Challenges in recruiting Mexican women for cancer genetics research

Gwendolyn P. Quinn · Jessica Q. McIntyre ·
Susan T. Vadaparampil

Received: 2 August 2010 / Accepted: 17 November 2010 / Published online: 1 December 2010
© Springer-Verlag 2010

Abstract Hispanic women often have low participation rates in cancer genetics research. Additionally, Hispanic sub-ethnicities may have varying accrual rates based on unique cultural factors. Hispanic women were recruited through flyers placed in the Tampa Bay Community to participate in an interview about knowledge of hereditary breast and ovarian cancer. The study goal was to recruit 20 women from each Hispanic sub-ethnicity: Puerto Rican, Mexican, and Cuban. This article reports on the difficulty in recruiting Mexican women. One hundred forty-three women called the study hotline to inquire about participation. Seventy-six callers were ineligible for the study. Thirty-four percent ($n=26$) of ineligible were Mexican women; within this group, 62% ($n=16$) were unable to participate because they did not know the cancer site of their first degree relative. Inclusion criteria requiring knowledge of family history of cancer for behavioral research may be too stringent. The socio-cultural norms of Mexican families may not include discussions of cancer specifics. This study demonstrates Mexican women may have limited knowledge about their family history of cancer. Considerations of these knowledge limitations should be built into cancer genetics-related research. Referral criteria to assess the risk of hereditary breast and ovarian cancer by cancer genetics professionals are predicated on the patient providing details about cancer within multiple generations of family members,

thus, posing a barrier for Mexican women who may have limited knowledge of their family history of cancer.

Keywords Hispanic · Recruitment · Genetics · Behavioral research

Introduction

More data are available among racial/ethnic minority women than ever before in the areas of cancer incidence, mortality, survival, risk factors, and early detection. However, this increase in available data on women are still lacking in some ways, including the paucity of data within sub-ethnic categories. Hispanic women represent the fastest growing population in the US (Naranjo 2007), yet there is wide variation in the sub-ethnicities of Hispanic women (e.g., Cuban, Mexican, Puerto Rican) particularly with regard to perceptions of cancer and associated risk reduction behaviors (Larkey et al. 2001). Lack of information on health behaviors and risk perception may be due to low participation rates among Hispanic women in cancer-related research (Underwood 2000). Furthermore, because participation rates have been low among Hispanics as a whole, the efficacy of some cancer-related treatments has not been ascertained within this group, and there are some pharmaceutical studies suggesting racial and ethnic differences in tolerance and efficacy with medications (Tejeda et al. 1996; Lahn & Ebenstein 2009; Phan et al. 2009).

Participation in health research for all sub-ethnicities of Hispanic women is fraught with multiple barriers, including distrust of research, misunderstanding of the consent process and language, and cultural barriers (Giuliano et al. 2000). However, the nature of the cultural barriers may

G. P. Quinn (✉) · J. Q. McIntyre · S. T. Vadaparampil
Health Outcomes and Behavior Program, Moffitt Cancer Center,
Tampa, FL 33612, USA
e-mail: gwen.quinn@moffitt.org

G. P. Quinn · S. T. Vadaparampil
Department of Oncologic Sciences,
University of South Florida College of Medicine,
Tampa, FL, USA

vary between each sub-ethnicity. The socio-cultural aspects of cancer and the manner in which it is discussed in Hispanic families may also impact participation rates in research (Giuliano et al. 2000). But it is not yet established whether the primary barrier is low desire to participate due to cognitive barriers, such as distrust, or inability to participate due to structural barriers, such as meeting research criteria. Additionally, looking at Hispanics as homogeneous, without regard for differences across sub-ethnicities, may also impact participation in research rates, as the strategies used to recruit one sub-ethnicity may not be appropriate, or appealing and may even be repelling for another (Daunt 2003).

Recently, a population-based study from the Northern California Cancer Registry reported that Hispanic breast cancer patients had higher *BRCA1* mutation prevalence rates when compared to non-Ashkenazi Jewish Whites, African Americans, and Asian Americans (John et al. 2007). Additionally, this study suggested the presence of a founder mutation specific to the Mexican–American population in the US (John et al. 2007). As a result of this possible founder mutation, it has become even more important to understand awareness about and informational needs related to genetic testing for hereditary breast ovarian cancer syndrome (HBOC) and genetic testing within this ethnic subgroup of Hispanic women (John et al. 2007). New discoveries concerning increased genetic risks give rise to the need for improved communication strategies that are culturally relevant and tailored to the traditions and values of ethnic sub-groups. Improvements in cancer treatment and risk reduction strategies are inherent upon involving underserved and underrepresented populations in research, including population science surveys, genetics research, and clinical trials.

This paper describes a unique challenge associated with recruiting Mexican women for a study, examining knowledge and attitudes about genetic testing for HBOC among Mexican, Puerto Rican, and Cuban women with a personal or family history of breast or ovarian cancer.

Methods

Participants were recruited after the project received institutional review board (IRB) approvals from the University of South Florida. Eligible participants were Hispanic women who: (a) were between 18 and 65 years old; (b) self identified as Mexican, Puerto Rican, or Cuban; (c) had a personal diagnosis of breast cancer prior to age 50 or ovarian cancer at any age or had at least one first-degree relative (mother, sister, daughter) diagnosed with breast cancer prior to age 50 or at least one first-degree relative diagnosed with ovarian cancer at any age (d) who had not

previously had genetic counseling and/or genetic testing for HBOC. These eligibility criteria were posted on the study flyer used to recruit. Participants were recruited from the Tampa Bay area through flyers written in Spanish and placed in the community (e.g., Hispanic grocery stores, public health clinics, health fairs, and churches) advertising the study and asking women to call a toll-free telephone number if they were interested in participating. Active-recruitment efforts were facilitated by a team of three bilingual–bicultural trained research assistants. The study took place in Hillsborough County, Florida, which has a population of 998,948 inhabitants of whom 18% are of Hispanic origin and 36% are foreign-born Hispanic (US 2000 Census Data; data provided by the National Vital Statistics System). Within this population, 15% report, either speaking Spanish only, or preferring Spanish.

Results

These results represent a short report on a unique recruiting trend that was observed during the course of the primary study, which attempted to recruit a total of 60 Mexican, Cuban, and Puerto Rican women (20 from each group) who met the study criteria. The goal of the parent study was to identify similarities and differences across the three groups regarding knowledge and attitudes about genetic testing and counseling for *BRCA*, as well as to determine if future educational and promotional materials should be uniquely tailored for each group. The parent study found low levels of knowledge within all three groups, and no significant differences across the groups (Vadaparampil et al. 2010a). Preferences for communication type and channels did vary across the three groups (Quinn et al. 2010; Vadaparampil et al. 2010b).

As shown in Fig. 1, 143 women called the toll-free number to participate in the study. Despite the fact, the study criteria were listed on the flyer, when all criteria were verified with each caller, 76 of those women were determined to be ineligible. Twenty nine percent ($n=22$) of the women were ineligible because their country of origin was outside the criteria (i.e., they did not self identify as Mexican, Puerto Rican, or Cuban). Reasons for ineligibility in the remaining 71% ($n=54$) included: (1) being diagnosed with breast cancer after the age of 50 ($n=15$); (2) reporting a personal or familial cancer site other than breast or ovarian ($n=6$); (3) Already having attended genetic counseling/testing for hereditary cancer ($n=4$); (4) no personal or first-degree relative cancer diagnosis ($n=13$); and (5) unknown familial cancer history ($n=16$). Within the Mexican group, 62% ($n=16$) were unable to participate because they did not know the specific cancer site of a mother or sister's previous cancer, and therefore, could not

Fig. 1 Recruitment flow chart

verify a family history of breast or ovarian cancer. The most common response was “I know my mother had a female cancer, but I do not know exactly where.” None of the other sub-ethnicities of ineligible respondents were unaware of family history, and all the 16 women in the unknown familial cancer history were Mexican.

Discussion

Recruiting Mexican women for this study was a challenge. Ultimately, we did not recruit our quota for Mexican women ($n=20$); however, quotas were met for the other two sub-ethnic groups. Anecdotal reports from the research assistants who recruited in the community at health fairs and church activities noted a sense of distrust among Mexican women. They also noted that it was only upon returning to a site or location multiple times that a Mexican woman would approach them to ask for more information

about the study. This is consistent with other research in which Mexican women reported having a greater sense of distrust of health research or uncertainty about providing personal information (Naranjo 2007; Daunt 2003).

Recent data suggest that despite increased risks for carrying *BRCA* mutations, Hispanics of all ethnicities are currently underutilizing cancer genetic services (Ricker et al. 2006). Leading health organizations have established referral criteria to assess the risk of HBOC by cancer genetics professionals. However, many of these referral criteria and subsequent genetic risk assessments are predicated on the patient providing details about cancer within multiple generations of family members (e.g., cancer site, age of onset). In our study, 62% of the Mexican women who called to inquire about participating were ineligible to participate because they did not have a personal history of cancer but had a family history but did not know the site of the cancer of their first-degree female relative. This may be due to cultural factors. An often noted

theme among Hispanic cultures, in general, but particularly among Mexican families, is that cancer is not discussed. Several studies have identified that Mexican women tend to have lower levels of knowledge about cancer, particularly with regard to screening behaviors (Ramirez et al. 2000) and having a fatalistic view of cancer (Austin et al. 2002). These cultural mores and beliefs about cancer can pose powerful barriers to open communication about a cancer diagnosis in Hispanic families (Orom et al. 2007). It has also been noted that in some countries, including those with Hispanic groups, there is a personal preference for not disclosing cancer diagnosis and prognosis information to other family members (Shields et al. 2008). Thus, this nondisclosure severely impacts communication about family history of cancer. Furthermore, first-generation Mexican-Americans are often separated from extended and even immediate family members who live in Mexico. It is possible that they have fewer opportunities to learn about their family history and fewer opportunities to exchange information on health and illness (Orom et al. 2007). Incomplete knowledge of family history may contribute to decreased access to provide discussion about HBOC syndrome. Recent results of a national survey reported that minority-serving physicians were significantly less likely to have ever ordered a genetic test to assess cancer risk (Mystakidou et al. 2004). Levels of acculturation may also play a role in the knowledge of cancer family history; however, we were unable to collect this data from ineligible women in our study. A recent study concludes that health care providers should consider that self-reported family history of cancer may misrepresent true risk, due to low rates of reporting family cancer by foreign-born patients. They further suggest that existing health disparities will continue if cancer screening and genetic testing is underutilized by immigrants and ethnic minorities based solely on the self report of cancer family history (Orom et al. 2007).

Kinney et al. conducted focus groups with Latina women of undisclosed sub-ethnicities and noted that Latino woman had overall low levels of knowledge about familiar cancers and prevention strategies. Kinney's study concludes that communications about genetics should be infused with cultural and community perspectives to increase the likelihood of relevance to this population. (Kinney et al. 2010)

Conclusion

Criteria for some behavioral research, particularly genetic research, may be too stringent for some minority populations and a deterrent to participation in research, especially when knowledge of family history is required. Ultimately, our data show that desire to participate is high; however, ability to

participate is hindered by stringent inclusion criteria, which are based on biological criteria and do not account for cultural norms. Furthermore, referral criteria to assess the risk of HBOC may pose a barrier for some Mexican families to undergo genetic counseling, particularly for those who are unable to provide details about family history of cancer. Furthermore, genetic risk assessments may not be plausible in this population, since they may be unable to provide details about the specifics of a cancer diagnosis within multiple generations of family members. The socio-cultural norms of Mexican families often include limited discussions of cancer within the family, especially between parents and children (Rojas-Guyler et al. 2008). Considerations of these knowledge limitations should be built into cancer-related research, particularly genetic-related research.

Acknowledgments The work contained within this publication was supported in part by the Survey Methods Core Facility at the Moffitt Cancer Center & Research Institute

Funding for this project was provided by grant 1 R03 HG003887 from the National Human Genome Research Institute.

References

- Austin L, Ahmad F, McNally MJ, Steward D (2002) Breast and cervical cancer screening in Hispanic women: a literature review using the health belief model. *Women's Health Issues* 12:122–128
- Daunt DJ (2003) Ethnicity and recruitment rates in clinical research studies. *Appl Nurs Res* 16(3):189–195
- Giuliano AR et al (2000) Participation of minorities in cancer research: the influence of structural, cultural, and linguistic factors. *Ann Epidemiol* 10(8 Suppl):S22–S34
- John EM et al (2007) Prevalence of pathogenic BRCA1 mutation carriers in 5 US racial/ethnic groups. *JAMA* 298(24):2869–2876
- Kinney AY, Gammon A, Coxworth J, Simonsen SE, Arce-Laretta M (2010) Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies. *Genet Med* 12(2):105–115
- Lahn BT, Eisenstein L (2009) Let's celebrate human genetic diversity. *Nature* 461(7265):726–728
- Larkey LK et al (2001) Hispanic cultural norms for health-seeking behaviors in the face of symptoms. *Health Educ Behav* 28:65–80
- Mystakidou K et al (2004) Cancer information disclosure in different cultural contexts. *Support Care Cancer* 12(3):147–154
- Naranjo LE (2007) The recruitment and participation of Hispanic women in nursing research: a learning process. *Public Health Nurs* 15(1):25–29
- Orom H et al (2007) Family history of cancer: is it an accurate indicator of cancer risk in the immigrant population? *Cancer* 112(2):399–406
- Phan VH, Moore MM, McLachlan AJ, Piquette-Miller M, Xu H, Clarke SJ (2009) Expert Opin Drug Metab Toxicol 5(3):243–57, Mar
- Quinn GP, McIntyre J, Vadaparampil ST (2010) Preferences for hereditary breast and ovarian cancer information among Mexican, Cuban and Puerto Rican women at risk. *Public Health Genomics*. doi:10.1159/000284582
- Ramirez AG, Talavera GA, Villarreal, Suarez L, McAlister A, Trapido E, Pérez-Stable E, Marti J (2000) Breast cancer screening in regional Hispanic populations. *Health Educ Res* 15(5):559–568

- Ricker C et al (2006) If we build it ... will they come?—establishing a cancer genetics services clinic for an underserved predominantly Latina cohort. *J Genet Couns* 15(5):505–514
- Rojas-Guyler L, King KA, Montieth BA (2008) Health seeking behaviors among Latinas: practices and reported difficulties in obtaining health services. *Am J Health Ed* 39(1):25–33
- Shields AE et al (2008) Differential use of available genetic tests among primary care physicians in the United States: results of a national survey. *Genet Med* 10(6):404–414
- Tejeda HA, Green SB, Trimble EL et al (1996) Representation of African-Americans, Hispanics, and whites in National Cancer Institute cancer treatment trials. *J Natl Cancer Inst* 88:812–816
- Underwood SM (2000) Participation of minorities and women in clinical cancer research. *Ann Epidemiol* 10(8 suppl):S1–S110
- Vadaparampil ST, Quinn GP, Small BJ, McIntyre J, Aguado Loi C, Closser Z, Gwede CK (2010a) A pilot study of hereditary breast and ovarian knowledge among a multiethnic group of Hispanic women with a personal or family history of cancer. *Genet Test Mol Biomarkers* 14(1):99–106
- Vadaparampil ST, McIntyre J, Quinn G (2010b) Awareness, perceptions, and provider recommendation related to genetic testing for hereditary breast cancer risk among at-risk Hispanic women: similarities and variations by sub-ethnicity. *J Genet Couns* 19:618–629