal experience.[4–16]

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The Study of Women Across the Nation (SWAN) is a multi-site longitudinal, epidemiologic study designed to examine the physical, biological, psychological and social changes of the midlife transition in a non-clinical, population-based multiethnic sample of women. The goal of SWAN is to help identify how mid-life experiences affect health and quality of life during aging. From more than 16,000 women aged 40–55 years screened during 1995–1997, 3,150 women aged 42–52 years were recruited to comprise SWAN's longitudinal cohort of women (450 from each of seven clinical sites): 1398 European American women (total from all sites); 935 African Americans from Pittsburgh, Pa., Boston, Mass., Ann Arbor, Mich., and Chicago, Ill.; 281 Japanese Americans in Los Angeles, Calif.; 250 Chinese Americans in the San Francisco East Bay region, Calif.; and 286 Hispanic (Puerto Rican) women in Newark, N.J. and Mexican American women in Ann Arbor, Mich. More details of the study can be found on the SWAN website (http://www.edc.gsph.pitt.edu/swan/).[1,7] The focus group results of each ethnic group have been reported elsewhere.[9,14–16]

This article describes how formative focus group methods were used to expand the domains of information investigated in SWAN and to increase the scientific validity of the questions asked. We describe the advantages of and barriers to conducting these focus groups across multiple sites and with multi-ethnic populations. We also identify the challenge of comparability or equivalency of cultural concepts, mea-

Table 1. Total Focus Group Participants at Each Site

Ethnic Group	*N*	Age Range (yrs)	Grade Level
Pre-Menopausal Women			
African American	24	39–53	13.2 (*N*=14)
Chinese American (Cantonese)	15	43–46	N/A
Chinese American (English)	15	43–46	N/A
European American	34	40–54	14.2 (*N*=18)
Japanese American (English)	8	43–50	13.7 (*N*=6)
Japanese American (Japanese)	8	N/A	N/A
Puerto Rican	7	43–52	11.3 (*N*=7)
Total	111		
Post-Menopausal Women			
African American	21	39–68	14.6 (*N*=13)
Chinese American (Cantonese)	7	54–56	N/A
Chinese American (English)	5	54–55	N/A
European American	30	47–61	12.3 (*N*=20)
Japanese American (English)	4	51–67	18.0 (*N*=3)
Japanese American (Japanese)	8	N/A	N/A
Puerto Rican	9	N/A	N/A
Total	84		

sures, and outreach strategies among diverse ethnic populations, and we illustrate how and why we applied two different research paradigms, inductive and deductive, to our focus group design.

METHODS

As a preliminary, formative step to the deductively designed multi-site, multi-ethnic, longitudinal SWAN study, four or five focus groups were conducted in each of the six ethnic populations to identify unique culturally based concepts and beliefs about this life stage that might be integrated into the national study protocols to ensure that they were more culturally valid. Participants were selected according to criteria similar to the longitudinal study to obtain culturally relevant information about the mid-life transition and information that could be integrated to increase the effectiveness of recruiting and retaining SWAN participants at all seven sites.[1,17] The same cohort of women at each site participated in the full set of four or five focus groups. The strategies varied but were tailored to the population, enabling reliable comparability.

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Sample

Each site obtained a randomly selected sample. The seven sites conducted 27 focus group sets with a total of 195 women. Each ethnic group was divided by menstrual status: 14 groups with 111 pre/perimenopausal women and 13 groups with 84 post-menopausal women. Pre/perimenopausal women were aged 39–54 years and the post-menopausal women were aged 39–71 years. Premenopausal women were defined as those currently having regular menstrual cycles, while perimenopausal women experienced irregularity of cycle length not due to birth control pills or pregnancy. Post-menopausal women had not had a menstrual period in the prior 12 months. Group size ranged from 3–13 women. (Table 1)

We obtained written informed consent for all sessions at the first session. The institutional review boards at each clinical site approved all study procedures.

Focus Group Guides

The moderators and co-moderators at each site used uniform discussion guides that were developed for each of the four sessions. A 2½-hour conference phone-call training was conducted to brief all focus group moderators and co-moderators on the purpose of the focus groups, rationale for design, key focus group questions, and moderating strategies.

Focus Group Sessions

Each session addressed a different topic: 1) Conceptualizations about the mid-life transition, 2) instrument reviews of the epidemiological screening interview for phone administration, interviewer-administered epidemiological interview, and a self-administered epidemiological interview, 3) instrument review of the psychosocial screening interview for phone administration

and the psychosocial interviewer-administered interview, and 4) barriers to recruitment and retention. Each session was designed to last about two hours. The monolingual non-English or limited English-speaking groups (Spanish, Japanese, and Cantonese) were moderated by at least one bilingual, bicultural health professional.

Each participant also received a modest gift of appreciation that was predetermined to be culturally acceptable for each site. Some groups preferred cash, another received a women's health book on menopause, and others were given grocery store certificates. The values ranged from $45–$65. Notably, not all sites had included formative focus groups in their proposals, therefore, their budgets had not included funds for such gifts.

Session one was inductively designed to explore potential ethnic differences in the conceptualization of the midlife transition and to identify the language of discourse about this life stage in each ethnic group. We sought to avoid the ''category fallacy,'' which requires differentiating between etic and emic constructs. Etic constructs are thought to be universal and commonly understood. Emic constructs are culturally specific (ie, possess important meaning within certain cultural groups and are understood differently, if at all, by others). In multicultural societies like the United States, a survey question presumed to be etic may in fact be emic and, therefore, answered differently by informants of varying educational and ethnoracial backgrounds.[20]

When emic constructs are treated as etic, a *category fallacy* results, the practical significance of which may constitute a problem in generalizing data across respondents and/or a failure by the respondent to answer the question the investigator thinks is being asked.[22] Consequently, the respondent and questioner may have different understandings of the question's meaning, even though the question is in a language common to both, resulting in potential misinterpretations of data. Moreover, if the interpretive context being used by participants is not clarified, the problem will be further exacerbated across studies if assumed ''equivalent'' wording is substituted for exact replication,[20,21] thus, concepts presumed to be universal by the originating culture might, in fact, be culture-specific. The methodological tendency in quantitative studies to standardize unvalidated questions across ethnoracial population groups promotes category fallacy.

The focus group guide, therefore, used minimal preconceptualized categories and wording to explore aging as a normal, developmental process in the life course of women. For example, the word menopause only emerged after the participants used it themselves or the moderator felt the groups had exhausted use of their own descriptions and had not specifically used the term.

Topics explored were: conceptualizations of health, perspectives on what occurred during this time in their lives, the beliefs, tales about and expectations of the mid-life transition, reports of physical, emotional, social, and sexual changes experienced or expected, descriptions of how they adapted to these changes, and the meaning they attributed to these experiences. The moderator facilitated the discussion to elicit information about each topic. The terminology and concepts used by the women in particular groups informed the development of the survey questions for the larger study across all groups. These questions, containing unique ethnic-specific concepts, would likely capture a broader, more inclusive range of physical, emotional, and social changes experienced by a multicultural group of women.

Sessions two, three, and four were deductively designed to evaluate the acceptability and comprehensibility of the proposed screening, epidemiologic and self-administered interviews, psychosocial questionnaires, and recruitment and retention protocols. The proposed questionnaires were evaluated in sessions two and three for cognitive validity, ie comprehension of questions and cultural appropriateness of the wording.[18] SWAN also proposed non-invasive medical tests such as full-body bone scans to assess bone loss and carotid artery assessments of the integrity of blood flow and collection of numerous biologic samples. Focus group participants were asked for their reactions to and suggestions regarding the feasibility and acceptability of these tests, the most acceptable manner in which to present the testing, and the feasibility and acceptability of specimen collections, such as storage of their daily urine samples in their homes. The last session was designed to gather information on recruitment and retention of ethnic minority women for the initial five years of the study, since several previous national longitudinal studies of women's health had significant difficulty recruiting and retaining adequate numbers of ethnic minority women to their clinical trials.[19]

The same set of 4 (or 5) focus groups were conducted at each site. The cohort at each site (English-speaking and monolingual African, Chinese, Japanese, Puerto Rican and Mexican American groups) met for 79 sessions, each session lasting 1–3 hours (48 sessions with pre/peri-menopausal women and 31 sessions with post-menopausal women). Most sites administered the basic set of four sessions, but some sites held two sessions on conceptualizations of the mid-life transition to enable more in-depth exploration of potential ethnic differences for a total of 5 sessions.

Focus Group Data

Each session was audiotaped and transcribed verbatim at the local site. Copies of both the audiotapes and transcripts were sent to the Study Coordinating Center as a central repository. Each site's qualitative research

team did the initial analysis of their transcripts using an iterative process of content analysis and assigned descriptive codes to segments of text until the coding was saturated.[20] Concepts, themes, and domains were developed for each focus group session, shared and integrated among the teams at each site, distributed to the Study Coordinating Center, and presented to the study-wide steering committee to inform the planning of the quantitative study.

RESULTS

Important information about ethnic variations emerged. The conceptualization sessions demonstrated that the terminology used to describe menopause and the symptoms associated with the menopausal transition were defined culturally, in how the terms were used, as well as the actual concepts themselves. For example, for Japanese and Chinese American women, the term ''menopause'' as conceptualized in the medical sense had no direct translation in either of the two Asian languages.[9] When contemplating menopause, they thought of ''getting old,'' being ''over the hill.'' For Japanese-speaking groups, the years from the late 40 s through the 50 s covered the transition called ''kounenki'' - a phrase associated with a time of ''maturity or harvest.'' One woman said this stage is when ''people may feel like they are no longer young.'' Chinese American women tended to weave meanings of menopause with midlife during which a ''change in life'' occurred. They found the biologic definitions of menopause too narrow in describing the transitions associated with midlife.

Menopausal symptoms such as hot flashes were also less relevant for the Asian American women: neck and shoulder pains were more prevalent. Thus, these symptoms were added to the standardized questionnaire.[7]

Some of the African American women were offended at the phrasing of several of the sexuality questions, which seemed to assume that they were sexually active, although single. These women, who tended to be more religious, said that the implicit assumption was offensive, and there was no option in the questionnaire to respond that, by choice, they were not having sex. Therefore, this option was added. Additionally, some of the African Americans found the idiomatic vernacular language for sexual practices to be insulting. The researchers responded to their opinions and substituted the proper terminology.

Attitudes toward the symptoms, also varied by menopausal status. Pre- and peri-menopausal women expressed much greater anxiety about the potential emotional changes than postmenopausal women. The pre- and peri-menopausal women expressed concerns about the ''emotional roller coaster'' and heightened excitability:

> ''By [menopause] I will probably get very irritable. This will be my main concern. I'm afraid that I might offend someone without realizing it or that it might affect my relationship with my family.''
>
> ''I'm afraid my children would not be close to me because I'm getting old and constantly getting irritable.''

In contrast, the post-menopausal women across all ethnic groups were pleasantly surprised that the transition occurred relatively uneventfully, and many downplayed the importance of physical changes they experienced. At one site, both the African American and European American groups noted that the ''crankiness'' and ''irritability'' some attribute to ''The Change'' is actually due to the fact that women felt their wisdom and maturity gave them a positive sense of themselves and the ability to say ''no'' to requests from those they had ''nurtured'' all these years. One woman said, ''In fact, maybe they weren't such cranky old women;'' maybe they were finally saying ''It's my turn.''[14] Another explained, ''We are much more aware of what's going on and more in tune with what we are feeling.''

Using the focus groups to define study terminology also affected the selection of the study's name. For one group of African American women, the acronym SWAN prompted discussion of the racial overtones of the imagery and symbolism of a white bird. The decision was made to use another name for local recruitment in the community at this site.

An analysis of all the conceptualization sessions revealed a broad range of both positive and negative experiences yielding numerous unexpected variations in physical, social, and emotional changes. One notable unexpected commonality, however, was the increased awareness of personal mortality and death evoked by the recognition that the mid-life transition signaled that their future would be shorter than their past, and that they must seriously consider what they wanted to accomplish in their remaining time. For example, women stated:

> ''Life doesn't stretch on endlessly.''
>
> ''There are so many sicknesses and diseases that come from aging, from being older, and for women in particular. I'm scared.''
>
> ''In a way, it's telling me that I'm old—then I think of dying.''
>
> ''It's like we now have one foot in the grave.''

Most women, however, felt positive about this time of their lives because they were now comfortable with themselves. Aging itself, though, was viewed more negatively by the European American groups than among the women of color. The latter group viewed aging as a more natural and welcomed process that brought more respect and fewer encumbrances of female-role responsibilities. Thus the meaning of the midlife transition had a more positive social value than for the European American women. More extensive descriptions of specific ethnic group findings are published elsewhere.[9,14–16]

Recruitment and Retention

The recruitment and retention session informed the scheduling patterns of local sites and methods of data collection. At the New Jersey site, the data alerted researchers to the geographic shift of the community of focus since the last census. This information helped avoid expending unnecessary recruitment efforts in the wrong communities. For some ethnic groups, extending hours beyond 9:00 AM–5:00 PM, Monday through Friday was necessary to allow for better recruitment and retention. This information enabled the sites to provide required flexibility in hours before the start of recruitment.

Transportation to the study office sites for the interviews, blood tests, and other medical tests posed problems in most communities. The Los Angeles SWAN staff opened their study office in the community with the largest concentration of Japanese Americans in order to reduce the commute time and parking costs and to increase local visibility of the study. For retention, participants stated that rather than ''gifts'' like bags or mugs, they wanted newsletters or meetings to keep them apprised of the study's findings and how the findings might inform their lifestyle choices. Each study instituted such strategies.

Research Protocols

The women also suggested strategies to minimize some of the more burdensome and onerous data collection procedures. Examples included: reducing the number of psychosocial questions (the final questionnaire for the first five years consisted of about 108 questions), scheduling blood collection for the early morning so women could stop by on their way to work, having in-home mini-freezers for urine collection, and tailoring the process of collecting daily menstrual calendar information and the size of the forms for ease of record-keeping, and confidentiality from family. All these suggestions were incorporated into the protocols.

Due to the intensive nature of the data collection required for the quantitative portion of the study, these focus groups were invaluable. The findings enabled each site to improve and ensure full participation and maintain retention rates of more than 78% of the original 3150 participants during the 10 years of the study. Attrition was primarily due to women who have moved away and could no longer return for the collection of biologic materials or the few who have died.

DISCUSSION

We identified both advantages and challenges incorporating focus group methodology into the SWAN study.

Advantages

The mixed method approach yielded several important advantages. First, the inductive focus group methodology provided the investigators with a broader definition and understanding of the biological, psychological, and social meaning of the menopausal transition for women in diverse ethnic groups, and highlighted that the conceptualization of the menopausal transition has been drawn primarily from a Eurocentric perspective. Access to these women's perspectives was essential to developing a multicultural understanding of this period of life, and thus fulfilled the aims of the project. Second, the findings enabled the researchers to modify and tailor some of the questions to capture the variations among the diverse ethnic groups. Third, the focus groups provided key information to more efficiently and effectively recruit and retain the target cohort size, and conduct the full data collection. Finally, the qualitative focus groups provided a minimal level of face and construct validity to the survey instrument. The longitudinal aspect of the study has allowed for the addition of more cross-culturally supported questions in various domains, and thus mitigated the effects of relying on questions that were not given at least face-validity assessment in all of the ethnic groups. Fuller development of the focus groups for conceptual equivalence of additional constructs, however, could have strengthened the survey aspects of the quantitative study.

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Challenges

Although the SWAN study was initially developed to identify and study potential differences in the social, cultural, and psychological meanings of menopause among diverse populations, the implications and metrics of assessing these differences were not considered. All of the principal investigators were trained in deductive research methods with limited inductive research experience. This lack of familiarity with the inductive paradigm required additional time during the early planning regarding implementation of the research protocol to inform these scientists about this paradigm, the required protocol, and its value in eliciting probable cultural variations in the concepts of focus in the study. This process required several unbudgeted elements, in both time and money.

After discussions with the Diversity Task Force (authors of this manuscript),

the leadership of the cooperative study supported the development and implementation of these focus groups. Researchers with inductive research expertise and cross-cultural focus group interviewing skills, however, were not part of the investigation teams at all seven sites.

The usual tensions inherent in coordinating multi-site projects with disparate objectives were occurring simultaneously with the addition of this formative phase. The steps to coordinate a mutually acceptable protocol for the deductive hypotheses driven multicentered clinical trial consumed time and resources. Nevertheless, the combination of research strategies assured better comparability of hypotheses, appropriate and adequate sampling strategies, adequate sample size requirements for statistical analyses, instrument selection, data collection and storage procedures, and improved protocol for coordination strategies over the study period. Once the value of inductive strategies and qualitative methodology was recognized, the actual planning progressed expeditiously, although not without problems.

For example, differences in expectations of the timelines due to methodological demands of the two research paradigms created tensions. The data analysis time period is relatively brief for deductive, quantitative studies compared to inductive, qualitative projects in which the data analysis phase is often the longest and most labor intensive period of the study. In SWAN, this time discontinuity led to delays in conducting the focus groups and established unrealistic expectations during the analysis phase of the transcripts.

In addition, the time and resource intensive requirements of this phase were absent from the initial funding at three of the sites, and only four of the seven sites had included qualitative personnel with inductive, cross-cultural expertise on their study teams. The resultant lack of time, money, and personnel with qualitative expertise significantly delayed this phase and created tensions.

The need for translation of the instruments of both the formative and deductive phases was unanticipated and unbudgeted. Most of the principal investigators lacked experience with non-English speaking populations, but SWAN had targeted non-English speaking, monolingual members at each site. Accurate translations require interpretation and translation by bicultural as well as bilingual translators for basic conceptual equivalence across sites and ethnic groups.[22,23] The group facilitators had to be bilingual and bicultural to ensure valid responses, and the verbatim transcripts had to be translated and interpreted without editing or summarizing the meaning to enable accurate interpretation.[24] Incorporation of the findings into the study protocols, although helpful, was also unbudgeted and created further delays.

Lastly, due to the inherent difficulties of establishing common protocols and timing across sites, integrating the findings of the focus groups into the overall study could not be performed uniformly. For example, coordinating the focus groups across sites was problematic due simply to weather conditions. Focus groups in Michigan, Boston and New Jersey had to contend with potential winter storms, reducing the likelihood of session attendance. After we conducted the focus groups, however, all sites found the results insightful and helpful, and the scientific structure of the study as well as the logistics for entrée into the communities was significantly enhanced and facilitated.

CONCLUSIONS AND RECOMMENDATIONS FOR RESEARCH USING MIXED METHOD APPROACHES

In this study, both inductive and deductive formative focus groups were used, and the designs and applications were specifically chosen to meet different objectives. The use of mixed paradigms and methods of research have become more recognized as an integral part of working with diverse populations,[25] but the researchers should have expertise in both inductive and deductive research paradigms to maintain the integrity and rigor of both approaches and methods, or the validity of the data is jeopardized. Moreover, the design requirements must be anticipated, adequately budgeted, and integrated into the timeline as essential parts of the overall strategy from the outset of the study. This requires that inductive, qualitative researchers be part of the research teams from study inception to inform the questions, study design, data collection, interpretation, and analysis phases.

All research team members must recognize the time and labor-intensive aspects of rigorous inductive data analysis. While data collection can be relatively expeditious, data analysis is a longer process, and therefore the timeline and resources budgeted must be appropriately scaled.

A secondary gain from this experience included mutual respect among research team members of diverse disciplinary backgrounds, a clearer understanding and appreciation of inductive and qualitative methodology, and specifically, appreciation for the insight gained from the inductively designed session(s) that produced previously unrecognized culturally-framed dimensions of the mid-life transition. We anticipate that our lessons learned can be generalized to other types of studies and populations. We stress, however, that since both inductive and deductive research use qualitative and quantitative methodologies, researchers need to be familiar with the different principles and methodologies of each paradigm to maximize their validity and utility.

Merging and triangulating inductive and deductive approaches enhances our ability to understand the nuanced and

complex phenomena that shape people's lives. As publications are produced from this national multi-site, multi-ethnic project, we anticipate that these focus groups have provided greater insight into the meaning of cultural or ethnic differences, and in turn, produce more cross-culturally valid interpretations of the data from the deductive longitudinal study. Ultimately, the result will enhance the validity, generalizability, and comparability of the findings and increase the relevance and applicability of the findings to the multicultural population of focus.

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