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Recruiting Low-Income Healthy Women to Research: An Exploratory Study

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Abstract

Objective—The study goals were (1) to assess the feasibility of using an existing telephone health information and referral service for low-income, ethnically diverse women to recruit women for research participation; (2) to assess the feasibility of recruiting low-income, African American and Latino men into health research through the women callers to the telephone service; and (3) to describe the challenges women face and the strategies they use when talking to men about the men's health and research participation.

Design—We recruited women for individual semi-structured qualitative interviews via the Every Woman Counts (EWC) telephone information and referral service, a California Department of Health Services Cancer Detection Program. This paper describes our eligibility and recruitment assessment, and our qualitative data from 23 interviews with low-income African American and Latino women who called EWC.

Results—We found that it was feasible to recruit women, but not to recruit men through women who call this telephone service. Almost 50% (113) of women *demographically eligible* for recruitment, completed our screening questionnaire, despite calling EWC for a different purpose. Some 48% (54) of those women were eligible for an interview. Of *interview-eligible* women, 58% (10) of African Americans and 35% (13) of Latinos completed an interview. Only 17% (4) of women referred a man for participation in an interview for our study. Several themes emerged from our analysis of interview data: (1) women's role in men's health can be significant but is often uneasy; (2) challenges when talking to men about their health include health access, gender dynamics, and men's fear of health care; (3) women's understanding of research may be limited; (4) women use a range of strategies to address and overcome men's resistance to taking care of their health and participating in research.

Conclusions—The challenges women face when talking with men about their health affect their ability to effectively speak to men about research participation. However, EWC and similar telephone health services may be an effective means for recruiting low-income women to chemoprevention and other studies requiring healthy participants.

Keywords

Telephone Recruitment; Clinical Trials; Gender; African American; Latino

Background

Historically, people of color have been regarded by researchers as ‘hard to reach’ when it comes to recruitment for clinical trials (Stallings *et al.* 2000; Ford *et al.* 2003b). While it is difficult to find disaggregated data for cancer treatment, chemoprevention and prevention and control trials, available data show that between 3 and 20% of all eligible individuals participate (Giuliano *et al.* 2000). Many clinical trials do not report data on minority enrollment; however, when reported, participation rates for minorities are much lower (Swanson & Ward 1995; Swanson & Bailar 2002; Christian & Trimble 2003; Corbie-Smith *et al.* 2003; Hussain-Gambles *et al.* 2004; Murthy *et al.* 2004; Jolly *et al.* 2005; Grandison 2006; McDaid, 2006).

In the US, the NIH Revitalization Act of 1993 requires inclusion of ‘members of racial and ethnic minority groups’ and women in clinical research (Epstein 2004). Similarly in the UK, The Race Relations Amendment Act (2000) and the NHS strategy to address inequalities (2000) have raised the bar for clinical trials enrollment of ethnic minorities, (e.g. South Asians who currently make up 4% of the UK population) who are under-represented in clinical trials (Hussain-Gambles *et al.* 2006). For more than a decade, researchers in the US have been struggling to identify and overcome a wide range of barriers to minority accrual. Such barriers include socioeconomic constraints (language and literacy, access to medical care and transportation); physician concerns about referring patients; mistrust of the scientific community due to historical abuses and negative experiences with the medical system (Killien 2000); lack of knowledge about clinical trials (Swanson & Ward 1995; Giuliano *et al.* 2000; Ruffin & Baron 2000; Lara *et al.* 2001; Grunfeld *et al.* 2002; Burroughs *et al.* 2003; Adams-Campbell *et al.* 2004; Hussain-Gambles *et al.* 2004; Witte *et al.* 2004; Gross *et al.* 2005; Hudson *et al.* 2005; Kaas *et al.* 2005).

Low socioeconomic status (SES) has also been shown to be associated with enrollment disparities (Burroughs *et al.* 2003). While the literature on ethnic minority recruitment is predominantly focused on the US, similar barriers have been raised in the UK (Jolly *et al.* 2005; Hussain-Gambles *et al.* 2006; McDaid 2006), and it is likely that these issues are relevant in other countries with increasingly diverse populations and persistent health disparities (e.g. in European and South American countries). Recent reviews of literature on minority participation in health research (not cancer specific) in both the US and UK concluded that access to studies and institutional racism rather than attitude toward them is key to enrollment (Hussain-Gambles *et al.* 2004; Wendler *et al.* 2005; McDaid 2006). That is, structural and systems issues, such as recruiter stereotyping of minorities, lack of knowledge about minorities, lack of resources for interpreters and translation of consents,

can lead researchers to not offer or otherwise preclude the participation in trials by ethnic minorities.

Specific characteristics of a given trial or the eligibility requirements also impact recruitment (Avenell *et al.* 2004). For example, a challenging enrollment criterion for many prevention and chemoprevention (developing and testing agents that would decrease the incidence of some common cancers) trial participants is that they must be healthy adults (though they may be at high risk for a given disease). Some recent large chemoprevention trials (Moinpour *et al.* 2000; Ford *et al.* 2003a; Higgins & Thompson 2004; Lippman *et al.* 2005) have failed to recruit minorities in adequate numbers, or were somewhat successful but only with great effort and at considerable cost (Cook *et al.* 2005; Lippman *et al.* 2005). In addition to individual barriers, such as patient desire for control over medical decisions, fear of risks, loss of privacy and lack of family support, many of the barriers noted for recruitment of healthy participants are structural and access issues that may reflect institutional racism, such as: complex trial design, primary care provider reluctance; transportation and costs associated with participation; and characteristics of the health care system (Tangrea 1997; Kinney *et al.* 1998; Ruffin & Baron 2000; Frayne *et al.* 2001; Ford *et al.* 2003a). For breast cancer prevention trials, bias in the GAIL model (a risk assessment tool for general breast cancer risk screening) (Gail 1992) for assessing genetically-based breast cancer risk reduced the eligibility of ethnic/racial minorities according to one recent study (Grann *et al.* 2005). Younger age and higher socioeconomic, education, and occupational status, as well as prior experience with a clinical study have been shown to increase the likelihood of participation in chemoprevention and other prevention studies (Tangrea 1997; Zhu *et al.* 2000).

In addition to identifying a range of barriers, investigators have identified some effective methods for recruiting ethnic minorities and other underserved populations for health research. Recruitment may be more successful when culturally tailored materials are used, when one-to-one contact is made, and when the message comes from a respected member of the community, a personal physician, or another known person (Klabunde & Kaluzny 1995; Gilliss *et al.* 2001; Ford *et al.* 2004; Sheppard *et al.* 2005; Cook *et al.* 2005; McCaskill-Stevens *et al.* 2005). These strategies can enhance the trust in researchers that is often lacking in marginalized communities or among groups who have experienced discrimination or abuse (e.g. Tuskegee and Thalidomide) (Shavers 2000; Freimuth 2001). However, personal contact involving one-to-one or group presentations require trained staff, and these activities tend to be low-yield, and, thus, must be continuously repeated. While appropriate for geographically limited or small-scale studies, for large-scale trials taking place over a wide geographic area, such local recruitment becomes onerous in terms of labor, cost and time, and its effectiveness is still limited. For example, The Prostate Cancer Prevention Trial (PCPT) utilized a half-time minority recruiter, workshops for potential participants, specially designed materials, and involvement of African American cancer survivors at each of five sites, yet only 4% of 18,882 participants enrolled at 219 sites were African American, 50% of the target 8% (Woods *et al.* 2004; Moinpour *et al.* 2000). The SELECT trial (Phase II study of Selenium/Vitamin E) met the overall enrollment goal, but only 15% of 35,534 accrued were African American, significantly lower than the goal of 20%. These

examples attest to the importance of finding more effective and efficient means of minority accrual (Cook *et al.* 2005).

As part of the effort to increase minority enrollment in cancer prevention trials, we developed this study to explore use of an existing health communication channel for low-income, minority women as a bridge to low-income, minority men for participation in prostate prevention trials. Compared with non-Latino White American men, African Americans have a 60% higher incidence of prostate cancer, and a two-fold greater mortality rate (Stanford *et al.* 1999). While more than 92% of prostate cancer cases occur in men aged 55 and older, prostate cancer in African American men is more likely to strike at an earlier age and in an aggressive form (California Department of Health Services 2004). Latino men have a lower incidence than both African Americans and Whites but, like African Americans, they are likely to present at more advanced stages (California Department of Health Services 2001; Hoffman *et al.* 2001; Zietman *et al.* 2001).

Since women tend to take responsibility for the health care of the entire family as part of their general care-giving activities, an effective way to reach men regarding health care issues may be through the women in their lives (e.g. wives, daughters, mothers, sisters) (Guberman *et al.* 1992; Umberson 1992; Neal *et al.* 1997; Burke *et al.* 2000; Bull 2001). The potential of this mechanism was briefly noted, but not analyzed, in a report by the Latin American Cancer Research Coalition (Sheppard *et al.* 2005). Thus, our study built on two key elements of previous research—the effectiveness of messages from a known person and the woman's role as caregiver—to explore reaching low-income men via the women in their lives. Study questions were: using a toll-free telephone service for recruitment, how many women can be recruited to discuss health and health research with the men in their lives? Will women be receptive given that they are calling for a different purpose? How do women callers feel about their men participating in research? What information, guidance, and strategies will women need to communicate effectively with men about research? And, finally, do women think the men in their lives will be receptive to getting health and health research information from them? This paper reports the eligibility and recruitment assessment results from our recruitment efforts at Every Woman Counts (EWC), a telephone information and referral service, as well as the qualitative data from semi-structured interviews we conducted with women callers to EWC.

Methods

EWC provides free breast and cervical cancer screening and diagnostic services to low-income California women via a free telephone information line operated by the Northern California Cancer Center (NCCC) and funded by the CDC and a California tobacco tax. It attracts a high volume of callers from diverse racial and ethnic backgrounds. For example, during the period 1 July 2005 through 30 June 2006, there were 10,446 calls in English (57%), 5,967 calls in Spanish (33%), 409 in Mandarin (2%), 192 Cantonese (1%), 509 Vietnamese (3%) and 517 in Korean (3%). On average, 5% of callers statewide are African American and 50% Latino. Callers are asked to self identify by race (e.g. African American) and ethnicity (e.g. Hispanic) as part of routine demographic data collection by Information Specialists.¹ Callers are asked two questions:

Q1: Are you Hispanic or Latino?

Q2: I'm going to read a list of categories. Which of these groups would you say best describes you? Are you American Indian or Alaska Native; Asian; Black or African American; Pacific Islander; or White? (This question allows multiple selection.)

UCSF researchers collaborated with the staff at the telephone service to develop an appropriate script for EWC Information Specialists to use in recruiting women for in-person interviews. (See Figure 1 for Recruitment Protocol.)

The first component of the study consisted of screening all EWC callers for eligibility during the study period. EWC computers were programmed to identify *demographically eligible* callers for the Information Specialists. Next, the Specialists asked this subset of callers for permission to screen them for the study. Callers who consented were asked two screening questions, and, if *interview-eligible*, were recruited for the study. We tracked recruitment as we invited callers to participate in our study. The recruitment period was seven months for Latinos and nine months for African Americans; the difference was due to the significantly greater number of Latino callers to EWC. Initially, recruitment was restricted to callers in Alameda and Santa Clara counties, ages 40–60. We expanded recruitment to San Francisco callers in month four, and dropped the age requirement in month six to speed the recruitment process.

The second component of the study consisted of in-person semi-structured interviews with 23 women (13 Latino and 10 African American) recruited via the EWC telephone service. For this exploratory study, our goal was to recruit at least 10 women in each group to discuss their communication about health with the men in their lives. We expected that with 20 interviews we would learn about the range of key issues in the domain we intended to explore, and reach sufficient theoretical saturation (no new ideas) for this narrowly focused exploratory study (Glaser 1978; Sandelowski 1986). Initial analysis indicated that we reached saturation at 23 interviews, and we stopped recruitment at that point. Interviews were conducted in the participant's home or another location of her choosing, and lasted between 40 and 90 minutes. Bilingual research staff conducted the interviews with the 11 Spanish-speaking Latino participants. (Two Latino participants preferred English.) The average age of Latino participants was 44 with a range of 21–54. For African American participants, the average age was 49 with a range of 41–59. Overall, African Americans had completed more formal schooling. Almost all the African American participants had completed high school, and several had some college education. Less than half the Latino participants had graduated from high school, and many had only attended grade school. Almost all participants were uninsured. Discussion topics included: (1) communication about health with the men in their lives; (2) health research participation for themselves and their men (our study and hypothetical studies related to prostate screening that we described to them); and (3) strategies for talking to men about health in general, and participation in

¹We follow the EWC in using the term African American. EWC reports their data using the term Hispanic. We use Latino instead of Hispanic because Hispanic is a government-defined category, while Latino tends to be the preferred term among Californians of Latin American origin, such as those in our study. We view all such terms and categories as markers of social rather than biological differences.

prostate health studies in particular. The multi-ethnic interview team (African American, Latino, White) included an anthropologist and two public health researchers. (The anthropologist and one of the public health researchers were bilingual Spanish speakers.) The two bilingual investigators monitored the translation of all protocols, consents and interview transcripts. Any discrepancies in the two language versions were discussed with other bilingual research staff and differences were resolved.

We were careful to ensure that all participants were given the usual service for which they called before being asked if they were interested in hearing about a research study. Approximately half said no. For those who said yes, informed consent was administered informing them of their rights including the fact that refusal to participate or refusal to answer any study questions would not affect their receipt of services. The research protocol was approved by the institutional review boards at both the University of California, San Francisco and the Northern California Cancer Center. Similar research using telephone lines to implement various types of health interventions has been performed in diverse settings for non-minority populations (Darrow *et al.* 1998; Davis *et al.* 2004; Heimendinger *et al.* 2005; Marcus *et al.* 2005; Miller *et al.* 2005; Strecher *et al.* 2005).

Data Analysis

Eligibility and recruitment data were collected through the NCCC, including the number of eligible callers and the proportion of those who agreed to participate. All in-person semi-structured interviews were tape recorded and transcribed (Spanish interviews were translated and transcribed) by professional transcribers. Transcription and translation by our professional bilingual transcriber took four to seven hours per interview to complete; English transcriptions took two to four hours each. Bilingual members of the research team reviewed translations for accuracy, and final transcripts were entered into Atlas-ti qualitative data analysis software program. Transcripts were read and coded independently by two members of the research team (Project Director and Research Associate). Disagreements were discussed, and codes were reconciled to ensure consistency and trustworthiness before being entered into Atlas-ti (Ulin 2005). Subsequently, the text segments associated with the most common codes were retrieved and analyzed for themes. In this way, the research team developed successively more refined understandings of the data, and developed the four themes discussed below.

Results

Eligibility and Recruitment Assessment Results

Figure 2 shows our recruitment data. We distinguish between: (a) *eligible for recruitment*, i.e. *demographic eligibility* (women who fit our race/ethnicity, age and geographic criteria); and (b) *interview eligibility* (the demographically eligible women who indicated that they had an age and geographically appropriate male family member or friend with whom they could talk about health, and that they were interested in participating in an interview for our study).

As shown in Figure 2, a total of 312 African American (69) and Latino (243) women called EWC from our recruitment counties during our recruitment period. Of these, 228 (73%) met the age requirement (between 40 and 65) we had in place for the first five months of recruitment, and, thus, were approached for eligibility screening (46 African American and 185 Latino). (After eliminating the age requirement, all African American and Latino callers in our recruitment counties were approached.) Of the 228 approached, 113 (50%) were willing to complete our screener questionnaire despite calling EWC for a different purpose. Twenty-six (57% of demographically eligible) were African American, and 87 (47% of demographically eligible) were Latino. Due to the limited nature of this feasibility study, we were unable to compare characteristics of those who declined and those who were willing to answer our screening questions. These 113 women gave verbal informed consent, and were then asked two screening questions to determine if they were interview-eligible:

Q1: Do you have any of the following male relatives or close male friends age 45 or over? (Husband Significant Other, Son, Father, Brother, Uncle, Father in-law, Brother in-law, Any Other)

Q2: Does he live in Alameda or Santa Clara county? (*If more than one relative/ close friend checked in Q1, ask: Does at least one of these men live in Alameda or Santa Clara county?*)

Seventeen African Americans and 37 Latinos or a total of 54 women (48%) answered yes to both questions, and, thus, were eligible for an interview. The EWC Information Specialist completed the call, and UCSF researchers followed up to schedule an interview within three weeks. Of the interview-eligible women, 58% of African Americans (10) and 35% of Latinos (13) completed an interview. Seven interview-eligible African Americans and 24 interview-eligible Latinos were either not reached after several attempts, or declined to participate when reached to schedule an interview. Reasons given for declining participation at that stage included: not interested, no time (working, traveling, leaving the country) and no reason. Four (17%) of the 23 women who completed interviews (one African American and three Latinos) referred a man for participation in our study who completed an interview. Some of the women who answered yes to our screening questions subsequently said they did *not* have a man available in the Bay Area to be interviewed. The reasons for this discrepancy are unknown.

Qualitative Results

Several themes emerged from analysis of our semi-structured interviews. The themes discussed here cut across both groups, reflecting comments made by both African American and Latino participants. The one exception is with regard to the legacy of the Tuskegee Syphilis study, which was referred to only by a couple of African American participants (discussed as part of Theme 3), and which reflects the particular historical experience of African Americans. The goal of this type of qualitative exploratory research is to identify areas of interest worthy of in-depth investigation, and the themes represent such areas of interest. The number of participants makes it inappropriate to generalize. Further investigation might uncover significant differences between the women of African

American and Latino descent, or might reveal important differences based on other demographic or social contextual factors.

Theme 1. Roles in Men's Health can be Significant But are Often Uneasy

Many of the women we interviewed reported that they see it as their responsibility to 'persuade and facilitate' men in their lives to go to the doctor, and/or to go with them; some even take pleasure in this. When describing how they would persuade men to go to the doctor or take care of their health, women used terms such as: convince, push, remind, initiate, keep track, discuss, warn, advise, enforce, and bug. As one woman put it, '... you've got to kinda instill it. You kinda like be the enforcer. If you don't enforce it, they will just not do it' (AA01, 48, some college).² In the following exchange with the interviewer, a Latino participant explains that she made a doctor's appointment for her husband even though he said he would do it 'later'.

Interviewer: What did you do then?

Participant: Make the appointment for him.

I: You made the appointment for him even though he had said, "Later"?

P: Yes.

I: And when you told him you'd made the appointment, what happened?

P: He went. He said it was fine because I tried to get the appointment on his day off. (L01, 54, some high school)

The women also talked about their role involving specific tasks such as: providing information, providing the right food, learning in order to inform the men, getting support for themselves to be able to support their husbands, making doctor's appointments, providing transportation, accompanying men to the doctor, talking to other women in the man's life about his health, teaching men how to talk to doctors, providing support/sympathy, and providing a sense of control. For example, regarding her adult son, one woman said: '... short of just taking over, making the appointments myself, I just gave him the directive to do it himself and get it taken care of'. With her grandfather, the same woman offered advice and support regarding how to talk to doctors: 'I would just kinda like tell him what to say to the doctors if I couldn't go with him' (AA03, 59, post-graduate training). Some of the women in our study took on the role of teaching the men about the need to see a doctor regularly.

They don't understand the importance of going to the doctor. I'm the one who initiates everything. Yes, I'm the one who starts talking to him about all of these issues. And he does—afterwards he goes... And he's not embarrassed about it anymore. He no longer says, "No, I'm not going to the doctor for such-and-such a reason". Or, "Because I don't have time. I have to work"... He is starting to understand that he has to go to the doctor. (L04, 47, grade school)

²We identify each quotation with interview code showing ethnicity/race (AA for African American or L for Latino), age and education. Ethnicity, race, age and education are routinely collected by EWC.

On the other hand, some women pointed out limits to their responsibility. While they did not believe it was their responsibility to take care of men's health, they did take responsibility for persuading men of the importance of taking care of their own health and facilitating the care in a variety of ways. 'I just told him that if he needed me to drive him to the doctor, you know, that I would take him to the doctor' (L05, 43, high school graduate). The level of responsibility women felt and the roles they took on depended, in part, on their relationship with a given man. For example, some women talked about the limits of their own responsibility when it comes to the health of their married brothers, fathers etc., suggesting that the men's wives are more responsible and probably more effective in influencing them.

I've always looked out for him. But now we don't talk as much because now he's married, so things are different—he used to live with me. (L01, 54, some high school)

In the following situation, the woman felt that her adult nephew would be more receptive to health information and advice from a cousin of the same generation rather than from her or his mother.

Well I think he feels like we're suggesting that he's not smart or he's not competent or something like that. I think he's taking it more personally. From her, it's just like well, cousin to cousin. You know. And he don't feel like she's getting in his business. (AA06, 58, some college)

In another case, a woman found that her husband confided his fears about health matters to her mother rather than to her, suggesting that the wife may not be the ideal transmitter of health information in some situations, but another woman could be.

With my husband it was extremely difficult to tell he was afraid. Even when he was in the ICU, I would look at him and he seemed to be trying to hide it. My mom was the one he told he was afraid. He told her, not me.... He would just tell me, "Take care of our daughter". (L04, 47, grade school)

These decisions about which family members the men would talk with about their health may be specific to individual relationships, but may also be shaped by cultural values and beliefs about family roles and appropriate communication among family members.

Several women raised a few specific concerns about talking to men about prostate health because of the intimate nature of the topic, the potential side effects of prostate cancer, such as incontinence and impotence, perceptions that prostate cancer is caused by homosexual behavior, fear of cancer or the difficulty of discussing preventive care. One woman made it clear that she did not want to be responsible for a cancer diagnosis if she was the one who encouraged the man to get screened (AA10, 52, some college). Other women simply needed to find an occasion so the topic did not seem to come up out of the blue.

... when it comes to something like that, that could be life threatening, that he might not wanna know—some people just don't wanna know—it would probably take me a longer time to get him to do it because of the subject matter. So I'd have to really and then pull out this and say, "Look, this is it. You know you don't wanna be one of these percentages that was too late". (AA04, 46, some college)

Thus, the context—the relationship, family health history, the man’s orientation toward his own health, the particular health issue, and various other factors— influenced the level of responsibility and the type of role women in our study took on regarding the health of the men in their lives.

Theme 2. Barriers and Challenges to Health Discussions with Men

Some women in our study found that the men in their lives were receptive to their advice, facilitation and responsibility toward health, but others found that men did not listen, did not want to listen, or otherwise were not receptive. The barriers and challenges women confronted can be categorized as (a) health care access, (b), gender and other relationship dynamics, and (c) fear.

Health Care Access

Several women talked about men who said they did not want to miss work or did not have the time to go to the doctor because of their work schedule. This is likely due to the fact that many low-income workers are paid by the hour, do not have paid sick or vacation leave, or have seasonal work that cannot be made up if missed. ‘I’ve seen him go to work with a fever, for example, because he doesn’t want to miss a day of work’ (L02, 41, high school graduate).

Many women call EWC because they lack insurance, and many in our study reported that they and the men in their lives were intermittently uninsured. Regarding prostate screening, one woman told us that her husband was motivated to do it, but was waiting until his health insurance went into effect. Also, the type of care one might receive at a public hospital and the stigma of going to one were apparent in this exchange between a participant’s sister and brother.

... my sister was saying, “Well if you don’t have medical insurance... go to Hilltop³ [the public] hospital”. And he immediately just hackle, you know, he was, all his hackles were up and he told her, “I’m not going to Hilltop Hospital. Nobody goes there”. (AA06, 58, some college)

Gender (and Other Relationship Dynamics)

Several women used the term *macho* to describe the men in their lives. They reported that men associated going to the doctor with weakness or with femininity. ‘Men may feel that if there’s something with their health, some issue with their health that you know, “I’m not this macho image. I’m just this weakling” ’ (AA07, 45, high school graduate). Other women reported that the men in their lives did not want to talk to them about their health or to appear to be taking advice from women.

He thinks he’s so macho.... He doesn’t want his friends to say that he lets his woman tell him what to do. That’s another thing that’s important, especially among Latinos. Because Latino men are more “manly men”. They say they don’t let their

³Pseudonym.

women tell them what to do. So that's another problem. (L09, 43, some high school)

This woman also described the difficulty talking to her husband about prostate cancer because of his perception of the disease. He said, 'I won't get it because I'm macho'. He said the man who had it got it because he had sex with other men (L09, 43, some high school).

But some women acknowledged that not all men feel this way. For example, one woman described her husband as very macho, but contrasted him with her brother who was receptive to her advice. Another woman described the generational and cultural differences between her husband who was raised in Mexico, and her son who she raised in the US. While some of the Latino women attributed the macho attitude of the men in their lives to being Latino, both African American and Latino women in our study attributed men's resistance to taking health advice seeking healthcare to machismo.

Many of the women in our study talked about men's perception of their interest or advice about health as 'nagging' or condescending and insulting. They suggested that in men's eyes there is a fine line between offering help and nagging, and that they need to be careful not to cross it.

... probably the best that it could go you know, I mean between a sister and a brother; we have a really good relationship.... He seems to think that I nag him a lot. So I try not to get to the point where it sounds like I'm nagging him a lot. (L04, 47, grade school)

It seemed to some women that their attempts to talk about health were met with an indirect refusal. For example, one woman reported that she expects her husband to make her a 'fake promise' to follow her advice: 'He wouldn't probably say a whole lot. He'll probably just say he'll agree with me. "Yeah, that's important, I am gonna". You know, he'll probably make me some fake promise that he's gonna go and get tested' (AA03, 59, post graduate training).

Fear

Negative experiences with health care institutions and personal health history also influenced men's willingness to go to the doctor, according to the women we interviewed. This woman ascribed her husband's fear to experiences with health care as a child.

... it was so hard for me to get him to go to the hospital. And the burn was this big —pus was coming out of it and everything. It was incredible. But he did not want to go to the hospital. "No, no, no; it will go away. I'm going to put this or that on it". But it wasn't healing, and it was so hard to convince him, "Let's go now". I practically had to drag him in. And I think it's incredible; it's incredible how afraid he is to get medical treatment. (L02, 41, high school graduate)

In another case, an overload on doctor visits during an earlier period of his adult life made a woman's husband reluctant to go to the doctor for any reason now.

So I finally convinced him to go to the doctor. He did not know he was a diabetic at that time. I tried to get him to go but he would not go. He's afraid of doctors. And so anyway, his leg would hurt so bad until he was ready to go. (AA02, 47 college graduate)

Theme 3: Women's Perceptions of Research

Talking with men about research participation depends in part on women's understanding of research. Most respondents indicated that if they heard about a research study recruiting male participants, they would talk to the men in their lives about it. However, respondents also expressed that when it comes to research participation—in contrast to talking to men about their health—their role was more one of providing information than of persuading men to participate. 'Well, I could tell him, but it would be up to him to decide if he wanted to participate' (L06, 46, grade school). Furthermore, women perceived that research is 'not something that's been on the radar' (AA09, 41, some high school), and that because men rarely prioritized their health care, they seemed unlikely to prioritize participation in a research study.

I don't think it would be a priority. It might be something they might be interested in, but with my brothers, I just think that there's always going to be something else going on in their lives that they can't take time to you know, to participate in something like that. (L05, 43, high school graduate)

Women's perception of the value of research—their lack of clarity about its value or limited understanding of it—might limit their capacity to persuade a man to participate.

Well I think it would be different if I were trying to persuade them to be involved in the research. I would have to really think through why I would feel it would be valuable for them. Um, so I think the conversation might be difficult to have if I'm not clear on why I feel it's important to participate. (AA09, 41, some high school)

Most women indicated that they would appreciate having written information about the study—either for themselves so they would be prepared to answer the man's questions, or to give to the man to read himself. 'Because when I do get his attention, I have fifty million questions to answer. So I'd like to be able to answer them ... There's no reason for him to back out of it if I have some information about it' (AA04, 46, some college). In cases where women expressed confidence in their own ability to understand and explain the research, some were concerned that the men in their lives might not understand, or that they might not be interested.

The most difficult part is that they would think I was talking over their heads...I like to read and I like to look up stuff on the Internet and do things like that. But they don't necessarily like doing stuff like that... If I'm talking about research, it would be way too technical. I mean, it would be something that they would not be interested in, sitting and having that conversation. (AA06, 58, some college)

Many of the women in our study perceived the need for education about a variety of health topics (e.g. cancer), and they perceived research as a learning opportunity:

Because I think everything that is for the well-being of the community... and because I think there's a lack of information, especially about... Because I was telling my husband I was going to do this interview, that you were coming here, and I see that men are still like, "Oh, brother" [said with dismissive tone], like they still don't want to accept a lot of things. So I think we need to educate ourselves all together, to be able to talk to them and so they understand how many... I don't know how many people are affected by prostate cancer. I don't know. But if you can help people and talk to them, yes I would do it. (L12, 40, some high school)

A common confusion about research for our participants was its relationship to medical care. For people without insurance or with relatively little access to healthcare, like the women in our study, participating in research in order to access health care can be tempting. While this confusion can lead women to participate in health research or try to persuade men to participate, it can also be a hindrance if they are trying to convince a man to participate who is afraid of medical care.

It's hard to take them to the doctor, because they're afraid. But you do it so they can protect themselves or be more aware of what might happen to them. (L04, 47, grade school)

However, aside from the potential benefit of accessing healthcare, there was little clarity about the benefits of research. One woman was frustrated by the lack of short term benefits, and also articulated her expectation that as an African American, her community would not reap the benefits of research.

If it's something that's gonna help in the long run, ten or twenty years, or five or ten years down, then it's like, "What does that got to do about today?" So that's the hard part.... I may not [participate] Because you know, we have this thing about they do research on us, you know, and then we don't hear back from them. You know... there's a thing in the black community about the studies that they did at um, you know, ... And you know, I wouldn't want to be a guinea pig and then you know, I mean I wouldn't want to put myself in that position. And there's no benefit to me or my community... You know, it's like somebody's doing research on me to better, you know, to use that for some other community. (AA06, 58, some college)

This doubt about the benefits to her community was indicative of a more general distrust of the healthcare system that was evident among some participants in our study, and which has been shown in other research to be an issue in how Latinos and African Americans choose to engage with the healthcare system (Giuliano *et al.* 2000; Moreno-John *et al.* 2004). In particular, the effects of the Tuskegee Syphilis Study on African American distrust in health care and health research has been studied extensively (Shavers 2000; Freimuth 2001). One African American woman in our study anticipated her brother's refusal to participate in our study because of his awareness of the abuses of The Tuskegee Syphilis Study. 'I may be wrong, but I don't think my brother would go for it even though when he first came to California, he worked up in Warren Hall at UC.... I think he would bring up something like the Alabama study' (AA02, 47, college graduate).

On the other hand, some women in our study also articulated positive aspects of research participation. One who initially said she would not likely bring up research participation with the men in her life because it is ‘not something that they’re interested in’ changed her mind as the interview proceeded: ‘now that you and I are talking yes, I would’ (AA05, 44, high school graduate). Several women talked about research as a learning opportunity or an educational experience, and thus of value to the men in their lives. Some participants felt that participating in a research study might provide an opportunity for their men to learn something that she could not teach him, or that he would be more receptive to ‘objective’ sources than to her. Others saw it as an opportunity to do something for ‘the community’, to earn money, to be heard and counted, or to overcome their fear of doctors and health care.

Theme 4: Strategies for Overcoming Barriers in Talking to Men about Research Participation

When asked hypothetical questions about how they would talk to the men in their lives about research participation, women varied in their strategies and approaches. Some of these strategies and approaches overlapped with their tactics for getting men to take care of their health, and others were specific to research. Strategies for talking to men about research participation can be broken down into five categories:

1. *Emphasize personal benefits*, e.g. he could learn something, it could be good for his health in the short term, and it could lead to early detection or prevention, and, thus, benefit the man’s health in the long run.
2. *Pay attention to timing*, e.g. talk to the man when he is in a good mood, on more than one occasion, and help him to see that he can fit research participation into his schedule.
3. *Filter information*, e.g. inform herself before talking with him; simplify ‘technical information’ about research; use humor; and only talk to him about issues which they have already discussed (familiar topics).
4. *Emphasize altruistic aspects of research*, e.g. ‘set example for other men’, participate in a ‘good cause’; do something ‘for mankind’. A few African American women, knowing of the high rates of prostate cancer among African American men, talked about ‘helping some other brothers’ and doing something to ‘benefit the African American community’.
5. *Share the experience*, e.g. accompany him, participate with him, talk about her own experience in research or experience with cancer screening (mammograms and papanicolaou).

Discussion

The recruitment method tested in this exploratory study—recruiting women via the EWC telephone information and referral service—is a potential avenue for efficient recruitment to cancer prevention trials in need of healthy women participants. While the number of eligible women in our sample is small due to the exploratory nature of the study and our study

criteria, the percentage of *demographically eligible* women who were interested and willing to participate is notably high, especially given that they were calling EWC for a different purpose. Of the women who met our demographic criteria, 50% were willing to answer screening questions. While not all of these callers were eligible for an interview, the high rate of receptiveness to consider the study suggests that other studies with broader recruitment criteria might be equally or even more successful recruiting participants. For example, had we recruited in counties (such as Los Angeles) where the percentage of African Americans and Latinos is higher, we would have reached a higher number of potential participants. In short, EWC and other health telephone information and referral services are potential recruitment channels for cancer prevention (including chemoprevention) trials seeking healthy subjects, particularly in studies seeking subjects from a wide geographic area.

The majority of women we spoke to said they would be willing to talk to the men in their lives about health and about participating in health research, and in some cases, they saw little difference between the two. In many cases, women were used to talking to the men in their lives—fathers, brothers, grandfathers, sons, cousins, friends—about their health on a regular basis. The roles women took on and the amount of responsibility women felt varied somewhat, depending in part on the quality of the relationship, other women in the man's life, family medical history, and the particular health issue. In part, the lack of difference between talking about health and about health research seems due to perceptions of research as a learning experience and opportunity to improve one's health knowledge and health.

While the initial goal of the study was to find a method for efficiently recruiting men, we did not have success in that regard. Only 17% (4) of women referred a man for participation in an interview for our study. As part of our screening questionnaire, the EWC Information Specialist asked whether the callers had a male relative or friend age 453 living in the Bay Area. Some of the women who answered yes, subsequently (when called to schedule an interview or during the interview) said they did *not* have a man available in the Bay Area to be interviewed. We did not have the opportunity to explore the reasons for this discrepancy. Among the possibilities are: misunderstanding; discomfort referring man; change in circumstances between initial recruitment and interview date; false initial response because of desire to participate in study. In other cases, the men were out of town, too busy with work (height of the gardening season, away for work), or lived in a different country; in one case the man was married to another woman.

Given the exploratory nature of this feasibility study, we must acknowledge its limitations. The small number of participants makes it inappropriate to generalize from our findings. However, the quantitative component of the study, measuring the proportion of eligible and consenting respondents, is useful in demonstrating the utility of this approach, and the potential of further research to examine and refine recruitment through an existing telephone channel. The qualitative component explores the varied ways that women participate in men's health care, and the range of women's perceptions of research. Clearly, there is much more to be learned, and this study is a small first step. Further investigation is needed regarding the capacity of telephone health services as a source for recruitment to prevention trials and other types of health interventions. Further qualitative inquiry should examine the

meaning of research participation for women who are marginalized by the health care system, and the role of women in men's health.

Conclusion

In sum, recruitment through EWC and similar telephone services is a potential channel for recruitment of women, but recruitment of men via women callers is unlikely to succeed and not worth pursuing further. We found that: (1) women callers to EWC appear willing to participate in research; (2) women callers to EWC appear willing to talk to the men in the lives about research, but are often not able to recruit them to participate in research; (3) the relative ease of this channel for reaching low-income women justifies further exploration of telephone health services as a recruitment channel for cancer prevention and chemoprevention trials; (4) if viable, such channels could also be used for education, screening, and outreach. We suggest that the use of telephone health services serving low-income, ethnically diverse people (like EWC) be explored as a mechanism for recruiting women to chemoprevention as well as cancer prevention and control trials and health education interventions.

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Figure 1.
Recruitment procedures.

Figure 2.
Study recruitment flow and numbers.