Journal of Family Medicine

Open Access

Austin Publishing Group

Special Article – Patient-Centered Care

Toward Patient-Centered Care: Understanding Latina Patients' Perceptions of Screening Mammography

Martinez-Gutierrez J[1,2]*, Jhingan E[1], Black LE[3], Hayes Constant T[4] and Coronado GD[5]

[1]Cancer Prevention Program, Fred Hutchinson Cancer Research Center, M3-B232, Seattle, WA 98109, USA

[2]Department of Family Medicine, School of Medicine, Pontificia Universidad Católica de Chile, Macul, Santiago, Chile

[3]School of Medicine, University of Washington, 1959 N.E. Pacific St, Seattle, WA 98195, USA

[4]Department of Anthropology, University of Washington, Box 353100, Seattle, WA 98195, USA

[5]Kaiser Permanente Center for Health Research, 3800 N. Interstate Ave. Portland, OR 97227, USA

***Corresponding author:** Martinez-Gutierrez J, Department of Family Medicine, School of Medicine, Pontificia Universidad Católica de Chile, Av. Vicuña McKenna 4686 Macul, Santiago, Chile

Received: June 13, 2016; **Accepted:** July 20, 2016; **Published:** July 25, 2016

Abstract

Background: Understanding patient perceptions of breast cancer screening is important for developing breast-cancer screening programs and can enhance the delivery of patient-centered care. We identified factors influencing receipt of mammography screening among Latina patients at a Federally-Qualified Health Center.

Methodology: We held eight focus groups among Latina patients at four clinics in Washington State; focus groups were conducted in Spanish, recorded, and transcribed verbatim.

Results: We identified factors associated with individual health behaviors, social relationships, and institutional factors influencing cancer screening attitudes. One unique concept emerged from our participants: *desidia*. Translated as a "lack of motivation or inertia", it was described as unconsciously allowing barriers to interfere with taking care of oneself, to "let life get in the way" or to make one's personal health a low priority.

Discussion: Our findings will inform future patient-centered interventions to increase cancer screening rates among Latinas.

Keywords: Patient-centered care; Latina patients; Public health; Cancer screening

Background

Breast cancer is the most common cancer and leading cause of cancer death among Latinas. An estimated 19,800 Hispanic women were estimated to be diagnosed with breast cancer in 2015 [1]. Compared to non-Hispanic whites, Latinas have lower rates of early breast cancer detection and poorer 5-year survival [1]. A key behavioral factor underlying these racial/ethnic disparities is participation in breast cancer screening; breast cancer rates have been historically low among Latinas but have increased over the last five years Data from the American Cancer Society show that in 2013, the proportion of Hispanic women 40 and older who obtained a mammogram in the previous two years was 64%, compared to 69% for non-Hispanic whites [1]. Understanding and diminishing these disparities has been a major goalof legislators, researchers, and health professionals for decades.

For more than a decade, patient-centered care has been proposed as a strategy to raise quality of care [2,3]. In 2001, the Institute of Medicine (IOM) in their "Crossing the Quality Chasm" report described six specific areas for improvement to achieve a safe, effective, patient centered, timely, efficient and equitable health care system. Patient centered care (PCC) is described as "providing care that is compassionate, empathetic, and responsive to the needs, values, and expressed preferences of each individual patient; patients should be informed decision makers in their care" [4]. Patient centered care has proven to be effective in improving health outcomes related to patient satisfaction, and clinical outcomes such as treatment adherence in breast cancer [5].

Understanding factors that facilitate and impede Latinas' participation in breast-cancer screening programs is crucial to developing culturally relevant patient-centered interventions. We sought to identify these factors in order to develop an effective intervention to improve mammography screening in Latinas in a Federally Qualified Health Center (FQHC).

Methods

Setting

We conducted eight focus groups (38 participants) from April through October 2010 at four Latino-serving FQHC clinic sites in Washington State. These FQHCs provide comprehensive health and human services and specializes in serving low income and Hispanic populations. In 2010, about 93% of their clients had incomes below 200% of the federal poverty level, and about 91% were either uninsured or publicly insured. Through the clinics, patients have access to screening mammography on-site or through referrals to a nearby breast center. To pay for these services, patients may have access to the breast, cervical, and colon health program (BCCHP). BCCHP is a federal program that provides free breast, cervical, and colon cancer screening services for income- and age-eligible individuals in Washington State [6]. Patients who do not qualify for this program may be eligible for charity care, a sliding fee scale, or care through their own insurance programs.

Study procedures

Eligible participants were Latinas aged 40 to 74 who had had a clinic visit within 5 yearsand who had not had a mammogram in the past 2 years. Study staff held two focus groups at each site, one for

Citation: Martinez-Gutierrez J, Jhingan E, Black LE, Hayes Constant T and Coronado GD. Toward Patient-Centered Care: Understanding Latina Patients' Perceptions of Screening Mammography. J Fam Med. 2016; 3(6): 1071.

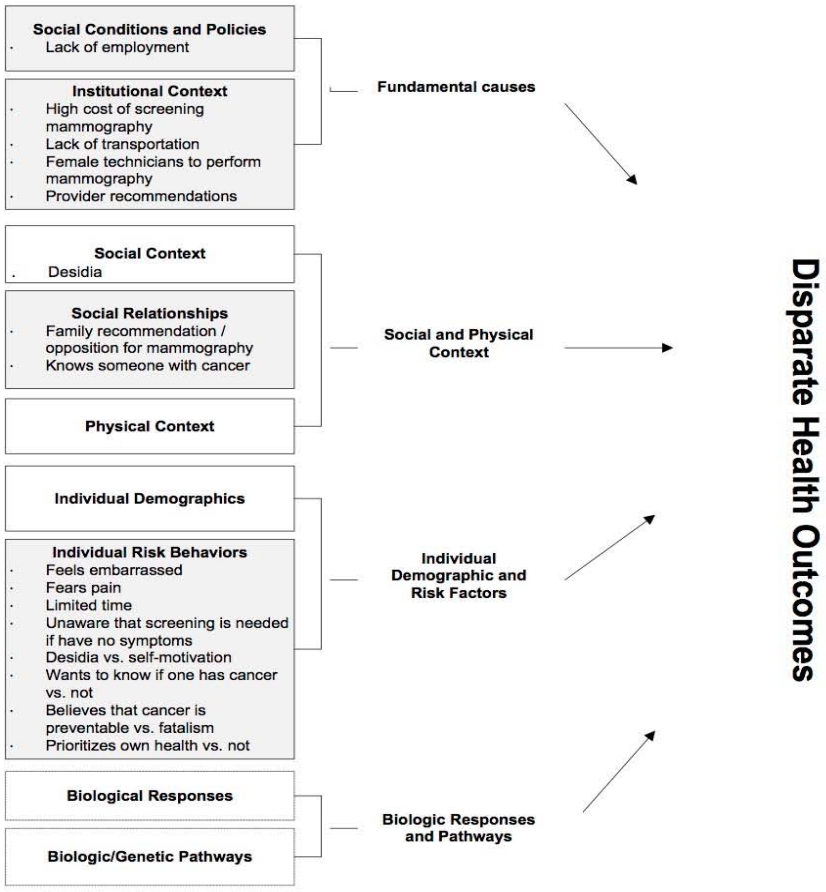

Figure 1: Conceptual framework, adapted from Warneke et al.

women aged 40 – 49 and one for women aged 50 – 74. Two bilingual project investigators moderated focus groups using an open-ended guide with questions regarding attitudes and beliefs about mammography screening. Participants received a $10 gift card for their time. Focus groups were conducted in Spanish, recorded, and transcribed verbatim. Transcripts were coded using Atlas ti 6.2. We used the data, existing behavioral theory, and available literature to develop codes and modify them through an iterative process to arrive at the themes. Each transcript was coded by at least two independent coders and checked for reliability. Discordances in the assignment of codes were resolved by consensus.

This study was approved by the Institutional Review Board at the Fred Hutchinson Cancer Research Center in Seattle, WA. IRB number: 7124.

Data analysis

We analyzed the data using a thematic network [7]. Using this approach, we separated the data into codes that were specific and discrete enough to portray details within the data but broad enough to include many different segments of the text. Then, we aggregated the codes into common meaningful themes (basic themes) that we further organized into broader and more complex themes (organizing themes) and finally into global themes that encompass the main points in the text. We then constructed our thematic networks and proceeded to explore, describe, and summarize the data through them.

Conceptual framework

Environmental, cultural, and community characteristics determine health outcomes as much as biological and personal factors. Werneke et al propose a population approach to health disparities that includes population determinants of health as well as individual risk factors for disease [8]. Using this model, we analyzed the data to identify factors on multiple levels that were associated with Latinas' attitudes towards mammography screening (Figure 1).

Results

Table 1 describes our participants' characteristics. Participants' average age was 49 and 82% were born in Mexico. The average number of years of schooling was 9 and less than half were employed either full or part time. Half of the participants were insured and nearly two-thirds had had a previous mammogram.

Individual risk/protective behaviors

We identified cancer risk/protective behaviors based on perceptions and cultural beliefs of our participants. Most commonly cited behaviors are explained below.

Risk perceptions

Lack of symptoms: Most participants knew that they could get a mammogram even if they had no symptoms of breast cancer.

Table 1: Demographic characteristics of focus groups participants.

Characteristic	
Age (years)	**48.6 (40-69)**
Country of origin Mexico Other in Latin America USA	**31 (81.6%)** **6 (15.8%)** **1 (2.6%)**
Years in the US (mean)	**16.7 (4-30)**
Years in the school (mean)	**9 (0-17)**
Employed (Full or part time)	**16 (42.1%)**
Insured (Private, basic health, coupons etc)	**19 (50%)**
Ever had a mammogram	**24 (63%)**

Nevertheless, most women stated that a mammogram was a low priority unless one experienced symptoms. The difference between a screening mammogram and a diagnostic mammogram was unclear to most participants.

Fear/Pain/Embarrassment: Participants commonly cited fear as a barrier to screening. This fear arose from a variety of sources. Some women reported fear of the actual procedure and fear of the pain resulting from it. Others feared receiving a diagnosis of cancer, feared undergoing potential treatment such as a mastectomy, or feareddying. Embarrassment was cited by women of all ages, but more frequently in the older age (50-74) groups.

Lack of awareness and information: Several women did not know the age at which women should begin screening. Specific gaps in knowledge with respect to mammograms included the fact that a mammogram can detect cancer at early stages when it is easier to treat, and lack of awareness that there are programs to assist women in paying for mammograms such as BCCHP.

Desidia: Notably, one interesting concept emerged from all the groups: *Desidia*. *Desidia*, literally translated as "idleness," was described as lacking motivation or being apathetic, lacking the ability to change one's routine or postponing something important for no clear reason.

"You get sucked into your routine (…) all the problems…they suck you in. It is not that you don't want to, it's the routine that sucks you in and years start going by, years go by and you don't do anything."

Women used *desidia* to describe a personal attribute, "I am just desidiosa,"

"And I think, really, no. I go to the clinic and they have sent me to my check up, to get the mammogram, but I am very "desidiosa", I hardly ever go."

Desidia was also used as a noun, "It is *desidia*". *Desidia* was considered distinct from laziness in that *desidia* implies unconsciously allowing mammography screening to become a low priority rather than simply lacking the initiative to get mammogram.Some women believed that Latinas have more *desidia* than women from other cultures.

"And I say. On my part, it's 'desidia'. They [Family, etc] say that 'if you want, you can and Mexican women, we are a little bit more 'desidiosas', like I say, as long as nothing is hurting, well no."

Desidia was often described as the underlying reason women delayed getting screened, and that personal or external barriers were simply excuses. *Desidia* was described as a barrier in itself and as a factor reinforced by other barriers, such as cost or lack of time.

"I forgot" How!? They notify you twice and they send a letter over the mail! It's only desidia. This is what I say: only desidia. "

Protective perceptions

"To just know": Some women were motivated to get a mammogram because of the peace of mind associated with knowing whether or not they had cancer.

Cancer is preventable: Several women stated that cancer could be prevented or treated successfully if caught early. Those who knew this also expressed motivations to get screened as it could allow them to live longer and spend more time with family and loved ones

Self motivation: The counterpart of *desidia* was *"self-motivation"*. Most of our participants mentioned they just needed to "stand up and do it". Some women cited the need for internal motivation to raise them out of their state of passivity; most took responsibility and believed they needed to mobilize and make the change to overcome *desidia*.

"If I don't do it, no one is going to do it for me."

Social relationships

Knowing someone with cancer: Several women recalled having friends, acquaintances, or family members who faced cancer. Knowing someone with breast cancer appeared to normalize the experience and reduce associated fears of undergoing treatment. Several women recounted stories of cancers that occurred in individuals with no family history of the disease; this information elevated a woman's perception of her own risk.

Family recommendation/opposition: Our participants expressed that they were influenced by the perceptions their family and friends had of a mammogram. If a husband should oppose, many women would not go get a mammogram and, conversely, they would feel bolstered by the support of their family to get it.

Institutional factors affecting mammography screening

High cost: Transportation and childcare were mentioned by a limited number of participants; however, the high cost of the exam was raised in all groups as a deterrent to screening. Likewise, across all focus groups, low cost and free mammograms were cited as a strong motivator for receiving screening; however, awareness about programs to reduce out-of-pocket costs for mammography (such as the BCCHP program) varied.

Provider characteristics: Having a female technician perform the mammogram was perceived as comforting and reduced the embarrassment associated with the exam.

Discussion

Women identified several factors at different levels that influenced their attitudes and behaviors towards cancer screening. They mentioned family support or provider recommendation, as facilitator's andinstitutional factors such as lack of transportation and cost of the exam as barriers to getting screened. This is consistent with other findings in the literature [9-15].

Individual health perceptions/behaviors mentioned included: fear of the procedure or the diagnosis, possible associated pain, limited time or being unaware that screening was needed.

A novel finding arising from this study is the concept of *desidia* or lack of motivation as being associated with attitudes about screening. A limited number of previous investigations in English-language literature have identified *desidia* as a deterrent to screening [16,17]; Fernandez et al [16] mentioned *desidia* as a "predisposing factor" influencing repeat mammography screening in a study they conducted using the PRECEDE model [18]. The authors translate this term as 'procrastination' explaining that women described it as delaying or putting off their appointments. They suggest that this was a theme mentioned both by adherent and non-adherent low-income and minority women, including both Latina and African-American women. Our findings suggest that the definition of *desidia* could be more complex than mere procrastination. As it was explained to us, *desidia* does not mean just delaying use of health services, but can be described as a personal characteristic or a force in and of itself. Our findings also suggest that given the interrelationship between *desidia* and other stated barriers to screening, *desidia* is more than a single predisposing factor, but a broader, more entrenched construct. In our conceptual model, *desidia* would be a social factor as well as an individual factor affecting cancer screening as it is mentioned as a personal characteristic as well as a moderator for other barriers to take over.

Desidia is mentioned more frequently in Spanish-language literature. García et al., in their study of 270 rural women in Mexico, mention *desidia* as a reason not to perform breast self-exams (BSE) [19]. Cumpián-Loredo studied 291 public health care workers' knowledge and attitudes towards breast and cervical cancer screening; the author mentions *desidia* as an important barrier to performing BSE and Pap testing [20]. Chiñas et al tested two interventions to increase Pap testing in primary care in Mexico. Of the 100 women in their study, 46% of controls and 44% of women in the intervention groups named *desidia* as a reason not to get their Pap test [21]. None of these studies explained what *desidia* meant to the participants or researchers.

Our findings show that women believe that getting a mammogram is possible, as long as they can overcome *desidia*; that is, it is within their control. The fact that women in our study were more likely to discuss individual perceptions of behaviors and facilitators, rather than social or institutional determinants to mammography screening, suggest that women feel self-efficacy is a key part of their decision-making regarding mammography screening. This is consistent with "overcoming *desidia*" and is also encouraging to researchers and health care professionals, since self-efficacy has been linked to higher mammography uptake [22-26].

Our results suggest finding ways to overcome *desidia*, helping women find their own personal inner motivation and resolving ambivalence may be promising strategies to increase mammography screening in Latino women. Using this information, we have developed a theory-based intervention using motivational interviewing techniques to address these topics [27].

Limitations

We invited age- eligible Latina women to participate based on a list of patients provided by our partner clinic. Many women were unreachable due to a wrong or disconnected phone number, some declined participation, and some didn't show up after agreeing to participate. As a result, our sample consisted of the women who were reachable and agreed to participate and therefore ourresults may not generalize to the whole Latinaclinic population. Nevertheless, demographic characteristics of our study population were similar to demographic characteristics of the general clinic population. Our sample was largely composed of Mexican-origin women who were uninsured and unemployed. Our results might not be applicable in rural setting or to other Hispanic subgroups.

Conclusion

A novel and culturally based concept emerged from our analysis that has not previously been fully described. Many of our participants mentioned *desidia* as an overarching reason why Latinas delay screening mammography; *Desidia* seems to be both an inner passiveness as well as a path for external/social factors to become barriers to cancer screening. This phenomenon seems to be a powerful deterrent to getting a mammogram. Understanding Latino cultural beliefs is critical to designing and implementing effective patient-centered strategies for cancer screening. Targeting the ambivalence toward mammography screening that *desidia* seems to create in this population may be a promising strategy to increase breast-cancer prevention in Latinas. Our findings have been used to inform the design and implementation of an intervention to address disparities related to timely breast cancer detection among Latinas.

Author´s Contributions

JMG: Collected, coded and analyzed the data and drafted the manuscript.

EJ: Participated in coordination of the study, collected, coded and analyzed the data.

LB: Participated in coordination of the study, collected and coded the data.

THC: Participated in coordination of the study, collected and coded the data.

GDC: Designed and participated in coordination of the study, collected data and drafted manuscript.

Acknowledgements

We would like to thank clinic staff for their collaboration in all levels of this project for allowing us to contact their patients, for providing space for our focus groups and for being readily available to help with any other request we had during this process.

This research is supported by the NIH Center for Population Health and Health Disparities: 5 P50 CA148143.

References

1. American Cancer Society. Cancer facts and figures for Hispanics/Latinos: 2015 – 2017. Atlanta (GA): American Cancer Society.

2. Betchel C and Ness DL. If You Build It, Will They Come? Designing Truly Patient-Centered Health Care. Health Affairs. 2010; 29: 914-920.

3. Berwick D. What patient-centered should mean: Confessions of an extremist. Health Affairs. 2009; 28: w555-w565.

4. CROSSING THE QUALITY CHASM: A New Health System for the 21st Century. Committee on Quality of Health Care in America. INSTITUTE OF MEDICINE. NATIONAL ACADEMY PRESS. Washington, D.C.

5. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. Med Care Res Rev. 2013; 70: 351-379.

6. Washington State Department of Health. Breast, Cervical and Colon Health Program.

7. Attride-Stirling. Thematic networks: an analytic tool for qualitative research. Qualitative Research. 2001; 1: 385-405.

8. Warnecke R. Approaching Health Disparities From a Population Perspective: The National Institutes of Health Centers for Population Health and Health Disparities. Am J Public Health. 2008; 98: 1608–1615.

9. Royak-Schaler R, Blocker DE, Yali AM et al. Breast and cancer risk communication approaches with low-income African-American and Hispanic Women: Implications for Health Care Providers. J Natl Med Assoc. 2004; 96: 598-608.

10. Chavez LR, Hubbell FA, McMullin JM, Martinez RG, Mishra SI. Structure and meaning in models of breast and cervical cancer risk factors: A comparison of perceptions among Latinas, Anglo women, and physicians. Med Anthropol Q. 1995; 9: 40-74.

11. Erwin DO, Johnson VA, Treviño M et al. A Comparison of African American and Latina Social Networks as Indicators for Culturally Tailoring a Breast and Cervical Cancer Education Intervention. Cancer. 2007; 109: 368-377.

12. Tejeda S, Thompson B, Coronado GD, Martin DP. Barriers and facilitators related to mammography use among lower educated Mexican women in the USA. Soc Sci Med. 2009; 68: 832-839.

13. Aldridge ML, Daniels JL, Jukic AM. Mammograms and healthcare access among US Hispanic and non-Hispanic women 40 years and older. Fam Community Health. 2006; 29: 80-88.

14. Erwin DO, Treviño M, Saad-Harfouche FG, et al. Contextualizing diversity and culture within cancer control interventions for Latinas: Changing interventions, not cultures. Soc Sci Med. 2010; 71: 693-701.

15. Molina Y, Martínez-Gutiérrez J, Püschel K, Thompson B. Plans to obtain a mammogram among Chilean women: the roles of recommendations and self-efficacy. Health Educ Res. 2013; 28: 784-792.

16. Fernandez ME, Palmer RC, Leong-Wu CA. Repeat Mammography Screening Among Low-Income and Minority Women:A Qualitative Study. Cancer Control. 2005; 12: 77-83.

17. Hayes-Bautista D. Latina Breast Cancer Patients and Their Informal Support System. 1-85. 2001.

18. Green LW, Kreuter MW, eds. Health Promotion Planning: An Educational and Ecological Approach. 3rd ed. Mountain View, Calif: Mayfield Publishing Co; 1999.

19. García MLR, Lozano MM. Estrategia Educativa aplicada a mujeres michoacanas de comunidades rurales para favorecer la prevención primaria y secundaria del cáncer de mama. Sinnc O. 2009.

20. Cumpián-Loredo BP. Conocimiento sobre detección oportuna de CaCu y mamario. Rev Enferm IMSS. 2000; 8: 129-132.

21. Chiñas Rojas H, Galán Cobos A, Pineda JM. Eficacia de dos intervenciones de sensibilización individualizada y la participación de la mujer en la detección oportuna de cáncer Cérvico-Uterino (Efficiency of Two Interventions in Making Individual Awareness and Women Participation in the Appropriate Detection of Cancer of the cervix). Aten Fam. 2009; 16: 48-51.

22. Lopez-McKee G, McNeill JA, Bader J, Morales P. Comparison of factors affecting repeat mammography screening of low-income Mexican American women. Oncol Nurs Forum. 2008; 35: 941-947.

23. Burke NJ, Bird JA, Clark MA, et al. Social and cultural meanings of self-efficacy. Health Educ Behav. 2009; 36: 111S-128S.

24. Palmer RC, Fernandez ME, Tortolero-Luna G. Correlates of mammography screening among Hispanic women living in lower Rio Grande Valley farmworker communities. Health Educ Behav. 2005; 32: 488-503.

25. Halabi S, Skinner CS, Samsa GP, et al. Factors associated with repeat mammography screening. J Fam Pract. 2000; 49: 1104-1112.

26. O'Neill SC, Lipkus IM, Gierisch JM, et al. It's the amount of thought that counts: when ambivalence contributes to mammography screening delay. Womens Health Issues. 2012; 22: e189-194.

27. Coronado GD, Jimenez R, Martinez-Gutierrez J, McLerran D, Ornelas I, Patrick D, et al. Multi-level Intervention to increase participation in mammography screening: ¡Fortaleza Latina! study design. Contemp Clin Trials. 2014; 38: 350-354.

J Fam Med - Volume 3 Issue 6 - 2016
ISSN : 2380-0658 | www.austinpublishinggroup.com

Citation: Martinez-Gutierrez J, Jhingan E, Black LE, Hayes Constant T and Coronado GD. Toward Patient-Centered Care: Understanding Latina Patients' Perceptions of Screening Mammography. J Fam Med. 2016; 3(6): 1071.