

Factors affecting participation in a breast cancer risk reduction telephone survey among women from four racial/ethnic groups

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Abstract

Background. Little is known about the participation of minorities in health behavior research. This manuscript assesses factors associated with participation among women in four racial/ethnic groups.

Methods. A total of 2800 Asian/Pacific Islander (API), Black, Latina, and non-Latina White women recruited through the San Francisco Mammography Registry was invited in 2002 and 2003 to participate in a telephone survey about breast cancer prevention.

Results. Minorities participated at lower rates (49% for APIs, 60% for Latinas, and 64% for Blacks) than Whites (77%). Increased participation was associated with younger age for Latinas (OR = 1.90, 95% CI 1.05–3.44) and Whites (OR = 1.77, CI 1.08–2.91), and with a family history of breast cancer for APIs (OR = 2.09, CI 1.24–3.52). Decreased participation was associated with having less than a high school education for APIs (OR = 0.47, CI 0.26–0.86), Blacks (OR = 0.29, CI 0.11–0.78), and Latinas (OR = 0.51, CI 0.28–0.94).

Conclusions. Results suggest minorities' participation in health behavior research does not match Whites' and should be enhanced.

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Introduction

Historically, minorities have been underrepresented in clinical research (Roberson, 1994; McCarthy, 1994; Killien et al., 2000). Increasing their participation is vital to identifying differences among various racial and ethnic groups in health behaviors, perceptions, needs, and health care utilization.

Researchers face numerous challenges in improving minority recruitment, including smaller total populations from which to draw participants (Profile of general demographic characteristics, 2000), lower rates of minority involvement in the health care system (Hargraves et al., 2001; Dunlop et al., 2002), and barriers related to low socioeconomic status, language, culture, and attitudes toward research (Roberson, 1994; Giuliano et al., 2000; Shavers et al., 2002; Shavers-Hornaday et al., 1997). Distrust of medical research is a noted problem, particularly among African Americans (Harris et al., 1996; Shavers et al., 2000, 2001; Corbie-Smith et al., 2002).

The first step in overcoming these obstacles and improving minority representation in research is to identify

Abbreviations: API, Asian/Pacific Islander; CI, confidence interval; HT, postmenopausal hormone therapy; OR, odds ratio; SFMR, San Francisco Mammography Registry.

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factors related to their participation. In 1993, the National Institutes of Health strengthened its requirement for recruitment of underrepresented minorities in federally-funded clinical research (NIH Guidelines, 1994). While some analyses have found minority groups' participation rates to be proportional to their disease burdens (Tejeda et al., 1996; Alexander et al., 2000), the published literature is still largely lacking in reports of recruitment rates by race/ethnicity, leaving it unclear to what extent and why rates vary (Ness et al., 1997; Corbie-Smith et al., 2003a). In particular, the participation of Asian/Pacific Islanders (APIs) and Latinos in clinical studies has received scant research attention.

Several factors have been shown to increase participation in clinical research: younger or older age (Corbie-Smith et al., 2003b; Chang et al., 2002; Sociodemographic and clinical predictors of participation, 2001; Richardson et al., 1998), higher educational level (Voigt et al., 2003; Rimer et al., 1996), higher socioeconomic status (Giuliano et al., 2000; Advani et al., 2003), and health factors related to the disease under study (Corbie-Smith et al., 2003b; Sociodemographic and clinical predictors of participation, 2001; Rimer et al., 1996). While race/ethnicity has also been linked to participation (Chang et al., 2002; Voigt et al., 2003; Advani et al., 2003; Holt et al., 1997), there is a dearth of research on how the above factors may uniquely affect participation among different racial/ethnic groups.

Data generated from population-based registries offer a unique opportunity to assess the barriers to participation. We examined participation among API, Black, Latina, and non-Latina White women (hereafter referred to as Whites) in a telephone survey of women's knowledge, attitudes, and practices concerning breast cancer risk reduction that recruited participants from the San Francisco Mammography Registry (SFMR). We sought answers to two questions: whether participation varies among these racial/ethnic groups and what factors affect participation in each group. We hypothesized that participation would vary by group, with minorities participating at lower rates than Whites, and that factors would vary among the groups studied.

Materials and methods

Sample

Potential participants were identified through the SFMR (<http://mammography.ucsf.edu/SFMR/>), a population-based registry in the National Cancer Institute Breast Cancer Surveillance Consortium (Ballard-Barbash et al., 1997). For the present study, patient data were gathered from five facilities, accounting for nearly half of the SFMR's 2001–2002 mammograms. The accessible population was comprised of patients who provided demographic and health information via SFMR's questionnaire (available in five

languages) at the time of their mammogram. Potential participants met the following eligibility criteria: (a) agreed to be contacted for possible participation in breast health research studies; (b) had no personal history of breast cancer or lumps at time of mammogram; (c) were female, age 40–70; (d) self-identified as API, Black, Latina, or White; and (e) spoke English, Spanish, or Cantonese.

Based on SFMR information, we stratified the sample by race/ethnicity and level of 5-year breast cancer risk (high versus low risk). Risk level was principally determined by the patient's 5-year Gail score (Gail et al., 1989; Gail and Benichou, 1994). Women with a score of at least 1.67%, with any first-degree relative with breast cancer, or with any personal history of breast biopsy were considered high risk (Fisher et al., 1998; Vogel et al., 2002). All others were classified as low risk. A random subset in each racial/ethnic group and risk group was invited to participate for a total target sample of 2800 women.

Procedures

Women were sent study information in English and either Spanish or Cantonese along with a postage-paid return postcard allowing them to decline or indicate interest. After approximately 2 weeks, interviewers began calling all eligible women who had not declined via postcard. Consent was obtained verbally and interviews were conducted in English, Spanish, or Cantonese. All procedures were approved by the University of California, San Francisco, Committee on Human Research and the mammography facilities whose registry patients we contacted. Mailings and interviews occurred between March 2002 and July 2003.

Measures

Each participant was assigned to one of four final outcome categories: completed survey, ineligible, declined (via postcard or telephone), or not reached (no valid address or phone number or no contact after 4 months of call attempts). The main dependent variable was whether the participant completed the survey or not.

Predictors of participation included age; education; median neighborhood household income; history of breast biopsy; family history of breast cancer in mother, sister, or daughter; 5-year Gail score (Gail et al., 1989; NCI, 2000); clinical breast exam within previous 3 months; current use of postmenopausal hormone therapy (HT); elapsed time between mammogram and invitation to participate; and mammography facility. Data were derived from participants' self-report on the SFMR questionnaire. Median neighborhood household income, a proxy for socioeconomic status, was assigned using U.S. Census data and was used as a control variable (Geronimus and Bound, 1998).

Additional descriptors included postcard response (interested versus declined), mode of refusal (postcard versus telephone), and reason for ineligibility.

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