

**Folic Acid and Birth Defects Prevention:
Focus Group Research and Materials Pre-Testing
with Hispanic At-Risk Women**

EXECUTIVE SUMMARY

1.1 Introduction

In preparation for a broad-based national campaign to educate the American public about the importance of folic acid for the prevention of birth defects, the Birth Defects and Pediatric Genetics Branch (BDBG) at the Centers for Disease Control and Prevention (CDC) has engaged in considerable research with potential target audiences. This formative research for the National Folic Acid Campaign was conducted in conjunction with Westat, under a health communication evaluation contract. The purpose of this research has been to provide target audiences with the opportunity to guide the development of the campaign and offer feedback as to how the campaign might best educate and motivate at-risk populations. Because Hispanic women disproportionately experience pregnancies that are affected by certain birth defects, they have been defined as a key target audience subgroup for CDC. Targeting Hispanics in such health communication campaigns is vital as the Hispanic population in the U.S. grows; in just a few years, Hispanics will form the largest minority group in the U.S.. The executive summary that follows provides an overview of the research conducted to insure that the voices of Hispanic women were actively included in the creation and development of the national folic acid educational campaign.

1.2 Background

In 1992, the U.S. Public Health Service (PHS) issued the following recommendation regarding the consumption of folic acid and subsequent prevention of certain birth defects:

All women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg. of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other NTDs [neural tube defects] (CDC, 1992).

This recommendation was issued after years of accumulated scientific evidence showing that consumption of folic acid during the periconceptual period can help prevent 50-75 percent of NTDs. In the United States alone, NTDs such as spina bifida and anencephaly affect approximately 4,000 pregnancies each year with Hispanic women having 1.5 to 3 times the rate of NTD-affected pregnancies compared to African-Americans or whites (Shaw et al., 1997). Babies born with spina bifida have an opening along their spine, through which the spinal tissue protrudes. These babies often need to have many surgical treatments when they are young, and most grow into adulthood with varying degrees of disability, including paralysis of the feet and legs, and lack of control of the bowel and bladder. Mental retardation sometimes occurs and learning disabilities are common. Lifetime costs for medical, developmental, and other services for children born with spina bifida are estimated to be about \$500 million annually. Anencephaly is a fatal condition in which most or all of a baby's brain and skull are missing. Babies with anencephaly are either stillborn or die within a very short time of birth.

1.3 CDC's Planned Communication Effort

Although educational campaigns on the importance of folic acid for preventing birth defects have been undertaken in the past, surveys indicate that these programs have not sufficiently addressed folic acid knowledge and behavior deficits. A 1997 March of Dimes commissioned Gallup poll, for example, found that 66% of women surveyed had heard or read about folic acid, yet only 22% were aware of the PHS folic acid guidelines, and only 30% of nonpregnant women reported taking a multivitamin containing folic acid on a daily basis (MOD, 1997). These findings combined with results from various other surveys, polls, and focus groups highlight and reinforce the need for additional educational efforts targeting knowledge levels and consumption of folic acid among childbearing women.

Responding to this need, BDBG has initiated a national health communication campaign to relay the PHS recommendation of folic acid to the American public. This broad-based campaign includes education, demonstration, and evaluation projects with the ultimate goal of increasing to 50% the proportion of women consuming the PHS-recommended level of folic acid. The BDBG campaign is based on a social marketing approach, which seeks to increase the acceptability of a social cause or behavior by focusing on the knowledge of the target audience, their perceptions, and behaviors. Extensive research was conducted with women of childbearing age to help gain their input into effective approaches for increasing knowledge and consumption of folic acid in the prevention of birth defects. Given the considerably higher rate of NTD-affected pregnancies among Hispanic (both English-speaking and Spanish-speaking) women, the research placed special emphasis on gaining their input into the design of the campaign.

The National Folic Acid Campaign was designed to target both women planning to become pregnant in the next year or so (referred to as contemplators) and women *not* intending to become pregnant in the near future (non-contemplators). Many of the campaign materials were developed specifically to appeal to either contemplators or non-contemplators. The decision was made to focus the Spanish-language materials on pregnancy contemplators for two primary reasons. First, budget constraints would not allow development and dissemination of both contemplator and non-contemplator materials in Spanish as well as English. Second, prior research has shown that Hispanic women are less likely to be non-contemplators, that is they are less likely to state that they do not intend to become pregnant in the future, in comparison to other women (Health Style Study, 1996 and 1997).

1.4 Scope of Focus Group Research with Hispanic At-Risk Women

In gaining an audience-centered perspective to guide the development of the National Folic Acid Campaign, BDBG contracted with Westat to conduct exploratory and concept testing research with primary target audiences. While all women of childbearing age are at risk for having a pregnancy affected by NTDs, particular subgroups of women were targeted for this campaign. Of these subgroups, Hispanic (both English-speaking and Spanish-speaking) women were identified as a key population due to their substantially higher rate of NTD-affected pregnancies as compared to African-American and white women. Hispanic women were also targeted because prior research suggested that Hispanic women are less knowledgeable about the benefits of folic acid and have higher risk behaviors (e.g., they are less likely to take multivitamins than other populations) (Health Style Study, 1996; Life Style Study, 1996).

As with other women who participated in the research, Hispanic women had to be between the ages of 18-35 with a household income of under \$50,000 to qualify for the studies. Because of their potential influence on women at-risk, health care providers who serve women of reproductive age were also a targeted subgroup. The project team actively recruited providers whose patient population was at least 1/3 Hispanic. Exploratory research was conducted with Hispanic women at-risk and their health-care providers from March-May, 1998, while concept testing research was conducted with Hispanic women at-risk during June-July, 1998. A brief synopsis of the research activities follows.

Exploratory Research Activities

The first step in the creation of the National Folic Acid Campaign was to conduct exploratory research to help inform campaign development. Two particular activities sought to solicit audience-centered input during the exploratory research phase.

- 1) *Focus groups with Hispanic women at-risk* - During March of 1998, six focus groups were held with Hispanic women (four with Spanish-speaking women and two with English-speaking women) to learn about their knowledge levels, attitudes, and behaviors surrounding folic acid and NTDs. Fifty-two Hispanic women participated in the groups. An additional 14 English-speaking Hispanic women participated in another 10 mixed-ethnicity groups also conducted during this time. The women were between the ages of 18 and 35 years and in lower to middle income brackets (less than \$50,000 annual household income), with emphasis given to women with annual household incomes less than \$30,000. The focus groups were held in Houston because of its large population of Mexican-American women and women of other Central and South American Hispanic descent, and Miami because of its large population of Cuban women and women of other Caribbean Hispanic descent. All groups were conducted at professional market research facilities and moderated by a native Spanish-speaking moderator with over 16 years of experience working with the Hispanic community and moderating focus groups. Participants received a \$50.00 incentive payment for attending; such incentive payments are standard practice in focus group research in order to encourage and facilitate participation (Morgan, 1998). In relation to the overall research conducted with all women during the exploratory phase, approximately 40% of the research (6 of 16 focus groups) was conducted with Hispanic women, while Hispanic women comprised 50% of total research participants (66 of 131).

- 2) *Focus Groups with Health Care Providers* - During April and May of 1998, seven focus groups with health care providers were conducted. The purpose of these groups was to gather information on provider knowledge, attitudes, perceptions, and behaviors relative to folic acid and perceived barriers to and opportunities for counseling women at risk about folic acid. For this research, health care providers were defined as physicians, nurses, nurse practitioners, pharmacists, and nutritionists. These specific health care provider categories were chosen because these medical specialties tend to have regular contact with women of childbearing age. Individual providers were recruited on the basis of their high volumes of service to the target populations for BDBG's National Folic Acid Campaign. Participation criteria included: regular contact with a patient population consisting of at least 1/3 women of childbearing age; at least half of time spent in direct clinical contact with patients; a majority of patients in the lower to middle income bracket; and a minimum of three providers in each focus group had to have a patient population that was at least 1/3 Hispanic. All groups were held at professional market research facilities in Atlanta and Bethesda, Maryland. Fifty-eight providers participated in the research. Forty percent of physicians, 78% of nurses, and 50% of nutritionists participating had a patient census comprised of at least 1/3 Hispanic women.

Concept Testing Research Activities

Findings from the exploratory research were used to create preliminary concepts that served as the basis for the campaign to encourage and motivate women of childbearing age to increase their consumption of folic acid. The research team engaged in concept testing in order to solicit audience-centered input into the campaign's creative direction. Draft campaign materials targeting contemplators were developed in Spanish and English. Spanish-language materials were tested in focus groups with Hispanic women. A description of this concept testing research follows.

- 1) *Focus groups with Hispanic women at-risk* - During June and July of 1998, four focus groups were held with Hispanic women (three with Spanish-speaking women and one with English-speaking women) to determine if potential campaign images and text would appeal to and influence them. For this testing, materials were produced in English and Spanish. Women were asked if they could identify the main idea of each campaign concept and if the concept would motivate them to increase their consumption of folic acid. Thirty-five women participated in the Hispanic groups. An additional five Hispanic women participated in another five mixed-ethnicity groups also conducted during this time. The age and income criteria used for the exploratory research described above were also used for the concept testing focus groups. The groups were again held in Houston and Miami, conducted at professional market research facilities, and moderated by a professional moderator who is a native Spanish speaker. Participants received a \$50.00 incentive payment for attending. In relation to the overall research conducted with all women during the concept testing phase, more than 40% of the research (4 of 9 groups) was conducted with Hispanic women, while Hispanic women comprised 50% of total research participants (40 of 79).

1.5 Overview of Focus Group Findings

The value of focus group research findings is dependent on researchers examining results systematically. In analyzing and interpreting the results of the folic acid exploratory and concept testing research, Westat researchers employed a notes-based process similar to that recommended by Krueger (1998). This analysis procedure involved processing each focus group briefly at its conclusion, then developing a total picture of all groups, and finally considering particular groups and responses to specific questions. All members of the research team reviewed and verified the findings and conclusions. Key findings in the context of implications for possible campaign message strategies that resulted from the exploratory

research as well as findings from the subsequent concept-testing work are briefly outlined below. Findings as they relate specifically to Hispanic women are also highlighted.

Exploratory Focus Group Findings

Findings from this series of focus groups suggested several implications for the communication campaign to increase knowledge and consumption of folic acid in the prevention of birth defects. In general, there were many similarities among all women who participated in the research. For example, among both Hispanic and non-Hispanic women, there was little knowledge about folic acid and its benefits in relation to the prevention of birth defects. Most women across all groups also agreed that credible spokespersons for the campaign would include those personally affected by NTDs, and most said that physicians, family members, and friends would play a vital role in influencing them regarding folic acid consumption. Like the target audience of reproductive age women, the health care providers also shared many similarities across groups. Findings here suggested that providers had a general lack of knowledge of the link between folic acid and the prevention of birth defects, a misperception among some women that sufficient folic acid can be obtained from prenatal vitamins taken *during*, rather than *before*, pregnancy, and a lack of awareness of the barriers women perceive to taking multivitamins as a means for folic acid supplementation.

However, the research also identified important differences among different groups of participants, particularly with regard to the motivators and barriers women said would influence their decision to take a daily multivitamin as a source of folic acid. Participants were given a list of potential motivators and asked to select those that would influence them to take a multivitamin every day. Most women – both Hispanic and non-Hispanic – said they would be motivated to take multivitamins to help them feel "their best," because they did not always eat right, for future pregnancies, and/or for long-term health benefits. Some differences between Hispanics and non-Hispanics emerged. For example, Hispanic women were more likely to say they would be motivated to take multivitamins "because I don't always eat right." Some of the Hispanic women described how their eating habits had worsened since they came to the United States (e.g., because of the rushed lifestyle in the U.S.). In addition, many Hispanic women said they would be motivated to take a multivitamin every day if it would enhance their appearance (e.g., more beautiful hair, stronger and longer nails, clearer skin). Some Hispanic participants associated vitamins with these kinds of benefits.

In terms of barriers to taking a multivitamin every day, many women across groups said that they would not or do not take multivitamins because it was not a habit, they forget, they do not feel they need them, multivitamins cause stomach problems (nausea, constipation), and the pills are difficult to swallow and leave a bad taste. The focus groups revealed another important barrier to multivitamin use not

previously identified by CDC: the perception that vitamins will increase appetite and cause weight gain. This concern was the primary barrier to multivitamin use among Hispanic women, and was also mentioned to a lesser degree by other women. Another perception mentioned by some Hispanic women was that vitamins are more necessary for children and for men more than for women. Researchers concluded that these important cultural differences between Hispanic and non-Hispanic women should be addressed by the campaign if it is to effectively reach out to and motivate Hispanic audiences.

Concept Testing Focus Group Findings

Findings from this series of focus groups provided valuable information for the further refinement of messages designed to persuade women of childbearing age to consume more folic acid. For example, the research showed that women who were planning pregnancies would be motivated by a message outlining folic acid's role in a healthy pregnancy, while those not planning pregnancies would be more persuaded by messages describing other benefits such as "feeling one's best," having more energy, or preventing disease. All women agreed that campaign messages should make it clear that a woman should take folic acid from the time she is capable of becoming pregnant, that messages should explain why folic acid is important, that messages should convince women that it is difficult to obtain adequate folic acid from food sources alone, and that the CDC was a credible sponsor for a National Folic Acid Campaign.

Yet while the concept testing research found many similarities across participants, as with the exploratory research, there were also some notable differences. These differences were most apparent in reactions to the concepts between Spanish-speaking Hispanic women and English-speaking Hispanic, white, and African-American women. For example, one campaign concept featured a reference to Brussels Sprouts that did not work for Spanish-speaking women because they were not familiar with this vegetable, while English-speaking Hispanics and all other women had no problem understanding this particular campaign message. In contrast, none of the Spanish-speaking women voiced objections to another concept that featured an illustration of a fetus, while several participants in the English-speaking focus groups were concerned that the picture would be mistaken for an anti-abortion campaign. These findings pointed to the important cultural and language differences that must be taken into account when finalizing appropriate messages that would appeal to all campaign audiences.

1.6 Materials Pre-testing

Based on the results of the exploratory and concept testing focus groups, BDBG contracted with a creative contractor to develop and pre-test creative executions of campaign materials. Television and print public service announcements (PSAs) were pre-tested in storyboard format with Hispanic and non-

Hispanic women. Eighteen interviews were conducted with Hispanic women to test the Spanish-language versions of materials. Respondents had to be between the ages of 18-34 years and have a total annual household income of no more than \$50,000. In addition, because the Spanish-language campaign materials specifically targeted pregnancy contemplators, to participate in the pre-testing women had to indicate that they were contemplating pregnancy within the next year.

The pre-testing resulted in some changes to the creative executions. For example, the tag line for the “Before You Know It” television PSA was changed from “Antes de que te des cuenta” (Before You Know It) to “Antes de que sepas que estas embarazada” (Before You Realize You Are Pregnant) to clarify the meaning.

1.7 Campaign Implementation and Evaluation

After incorporating feedback from at-risk women regarding creative content, materials were finalized and the national folic acid communication campaign was initiated in January of 1999. In reaching out to Hispanic women, to date, the campaign has produced several Spanish-language public service announcements for radio, television, and print media and campaign partners are working with a Hispanic-owned communications company to disseminate these materials to Spanish-language media outlets across the country. For evaluation purposes, a baseline survey was conducted with primarily Spanish-speaking Hispanic women prior to campaign initiation so as to collect data related to their knowledge, attitudes and behaviors (KAB) regarding folic acid and the prevention of birth defects. With this baseline data for comparison, outcome evaluation research will be conducted specifically with Spanish-speaking women to measure changes in KAB as a result of the campaign. The outcome evaluation research will be conducted utilizing telephone surveys planned for early 2000 and subsequent years.

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