HHS Public Access

Author manuscript

Disabil Health J. Author manuscript; available in PMC 2019 June 10.

Published in final edited form as:

Disabil Health J. 2013 October ; 6(4): 303–316. doi:10.1016/j.dhjo.2013.05.001.

Breast Cancer Knowledge and Practices Among D/deaf Women

Barbara A. Berman, Ph.D.,
Adjunct Professor Emeritus, Department of Health Policy and Management, Fielding School of Public Health, University of California, Los Angeles, Room A2-125 CHS, 650 Charles Young Drive South (Box 956900), Los Angeles, California, 90095-6900, Telephone: (310) 794-9283, FAX: (310) 206-3566

Angela Jo, M.D., M.S.H.S.,
Associate Professor, Department of Family and Community Medicine, University of New Mexico School of Medicine

William G. Cumberland, Ph.D.,
Professor, Department of Biostatistics, Fielding School of Public Health, University of California, Los Angeles

Heidi Booth, BS,
Dire tor of Health Education/Services, Greater Los Angeles Agency on Deafness, Inc. (GLAD)

Jon Britt, MS,
Graduate Student Assistant, Department of Biostatistics, Fielding School of Public Health, University of California, Los Angeles

Carolyn Stern, M.D.,
Family Physician, Medical Director and School Physician, Rochester School for the Deaf, Founder and Partner, DeafDOC.org

Philip Zazove, M.D.,
Professor, Department of Family Medicine, University of Michigan Health Systems

Gary Kaufman, M.D.,
Medical Director, Mount Sinai Health System's Deaf Health Program, Chicago, IL

Georgia Robins Sadler, BSN, MBA, Ph.D., and
Professor, Department of Surgery, Moores UCSD Cancer Center, University of California, San Diego

Roshan Bastani, Ph.D.
Professor, Department of Health Policy and Management, Fielding School of Public Health, University of California, Los Angeles

Abstract

Conflict of interest statement: The authors have no conflicts of interest to declare.

Background—Limited scientific evidence is available regarding D/deaf women's breast cancer knowledge and early detection practices, as well as about how to increase D/deaf women's breast cancer control practices.

Objective/Hypothesis—To assess baseline breast cancer knowledge and practices among a sample of D/deaf women recruited into a randomized controlled trial of a breast cancer education program developed for this population.

Methods—A written and signed (American Sign Language) survey was administered to a racially/ethnically diverse sample of 209 D/deaf women, 40+ years old, with lower levels of education, recruited in California between October 2008 and May 2009.

Results—There were misconceptions about breast cancer risk factors, screening, and treatment; only 64.2% of respondents correctly identified the purpose of mammography. Mammography in the prior two years was reported by 57.3% of the sample, by 69.8% of White women, and by 43.5% of women from other racial/ethnic groups. Rates also varied by education, having seen a physician in the prior year, and type of insurance.

Conclusions—This study underscores significant gaps in breast cancer screening knowledge and practices, communication issues in health care settings, and unmet needs for tailored health information and materials in this population. Challenges faced in conducting the research needed to develop and test such programs are noted.

Keywords

D/deaf women; breast cancer screening; breast cancer knowledge; communication barriers

Introduction

Sixteen percent of U.S. adults, approximately 36 to 37 million persons, report experiencing some degree of hearing loss [1]. This population include persons who identify as part of the Deaf community, a documented minority group that designates itself as Deaf (with a capital "D") as well as deaf or hard of hearing people (lower case "d" or "hh") with mild to profound hearing loss who self-identify as part of the hearing population [2–4]. The Deaf community has a unique culture, social history, and language [2–6], American Sign Language (ASL), a visual/spatial/gestural language with its own grammar, morphology and syntax [3,7,8]. To be inclusive and for simplicity, we refer to all participants in our program of research as D/deaf, although some self-identified as hard of hearing.

D/deaf women underutilize breast cancer screening and have incomplete breast cancer knowledge [9–15]. This is not surprising in light of the significant barriers to health information and resources facing D/deaf people. D/deaf sign language users experience socio-economic, educational, and health disparities [16–19]; inadequate communication in health care settings [9,10,18–27]; incomplete health and preventive health knowledge [2,11,28–34]; and low health literacy [35]. Increased use of preventive services by D/deaf American Sign Language (ASL) users has been reported when there is a language concordant clinician [36] or specialized program for the Deaf community [11], but access to such programs or clinicians is uncommon [25,36]. A recent study aimed at improving cancer

prevention knowledge through use of culture-specific language proved unsuccessful [2]. More research is needed to identify effective strategies for communicating cancer prevention and other health information among D/deaf people.

The limited research available suggests that D/deaf women from lower income and racial/ethnic minority groups have particularly low levels of breast cancer screening knowledge [34]. Underutilization of cancer screening is reported for persons with disabilities [37,38] but these reports do not always distinguish results for D/deaf persons [39], and we have not found any data regarding breast cancer screening for D/deaf women stratified by level of education, income, or race/ethnicity in the published literature. Evaluation of the few available breast cancer education programs tailored for D/deaf women is either not reported in the literature [40,41] or the assessment has been through pre/post design among well-educated White women and has not looked at behavioral outcomes [12]. To address this gap, we initiated a community-partnered research program to develop and assess a comprehensive, culturally and linguistically tailored, breast cancer educational program for D/deaf women.

In a pilot study conducted as the first step in this research program we completed signed interviews in which we obtained prior-year mammography information from 53 women 40+ years old [42]. Sixty-seven percent of these women (n=36/53) reported a prior two-year mammogram. Rates varied for women by level of education: 53.8% for women with less than high school education, 61.1% for women with high school education, and 80% for women who had completed college or more education. This clarified for us the importance of focusing particularly on developing and testing a program for D/deaf women with diverse educational backgrounds.

The purpose of this report is to describe baseline characteristics of the D/deaf women recruited into a randomized controlled trial to test the program we created with the goal of being accessible to D/deaf women with diverse levels of education. The survey obtained information about breast cancer knowledge and screening practices, and socio-demographic characteristics so that we could evaluate how knowledge and screening practices vary by such covariates as age, education, race/ethnicity, and income.

Methods

Community-Academic Partnership

Established in 1969, the Greater Los Angeles Agency on Deafness, Inc. (GLAD) is recognized throughout California and nationally for its leadership in the Deaf community. GLAD is known for direct service provision, health and other educational activities, advocacy, research, and information dissemination efforts on behalf of all persons regardless of hearing loss, communication mode, race, sex, or creed. Building on a fifteen-year research partnership between GLAD and UCLA, all aspects of the current study were conducted collaboratively, with the partners jointly identifying the research agenda, developing proposals, crafting intervention and data collection materials and strategies, implementing study procedures, analyzing and interpreting findings, and preparing joint publications and presentations. A Community Advisory Committee of D/deaf and hard of

hearing women and a panel of expert consultants was created to help guide the research. The community-academic partnership, Community Advisory Committee, expert panel, and research staff (field personnel, translation and back-translation group) included fourteen D/deaf and six hearing persons, and fourteen White, four Latino, and two Asian persons. Frequent in-person, email, mail, and videophone (VP) interaction ensured optimal communication among all research team members. This study was approved by UCLA's Institutional Review Board.

Theoretical/Conceptual Framework

The research study design, intervention and assessment content and strategies, and data analysis and interpretation, were guided by the Health Behavior Framework. This multi-dimensional theoretical/conceptual perspective synthesizes major theoretical formulations, takes into account socio-cultural and individual factors, and has been utilized in community-based research among diverse populations [43–47].

Recruitment

We recruited 209 women into a randomized controlled trial (RCT) to test the impact of the breast cancer education program. Recruiting D/deaf women into breast cancer research studies has proved challenging [12]. We therefore utilized diverse strategies (flyers, e-mails, presentations, informal person-to-person communication) at events, agencies, organizations, and community centers serving the D/deaf population in 17 California communities, 12 of which were in Southern California. Events, agencies, community organizations, and centers in each of these locations primarily serve women in their local area, and, therefore, participants were primarily from the areas where they were recruited.

Eligibility Criteria

Eligibility requirements for participation included being female, 40+ years old, self-identifying as D/deaf or hard of hearing (we use D/deaf in this paper for comprehensiveness and simplicity), not a breast cancer survivor, with no more than a high school diploma. Women were included who had some additional coursework but without a college degree.

Field Procedures

Three bilingual (ASL/English) Deaf community members, all with extensive community-based health education and research experience, conducted all field procedures after being trained by two research team members, a family physician (UCLA) and the community partner's Director of Health Education/Services (GLAD). Prospective participants were screened in-person by field personnel to ensure that they met eligibility requirements and understood participation expectations before consenting according to our IRB-approved protocol. Participants then completed the baseline survey. Following this, screening information was entered into a web-based screener in order to document eligibility and to generate randomization codes that would guarantee that field personnel could not influence group assignment in the clinical trial. Only if eligibility requirements were satisfied was a randomization code assigned. We excluded 12 women in this analysis who did not meet eligibility criteria.

These procedures, including baseline survey administration took place in 25 separate sessions at 17 community sites and one private residence between October 2008 and May 2009. See Appendix 1 for a list of locations and number of participants. Participants received a $50 honorarium at the end of the study.

Survey development

Currently, no validated breast cancer related survey is available in ASL. Therefore, we drew 200 candidate survey items from the limited number of health-related questionnaires that have been administered to this population [12,27,34], from standard survey instruments (e.g., Behavioral Risk Factor Surveillance System), and from a pool of items we have developed, validated, and successfully used in cancer prevention and control studies among other low-literacy, cultural and linguistic populations [43–47]. Initial items considered by the research team are listed at: http://www.biostat.ucla.edu/appendices/Breast_Cancer_Education_Preliminary_Survey_Items.pdf.

Each item was reviewed by the community-academic research team. Items were selected and modified for inclusion in the baseline survey instrument with the goal of ensuring that each question could be understood by D/deaf women with limited education. Guided by pilot study findings and the community partner, items were added and modified to maximize clarity and address issues of particular relevance to this population. Community team members played a central role in this determination; the final survey instrument was reviewed carefully by the community partner for content before translation into ASL. To reduce participant burden, the baseline survey was limited to 51 items and six domains: demographics/personal characteristics, deafness-related items, cancer (and breast cancer) experience (self/relatives), access to health information and services, breast health/breast cancer knowledge/attitudes, and breast and other health related practices and intentions, including mammography and clinical breast examination (CBE). Baseline survey items are listed in Appendix 2.

An ASL version of the English language questions was then prepared. As ASL is not a written language and a direct translation from English is not possible [48] the ASL version of each item was prepared independently by two Deaf community members who are native signers (ASL is their first language), fluent in English, and currently instructors of ASL at the college level. The ASL items were then video recorded via a web cam and stored on a computer. Three other Deaf community members and GLAD staff members (two health educators, one case manager), working independently, then prepared English language back-translations of each ASL clip. These GLAD staff members are all bilingual in ASL and English; they work with Deaf community members who are not fluent in English and who have high school or less education. This process continued for all survey items. The ASL versions were revised when discrepancies in meaning from the original English language version were identified. All translation and back-translation processes were supervised by the community partner researchers. When the community partner considered that the ASL version adequately captured the English language meaning, the agreed-upon ASL version was retained, providing a standard ASL instrument for field staff training and guidance for consistent survey administration. The videotapes were not used to administer the survey but

rather served to help maintain the integrity of the translation of the program materials throughout the study. The ASL translations were memorized by the field staff, and the videotape used as a reference and for review, as needed, during survey administration. All surveys were signed in ASL with written questionnaires distributed to complement the translations as is culturally appropriate.

Data analysis

Stata version 10 was used to perform all statistical analyses. Chi-square tests of independence were performed to assess significance at the alpha=0.05 level. Each test was performed based on available data for that question; no adjustments were made for missing data.

Results

Demographic characteristics

Table 1 reports participant demographic and deafness characteristics. Most of the women self-identified as Deaf and as prelingually deafened, deafened by three years old. The sample was racially/ethnically diverse; half of the women were White and nearly a quarter Latino. Most women reported annual family income of less than $30,000; over 90% reported insurance coverage, primarily Medicare or Medicaid/Medi-Cal; and 32.1% had less than high school education.

Health communication patterns, decision-making preferences, sources of health information

Table 2 reports responses relating to obtaining health services. Most respondents reported seeing a doctor in the prior year and being satisfied with the communication they had with their doctor. Physicians were the most frequently cited source of health information, by 58.4% of respondents, with 60.5% reporting having asked a physician for information or suggestions about how to protect their health in the prior year.

Breast cancer knowledge and screening practices

Table 3 reports responses to items regarding age when breast cancer screening should begin, screening frequency, and risk factors for the disease, along with reported screening practices for the sample overall.

Nearly half, 46.2%, of the sample identified age 40 as the age when mammography should begin, and 85.6% knew screening should occur every year/every two years. When asked to select from a list of possible breast cancer risk factors a number of women made incorrect choices (hitting or bumping the breasts, wearing tight bras or other clothing, breast-feeding, and exercising a lot/jumping around), and failed to recognize several known risk factors (age, early period/onset of menarche, late menopause, being obese).

Guidelines (e.g., American Cancer Society, U.S. Preventive Services Task Force) vary for frequency with which mammography should occur, age when screening should begin, and whether screening should continue after age 75 [49,50]. In our analyses we use the

commonly reported screening interval of at least every two years and mammography initiation at age 40. We examined mammography rates for women ages 40–75 and older than 75, finding virtually no difference in past two-year mammography (57.1%, *n*=88/154 vs. 55.6%, *n*=15/27, *p* =.88). Hence we report screening for all women in the sample, including those age 75 or older, following American Cancer Society guidelines.

Seventy-nine women had not been screened in the prior two years and were therefore noncompliant with respect to screening guidelines. Of these women 62.7% (*n*=47/75) reported seeing their doctor in the prior year, and 69.7% (*n*=53/76) expressed satisfaction with the communication they had with their doctor. Nevertheless, among these noncompliant women, not receiving a referral from the doctor was the most frequently noted reason for non-receipt of a mammogram in the previous year (43.0%, *n*=34/79). Logistical, psychological and cost issues were also noted, albeit by far fewer women; 13.9% (*n*=11/79) described cost and lack of insurance as a barrier to past year screening despite the high rate of reported insurance that would cover the cost of a mammogram, as well as the availability of California's free mammography program for low income women. One hundred sixteen women reported not being screened in the prior year and were therefore due for a mammogram in the coming year. One hundred fifteen of these women provided an indication of their future screening intentions. Of these women only 65.2% (*n*=75/115) reported definitely intending to be screened in the next year.

Table 4 reports associations with age, education level, race/ethnicity, and income for selected breast cancer knowledge questions and screening practices. Associations with three other variables are reported only in the text: seeing a doctor in the past year, having a hearing adult in the household, and source of insurance.

Nearly three quarters of the women agreed that the earlier you find cancer, the better chance of cure, with correct answers more likely among women 60+ years old (*p* = .023), White women (*p* <.001) and women with higher income levels (*p* = .001). Half of the women answered correctly when asked if a tumor is not cancer until it is large enough to be felt by a doctor.

Fewer than half of the women (46.6%) correctly answered when asked if women only need a mammogram if there is a lump in the breast. Correct answers to this question were *less* often given by women with high school or more education (*p* = .048), White women (*p* = .012), and women who reported seeing a doctor in the past year (42.0%, *n*=66/157 vs. 71.0%, *n*=22/31, *p* = .003). When asked if a woman was screened in the past and was OK, does she have to worry about getting breast cancer in the future, 61.2% of respondents answered correctly. Women with high school or more education were more likely to answer correctly (*p* = .015), as were younger women (*p* = .005) and women who reported a hearing adult in the household (70.7%, *n*=70/99 vs. 50.0%, *n*=43/86, *p* = .004). When asked if excess weight can increase the risk of cancer, of those responding 38.8% (*n*=188) indicated that it could. Fewer than half of the women, 43.8%, answered correctly, responding 'no' when asked if the only way to get rid of breast cancer is to remove the entire breast. White respondents were *less* likely to answer correctly (*p* = .035) as were women who had seen a doctor in the prior year (37.0%, *n*=54/146 vs. 68.8%, *n*=22/32, *p* = .001).

Only 64.3% of the sample answered correctly regarding the goal of mammography (diagnose cancer, provide x-ray picture, show problems in the breast), with women with high school or more education more likely to answer correctly (p = .034). Even fewer, 51.8%, answered correctly regarding the goal of a biopsy (diagnose cancer, test a piece of tissue, show problems in the breast) with women with higher levels of education (p = .037), income (p <.001), and White women (p = .001) more likely to respond correctly. Only 34.5% of the sample answered correctly when asked the goal of chemotherapy (to kill cancer cells), with women with high school or more education more likely to respond correctly (p = .007). Women who had seen a doctor in the prior year were more likely to answer correctly regarding the goal of mammography (69.7%, n=108/155 vs. 40. 6%, n=13/32, p = .002), biopsy (55.8%, n=86/154 vs. 31.3%, n=10/32, p. = .011), and chemotherapy (38.9%, n=61/157 vs. 16.1%, n=5/31, p = .015).

Most respondents (89.2%) indicated that they had ever received a mammogram, with women under age 60 less likely to have ever been screened (p = .002), as were women with an annual income under $10,000 ($p$ = .003) and White women (p = .002). Overall 57.3% reported receiving a mammogram in the previous two years, with rates higher for women with high school or more education (p = .002) and for White women (p < .001). For Latinas, a quarter of our sample, the two-year screening rate was 42.1%. Almost all participants (94.2%) reported having insurance. Among insured women 58.8% (n=161/177) had a mammogram in the prior two years. Rates were 73.1% (n=19/26) for women with private insurance, 64.9% (n =50/77) for women with Medicare, and 45.5% (n=30/66) for women with Medicaid/Medi-Cal (p = .016). About half of the respondents reported receiving a CBE in the prior two years, with women with high school or more education (p <.001), White women (p= .046) and women with an annual income over $20,000 (p = .007) more likely to have received this examination. Most women (83.2%) reported seeing a doctor in the prior year, of whom 93.7% (n=138/148) reported ever having received a mammogram, significantly more than among women who had not seen a doctor (67.7%, n=21/31) (p = <.001). Women who had seen a doctor in the prior year were also far more likely to have received a mammogram in the prior two years (68.2%, n=101/148 vs. 9.7%, n=3/31, p < .001), and to have received a CBE in the prior two years (64.4%, n=94/146 vs. 13.8%, n=4/29, p < .001).

Discussion

Breast cancer knowledge

Our findings confirm reports of incomplete breast cancer knowledge among D/deaf women [11,12]. This is a concern in that inadequate and incorrect knowledge has been identified as a barrier to breast cancer screening among racial/ethnic minority women [51] including some women with health insurance [52], and as a predictor of other significant barriers to mammography among low-income women [53]. Results for a number of knowledge items were consistent with findings from the hearing population, that women with lower levels of income, education, and from racial/ethnic minority groups have lower levels of breast cancer knowledge [54,55]. National data supports that these women are less likely to be aware of breast cancer screening tests, that screening is necessary, to have heard of mammograms, to

know at what age screening should begin, or how frequently it should occur [56–59]. We also found that living with a hearing adult in the household was associated with correct responses to one knowledge item, providing some support for the finding that having a hearing spouse is positively associated with cancer prevention knowledge [2].

However, some findings were surprising, such as when women with less education, women from racial/ethnic minority groups, and women that had not seen a doctor in the past year more frequently responded correctly to some knowledge questions. It may be that barriers to adequate communication experienced by D/deaf persons reduces the benefits of having more education or being White. These findings may also relate to some of our study procedures and to issues regarding conduct of research in this population. Some study participants with limited proficiency in both English and ASL struggled with hypothetical questions outside their own experience and with concepts involving something occurring “only” in some circumstances, and asked the interviewer for assistance and clarification. Similar difficulties have been found in other studies in this population [60]. While this anecdotal information cannot confirm that those asking for (and receiving) clarification, and therefore, more likely to answer these questions correctly, were disproportionately women from racial/ethnic minority groups or women with fewer years of formal education, this may have been the case. These results highlight the difficulties faced in crafting health surveys for this population: the challenge of translating complex concepts from English into ASL, the problem of standardization in survey administration [61], and the cultural and linguistic barriers relevant in considering health literacy in this, and other, minority populations [60, 62]. The D/deaf population has been found to be at greater risk for miscommunication with health care providers than other non-English speaking persons, such as immigrants [62].

Breast cancer screening practices

We found extremely low rates of breast cancer screening for the women in our study. One in ten had never been screened and only 57% were adherent to prior two year screening guidelines, a far lower rate than the 79% among California women overall in 2008 [63]. This is consistent with findings reported elsewhere for this population [10,12,13]. It is of particular interest that current screening was incomplete despite over 90% of the women in our sample reporting insurance, comparable to the rate of insurance coverage for women in the general population nationally [64], and the availability of California’s free breast cancer screening and treatment program for low-income women [65]. The rate of prior two-year screening for insured women in our study, 59%, was lower than among insured women nationally, 78% in 2005 [64], or in California in 2009, 83% [66]. Type of insurance (private, Medicare, Medicaid/Medi-Cal) made a significant difference in screening among the women in our study, despite coverage of the cost of mammography under all of these plans, raising questions regarding awareness of services. Likewise, reflecting barriers that frequently confront D/deaf women, this California program, “Every Woman Counts” while available, may not be accessible for D/deaf women. Many D/deaf persons do not effectively read English, information on the program’s website is not provided in ASL, and directions are not provided as to how to receive signed language interpretation regarding services. This may have contributed to some women who were due for a mammogram indicating lack of insurance and cost as reasons for not being screened in the previous year.

While confirming that women from racial/ethnic minority groups or with lower levels of education are at elevated risk for incomplete current breast cancer screening [63,64,66–68], our findings also suggest that being D/deaf creates additional barriers to those experienced by other minority and less well educated populations. We found past two year mammography rates of 70% for White women and 44% for women from other racial/ethnic groups, lower than in the general population of women in California in 2009, 81% and 75% or higher, respectively[66]. Latinas, a quarter of our sample, had a prior two-year mammography rate of 42% compared to 79% for Latinas in California in that year [66].

Physician recommendation is a strong predictor of timely preventive health measures and the lack of recommendations has been identified as a barrier to cancer screening including among low literacy and other minority groups [51, 69–75]. In our sample, health care providers are seen as an important source of information and decision making, and 70% of the sample expressed satisfaction with the communication they had with their doctor. However, adequate communication, referrals, and recommendations for breast cancer screening may not actually be occurring. Women who reported not having received a mammogram in the prior two years and were, therefore, non-adherent to mammography guidelines, most frequently indicated that this was because the doctor had not ordered the examination. More than half of the sample reported needing assistance from family and friends in making appointments, getting to the doctor, or making important health decisions, also suggesting difficulties in obtaining services in clinical settings. These barriers within the health care environment, along with inadequate access to information about available screening programs and incomplete knowledge about the need for routine mammography, may all contribute to the suboptimal record of breast cancer screening among the D/deaf women in our study.

Limitations

Conclusions from our research need to be drawn with caution. Although we took steps to ensure that survey items were appropriate for the focus population, e.g., limiting the number of questions, developing an ASL version of our questionnaires, review of draft survey instruments by the community partner and members of the Deaf community, these steps may not have been enough. Just as hearing women have differing levels of English language proficiency, D/deaf women also have differing levels of ASL and English language proficiency. In our study, some women had difficulty with the survey items and offering assistance may have influenced study results. How questions were worded and interpreted in ASL may have influenced responses, as reflected in answers given to a question regarding the risk posed by obesity versus an item regarding excessive weight. Even fewer survey items might have been helpful, but this raises another issue. It is a limitation of our study that in consideration of respondent burden we reduced the number of questions, eliminating some items relating to cultural identity and language proficiency/usage. Therefore, we could not explore fully the role of these and other significant variables in the breast cancer knowledge and practices of the women in our study. Finally, our study involved a convenience sample and may not adequately represent D/deaf women overall.

Conclusions

Baseline data for a sample of D/deaf women consenting to participate in a randomized clinical trial provides evidence of inadequate breast cancer knowledge, particularly among the women with lower levels of education and from racial/ethnic minority groups. Almost all of the women in our study had insurance that covers the cost of mammography, and there are California programs that cover this cost for low-income women and women without insurance. Nevertheless we found underutilization of mammography and that a third of the women due for screening did not intend to get a mammogram in the next year or were uncertain if they would do so. These data point to the need for breast cancer education programs, insurance providers proactively providing accessible information informing D/deaf women about optimal health care practices, particularly Medicaid/Medi-Cal, and for increasing primary care providers' awareness of community options as well as the importance of referring their D/deaf patients for mammograms.

Our findings demonstrate that many D/deaf persons face significant barriers to receiving information, referrals, and services in clinical settings. Despite legal requirements for provision of adequate communication in health care settings, trained sign language interpreters are not always provided/available [10,25]. Lip-reading occurs with great difficulty; i.e., without sound, at best, only about 30% of speech is readable on the lips [4,7,61] and is not a viable communication option for many D/deaf people. Written materials for hearing people may be culturally or linguistically inappropriate for a portion of the Deaf community, and written at a proficiency level that is too high to be widely accessible throughout the Deaf community [11]. For many D/deaf people English is a second or third language, and on average high school graduates read English at a fourth grade reading level [4,76,77]. More research is needed to achieve a better understanding of the reasons for the poorer breast cancer knowledge among D/deaf women, the lack of adequate referrals, and underutilization of mammography in this population, and to craft, assess, and disseminate effective interventions that can bring about change.

Acknowledgements

The authors wish to express their appreciation to the D/deaf women who participated in this research; the members of our Community Advisory Committee, Ms. Mary Blockinger, Ms. Alicia Fernandez, Ms. Maria Smith, and Ms. Elena Whalen; Ms. Alicia Wolfson, Ms. Lauren Maucere, Ms. Erin Ross Zemlyankin, Ms. Evelin Gaina, Ms. Lilly Crisman, and Deaf community members and Greater Los Angeles Agency on Deafness, Inc. (GLAD) staff for their assistance.

This program of research was supported by the California Breast Cancer Research Program (CBCRP) Grant No. 12BB-1000, and by the Susan G. Komen Foundation Grant No. POP 70006. Dr. Cumberland was also supported by the National Cancer Institute through the UCLA Cancer Center Support Grant, CA16042.

Appendix

Appendix 1.

Workshop Sites and Number of Participants (N = 209)

Site	Location	Number of Participants(*n*=209)
Greater Los Angeles Agency on Deafness, Inc. (GLAD)	Los Angeles, CA	36 (5 sessions)

Site	Location	Number of Participants(*n*=209)
Tri-County GLAD (TC GLAD)	Ventura, CA	3
GLAD Employment and Development Dept.	Norwalk, CA	15
Bakersfield GLAD (B-GLAD)	Bakersfield, CA	5
Orange County Deaf Equal Access Foundation (OC Deaf)	Cypress, CA	15 (2 sessions)
Holy Angels Church	Vernon, CA	12
Temple Beth Solomon for the Deaf	Tarzana, CA	4
Pilgrim Towers (for the Deaf and Elderly)	Los Angeles, CA	16
Center for Deafness – Inland Empire (CODIE)	Riverside, CA	13 (2 sessions)
Deaf Counseling, Advocacy, & Referral Agency (DCARA) at the Fremont Oak Gardens (FOG)	Fremont, CA	11
Deaf Counseling, Advocacy, & Referral Agency (DCARA) at the Deaf Community Center (DCC)	San Leandro, CA	23
Deaf and Hard of Hearing Service Center, Inc. (DHHSC)	Fresno, CA	14
Awakenings Substance Abuse Recovery Programs for Deaf & Hard of Hearing Persons	Whittier, CA	8
NorCal Services for the Deaf & Hard of Hearing	North Highlands, CA	14
North Valley Occupational Center (NVOC)	Mission Hills, CA	4
Hacienda La Puente Adult Education – Hearing Impaired Literacy (HIL)	La Puente, CA	6 (2 sessions)
Deaf Community Services of San Diego (DCS)	San Diego, CA	1
Personal Residence	Northridge, CA	9

Appendix 2: Baseline Survey Questions

We would like to begin by asking you some questions about your health, your health care, and the health of your family

- Have you ever been diagnosed with breast cancer (yes, no)
- Have you ever been diagnosed with any other type of cancer (yes, no)
- Have any of your *female* blood relatives – mother, daughter, grandmother, sisters, aunts – ever been diagnosed with breast cancer? (yes, no)
- Did you see a doctor in the past year (yes, no)
- How did you communicate with your doctor? (You can check more than one answer.) [signing, lip reading, talking, gesture, professional interpreter, family member or friend, writing notes, other (specify)]
- Are you satisfied with your communication with your doctor? (satisfied, not satisfied)
- Where do you get health information (You can check more than one answer.) [doctor, nurse, friends or family, Deaf/HH agency, television, books/magazines/

newspaper, Internet, hearing agency, I don't get health care information, other (specify)]

- Do you *need* help from family or friends to make appointments, get to the doctor, or make important health care decisions (yes, no) If "yes" do you get this help? (yes, no)
- In the past year did *you ask* your doctor for information or suggestions about how to protect your health? (yes, no)
- What was the date of your last screening mammogram? [Month/Year; I never got this test, I don't remember, but it was more than: 2, 3, 4, 5 years ago (circle one)]
- If you did *not* get a screening mammogram in the past year, why not? (You can check more than one answer) [cost, no symptoms, transportation problem, communication problem, doctor didn't order, procrastinate -- put it off, no insurance, pain/embarrassed, hard to make appointment, afraid to find cancer, other (specify)]
- In the next year, will you get a screening mammogram? (yes, maybe, no)
- What was the date of your last clinical breast examination? [Month/Year; I never got this test, I don't remember, but it was more than: 1, 2, 3, 4, 5 years ago (circle one)]
- If you did *not* get a clinical breast examination in the past year, why not? (You can check more than one answer) [cost, no symptoms, transportation problem, communication problem, doctor didn't order, procrastinate -- put it off, no insurance, pain/embarrassed, hard to make appointment, afraid to find cancer, other (specify)]
- In the next year, will you get a clinical breast examination? (yes, maybe, no)
- How often do you make food choices to improve your health? (every day, a few times during the week, rarely or never)
- How often do you make physical activity choices– like taking stairs or walking instead of driving to improve your health? (every day, a few times during the week, rarely or never)

We would like to learn about your opinions and ideas

- Should a deaf/hh woman insist on a Sign Language interpreter if it is not something that the doctor wants? (yes, no)
- I would rather have doctors and nurses make decisions for me than make me choose what is best.(yes, no)
- The earlier you find cancer the better the chance of cure. (yes, no)
- A tumor is not cancer until it is large enough to be felt by a doctor. (yes, no)
- Women only need a mammogram if there is a lump in the breast (yes, no)

- If a woman was screened in the past and was OK does she have to worry about getting breast cancer in the future? (yes, no)
- Excess weight can increase the risk of cancer. (yes, no)
- The only way to get rid of breast cancer is to remove the entire breast. (yes, no)
- At least how many days a week are people supposed to exercise?[circle one] (1,2,3,4,5,6,7), I don't know
- At least how many servings of fruits and vegetables are adults supposed to eat each day? [circle one] (1,2,3,4,5,6,7,8,9, 10 or more, I don't know
- At what age are women supposed to start having mammograms? ____
- In general, once women start having mammograms, about how often should they have them? (every year, every 1–2 years, Every 3–4 years, every 5 years, every 10 years)
- The goal of chemotherapy is: (to diagnose cancer, to kill cancer cells, to provide an x-ray picture, I don't know)
- The goal of a biopsy is: (to kill cancer cells, to diagnose cancer, to provide an x-ray picture, to show problems in the breasts, to test a piece of tissue from the breast, I don't know)
- The goal of a mammogram is: (to kill cancer cells, to diagnose cancer, to provide an x-ray picture, to show problems in the breasts, to test a piece of tissue from the breast, I don't know)
- Which of the following *increase* the risk of getting breast cancer? (You can check more than one answer). (early period– before age 10, being a woman, having big breasts, older age, being obese, wearing tight bras and other clothing, exercising a lot/ jumping around, not getting enough exercise, breast feeding, late menopause--after age 55, drinking a lot of alcohol, hitting or bumping breasts)
- In the *PAST YEAR*, did you participate in any of the following to promote breast health awareness? (You can check more than one answer). [a community event such as a "run" or "walk," buy a specific product with a "pink ribbon," educated other deaf/hh women about breast cancer, some other activity (specify), I did not participate in any activities]
- In the *PAST YEAR,* which of the following did you do? (You can check more than one answer) (changed your diet to be more healthy, changed your pattern of exercise to be more healthy, changed the amount of alcohol that you usually drink to be more healthy, take part in some health related activity such as a community walk or lecture)
- Please put an "X" on the line to show how likely you are to do the following *IN THE NEXT YEAR.*
- For each item: (0 (not at all likely)___/___/___/ ___1 (very likely): Change your diet to be more healthy, Change your pattern of exercise to be more healthy,

Change the amount of alcohol that you usually drink to be more healthy, Take part in some health related activity such as a community walk or lecture

We would like to ask you some questions about yourself

- How old are you? _____
- Are you: (Married, Living with a partner, Separated, Divorced, Widowed, Never Married)
- What is your race/ethnicity? [White, Latino (Hispanic), African American or Black, Asian or Pacific Islander, Native American, Multi racial or other (specify)]
- What is the highest grade of education you completed? [Grade School K, 1,2,3,4,5,6,7,8 (Circle highest grade) High School 9,10,11,12 (circle highest grade), High School Diploma/GED/Certificate, Some college/community college/vocational, business/trade school, College (Bachelor Degree) or higher]
- Are you: (working full time, working part-time, receiving SSI/SDI, not working)
- What is your one year family income? (Less than $10,000, $10,000 - $20,000, $20,000-$30,000, $30,000-$40,000, $40,000 - $50,000, More than $50,000)
- What kind of health insurance do you have? [Medicare, Medicaid or Medi-Cal, private/other (specify), do not have insurance]
- Are you: (deaf, hard of hearing)
- How old were you when you lost your hearing? (born deaf, ___years old)
- Are there any hearing adults living in your household? (yes, no)
- What is your height? _____ feet _____ inches
- How much do you weigh? _____ pounds
- How many days per week do you exercise for 30 minutes or more? (circle one) (0,1,2,3,4,5,6,7)
- How many servings of fresh fruit or vegetables do you usually eat in a day? (circle one)
- 0,1,2,3,4,5,6,7,8,9, 10 or more] (serving = about 1 cup)
- Have you smoked 100 cigarettes (5 packs) during your lifetime? (yes, no)
- Do you now smoke cigarettes… (every day, some days, not at all)
- During the past month, on *how many days* did you drink an alcoholic beverage? ___
- In the past month, about *how many alcoholic drinks* did you tend to drink per day? _____
- did not have any alcoholic drinks last month

References

[1]. Schiller JS, Lucas JW, Ward BW, Peregoy JA. Summary health statistics for U.S. adults: National Health Interview Survey, 2010. National Center for Health Statistics. Vital Health Stat 10(252). 2012.

[2]. Zazove P, Meador HE, Read BD, Sen A, Gorenflo DW. Effectiveness of videos improving cancer prevention knowledge in people with profound hearing loss. J Cancer Educ. 2012 6;27(2):327–337. [PubMed: 22528628]

[3]. Dolnick E Deafness as culture. Atlantic Monthly.1993;272:37–53.

[4]. Barnett S Clinical and cultural issues in caring for Deaf people. Fam Med.1999;31(1):17–22. [PubMed: 9987607]

[5]. Padden C, Humphries T. Inside Deaf Culture. Cambridge, MA: Harvard University Press 2005.

[6]. Lane H, Hoffmeister R, Bahan B. A Journey into the Deaf World. San Diego, CA: Dawn Sign Press1996.

[7]. Phillips BA. Bringing culture to the forefront: Formulating diagnostic impressions of Deaf and Hard of Hearing people at times of medical crises. Prof Psychol Res Pr. 1996; 27(2):137–144.

[8]. Mitchell RE, Young TA, Bachleda B, Karchmer MA. How many people use ASL in the United States? Why estimates need updating. Sign Lang Stud. 2006;6(3):306–335.

[9]. Barnett S, Franks P. Health care utilization and adults who are Deaf: Relationship with age and onset of deafness. Health Serv Res. 2002:37(1):105–120. [PubMed: 11949915]

[10]. Steinberg AG, Wiggins EA, Barmada CH, Sulllivan VJ. (2002). Deaf women: experiences and perceptions of healthcare system access. J Womens Health 2002;11(8):729–741.

[11]. Orsi JM, Margellos-Anast H, Perlman TS, Giloth BE, Whitman S. Cancer screening knowledge, attitudes, and behaviors among culturally Deaf adults: implications for informed decision making. Cancer Detect Prev. 2007;31(6):474–479. [PubMed: 18061367]

[12]. Sadler GR, Gunsauls DC, Huang J. et al. Bringing breast cancer education to Deaf women. J Cancer Educ. 2001a; 16: 225–228. [PubMed: 11848672]

[13]. Iezzoni LI, McCarthy EP, Davis RB, Harris-David L, O'Day B. Use of screening and preventive services among women with disabilities. Am J Med Qual. 2001;16(4):135–144. [PubMed: 11477958]

[14]. MacKinney TG, Walters D, Bird GL, Nattinger AB. Improvements in preventive care and communication for Deaf patients. Results of a novel primary health care program. J Gen Intern Med.1995;10:133–137. [PubMed: 7769469]

[15]. Wollin J, Elder R. Mammograms and pap smears for Australian Deaf women. Cancer Nurs. 2003;26(5):405–409. [PubMed: 14710803]

[16]. Ries PW. Prevalence and characteristics of persons with hearing trouble: United States, 1990–91.Vital and Health Statistics. Series10: Data from the National Health Survey,188,1–75. 1994.

[17]. Schoenborn CA, Heyman K. Health disparities among adults with hearing loss: United States, 2000–2006. Centers for Disease Control and Prevention. National Center for Health Statistics 2008www.cdc.gov/nchs/data/hestat/hearing00-06/hearing00-06.htm. Retrieved February 1, 2011.

[18]. Barnett S, McKee M, Smith SR, Pearson TA. Deaf sign language users, health inequities, and public health: Opportunity for social justice. Prev Chronic Dis. 2011; 8(2).A45Epub 2011 Feb 15.

[19]. Smith SM, Kampfe CM. Interpersonal relationship implications of hearing loss in persons who are older. J Rehabil.1997;63(2):15.

[20]. Harmer L Health care delivery and Deaf people: practice, problems, and recommendations for change. J Deaf Stud Deaf Educ.1999;4(2):73–110. [PubMed: 15579880]

[21]. Iezzoni LI, O'Day BL, Killeen M, Harker M. Communicating about health care: observations from persons who are Deaf or Hard of Hearing. Ann Intern Med. 2004;140:356–362. [PubMed: 14996677]

[22]. Ebert DA, Heckerling PS. Communication with Deaf patients. Knowledge, beliefs and practices of physicians. J Am Med Assoc. 1995;273:227–229.

[23]. Ralston E, Zazove P, Gorenflo DW. Physicians' attitudes and beliefs about Deaf patients. J Am Board Fam Pract.1996;9(3):167–173. [PubMed: 8743229]

[24]. Sadler GR, Huang JT, Padden CA, et al. Bringing health care information to the Deaf community. J Cancer Educ. 2001b:16:105–108. [PubMed: 11440061]

[25]. Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P. Health care system accessibility, experiences and perceptions of Deaf people. J Gen Intern Med. 2006;21:260–266. [PubMed: 16499543]

[26]. Zazove P, Doukas DJ. The silent health care crisis: Ethical reflections of health care for deaf and hard-of-hearing persons. Fam Med.1994;26:387–390. [PubMed: 8050663]

[27]. Zazove P, Niemann LC, Gorenflo DW, et al. The health status and health care utilization of Deaf and Hard-of-Hearing persons. Arch Fam Med. 1993;2(7):745–752. [PubMed: 8111500]

[28]. Bat-Chava Y, Martin D, Kosciw JG. Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people. AIDS Care. 2005;17(5):623–634. [PubMed: 16036248]

[29]. Kaskowitz SR, Nakaji MC, Clark KL, Gunsauls DC, Sadler GR. Bringing prostate cancer education to deaf men. Cancer Detect Prev. 2006;30:39–448.

[30]. Margellos-Anast H, Estarziau M, Kaufman G. Cardiovascular disease knowledge among culturally Deaf patients in Chicago. Prev Med. 2006;42:235–239. [PubMed: 16460789]

[31]. Tamaskar P, Malia T, Stern C, Gorenflo P, Meador H, Zazove P. Preventive attitudes and beliefs of Deaf and Hard-of-Hearing individuals. Arch Fam Med. 2000;9(6):518–525, 526. [PubMed: 10862214]

[32]. Van Biema D AIDS. Time. 1994;143(14):76–77. [PubMed: 10134858]

[33]. Woodroffe T, Gorenflo DW, Meader HE, Zazove P. Knowledge and attitudes about AIDS among deaf and hard of hearing persons. AIDS Care. 1998;10(3):377–386. [PubMed: 9828980]

[34]. Zazove P, Meador HE, Reed BD, Sen A, Gorenflo DW. Cancer prevention knowledge of people with profound hearing loss. J Gen Intern Med. 2009;24(3):320–326. Epub 2009 Ja [PubMed: 19132325]

[35]. Pollard RQ, Barnett S. Health-related vocabulary knowledge among Deaf adults. Rehabil Psychol. 2009;34(2):183–185.

[36]. McKee MM, Barnett SL, Block RC, Pearson TA. Impact of communication on preventive services among Deaf American Sign Language users. Am J Prev Med. 2011, 7;41(1):75–79. [PubMed: 21665066]

[37]. Chan L, Doctor JN, MacLehose MS, et al. Do Medicare patients with disabilities receive preventive services? A population-based study. Arch Phys Med Rehabil. 1999;80(6):642–646. [PubMed: 10378489]

[38]. Nosek MA, Howland CA. Breast and cervical cancer screening among women with physical disabilities. Arch Phys Med Rehabil.1997;78(12 Suppl 5):S39–S44. [PubMed: 9422006]

[39]. Ramirez A, Farmer GC, Grant D, Papachristou T. Disability and preventive cancer screening: Results from the 2001 California Health Interview Survey. Am J Public Health, 2005;95(11): 2057–2064. [PubMed: 16195509]

[40]. Perlman TS.(Writer/Producer), Wexler D.(Director). Understanding Breast Health? Women CAN. [DVD] Northbrook, Illinois: Advocate Health Care 2005.

[41]. GLAD. Greater Los Angeles Council on Deafness, Inc. Tri-County Regional Partnership Breast Cancer Early Detection Program Grant, Santa Barbara County, State Department of Health Services Division of Cancer Detection Services, 2000.

[42]. Berman BA, Kleiger HB, Bastani R, Zazove P, Streja L. What do Deaf/HH women know and think about breast cancer and breast health? Presentation. American Public Health Association 134th Annual Meeting & Exposition, November 4–8, 2006, Boston MA.

[43]. Bastani R, Glenn BA, Tsui J, et al. Understanding suboptimal Human Papillomavirus vaccine uptake among ethnic minority girls. Cancer Epidemiol Biomarkers Prev. 2010;20(7):1463–1472.

[44]. Bastani R, Glenn BA, Taylor VM, et al. Integrating theory into community interventions to reduce liver cancer disparities: The Health Behavior Framework. Prev Med. 2010;50:63–67. [PubMed: 19716379]

[45]. Bastani R, Maxwell AE, Bradford C, Das IP, Yan KX. Tailored risk notification for women with a family history of breast cancer. Prev Med. 1999 11;29(5):355–364. [PubMed: 10564627]

[46]. Maxwell AE, Bastani R, Warda US. Mammography utilization and related attitudes among Korean-American women. Women Health 1998;27(3):89–107. [PubMed: 9698640]

[47]. Bastani R, Marcus AC, Hollatz-Brown A. Screening mammography rates and barriers to use: a Los Angeles County survey. Prev Med. 1991 5;20(3):350–363. [PubMed: 1862057]

[48]. Jones EG, Mallinson RK, Phillips L, Kang Y. Challenges in language, culture, and modality. Translating English measures into American Sign Language. Nurs Res. 2006;55(2):75–81. [PubMed: 16601619]

[49]. American Cancer Society. American Cancer Society Guidelines for the Early Detection of 1Cancer. Breast Cancer. Downloaded from http://www.cancer.org/Healthy/FindCancerEarly/CancerScreeningGuidelines/. Retrieved May 23, 2012.

[50]. Preventive US Services Task Force. Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement. Ann Intern Med. 2009;151:716–726. [PubMed: 19920272]

[51]. Alexandraki I, Mooradian AD. Barriers related to mammography use for breast cancer screening among minority women. J NatlMed Assoc. 2010;102(3):206–218.

[52]. Mack KP, Pavao J, Tabnak F, Knutson K, Kimerling R Adherence to recent screening mammography among Latinas: findings from the California Women's Health Survey. J Women Health (Larchmt). 2009;18(3):347–354.

[53]. Ahmed NU, Fort JG, Fair AM, Semenya K, Haber G. Breast cancer knowledge and barriers to mammography in a low-income managed care population. J Cancer Educ.2009;24(4):261–266. [PubMed: 19838882]

[54]. Watts T, Merrell J, Murphy F, Williams A. Breast health information needs of women from minority ethnic groups. J Adv Nurs. 2004;47(5):526–535. [PubMed: 15312115]

[55]. Luquis RR, Villanueva Cruz IJ. Knowledge, attitudes, and perceptions about breast cancer and breast cancer screening among Hispanic women residing in South Central Pennsylvania. J Community Health. 2006;31(1):25–42. [PubMed: 16482764]

[56]. Harris DM, Miller JE, Davis DM. Racial differences in breast cancer screening, knowledge and compliance. J Natl Med Assoc 2003;95(8):693–701. [PubMed: 12934865]

[57]. Rutten LJF, Nelson DE, Meissner HI. Examination of population-wide trends in barriers to cancer screening from a diffusion of innovation perspective (1987–2000). Prev Med 2004;38:258–268. [PubMed: 14766107]

[58]. Rutten LF, Moser RP, Beckjord EB, Hesse BW, Croyle RT. Cancer Communication: Health Information National Trends Survey. (2007) Washington, D.C.; National Cancer Institute NIH Pub. No. 07–6214.

[59]. Robb K, Wordle J, Stubbings S, Ramirez A, Austoker J, Macleod U, Hiam S, Waller J. Ethnic disparities in knowledge of cancer screening programmes in the UK. J Med Screen 2010;17:125–131. [PubMed: 20956722]

[60]. Meador HE, Zazove P. Health care interactions with Deaf Culture. J Am Board Fam Pract. 2005;18(3):218–222. [PubMed: 15879570]

[61]. Margellos-Anast H, Hedding T, Perlman T, et al. Developing a standarized comprehensive health survey for use with Deaf adults. Am Ann Deaf. 2005;150(4):388–396. [PubMed: 16466194]

[62]. McEwen E, Anton-Culver H. The medical communication of deaf patients. J Fam Pract. 1988 3;26(3):289–291. [PubMed: 3346631]

[63]. Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2009.

[64]. Kim J, Jang SN. Socioeconomic disparities in breast cancer screening among US women: trends from 2000–2005. J Prev Med Public Health. 2008;41(3):186–194. [PubMed: 18515996]

[65]. California Department of Public Health. Cancer Detection Programs: Every Woman Counts. http://www.cdph.ca.gov/programs/cancerdetection/Pages/cancerdetectionprogramseverywomancounts.aspx. Page last modified June 29, 2011. Retrieved August 2, 2011.

[66]. California Health Interview Survey. CHIS, 2005, 2007, 2009 Adult Public Use File. Los Angeles, CA: UCLA Center for Health Policy Research http://www.askchis.com. http://www.askchis.com/ Accessed June 5, 2010, August 1, 2011, May 21, 2012.

[67]. Ryerson AB, Miller JW, Eheman CR, Leadbetter S, White MC. Recent trends in U.S. mammography use from 2000–2006: a population-based analysis. Prev Med. 2008; 47(5): 477–82. Epub 2008 Jun 18.

[68]. Njai R, Siegel PZ, Miller JW, Liao Y. Misclassification of survey response and Black-White disparity in mammography use. Behavioral Risk Factor Surveillance System, 1995–2006. Prev Chronic Dis. 2011; 8(3). http://www.cdc.gov/pcd/issues/2011/may/10_0109.htm. Retrieved July 20, 2011.

[69]. Paskett ED, Tatum C, Rushing J, Michielutte R, Bell R, Long Foley K, Bittoni M, Dickinson S. Racial differences in knowledge, attitudes and cancer screening practices among a triracial rural population. Cancer 2004 12 1;101(1):2650–9. [PubMed: 15505784]

[70]. Klabunde CN, Vernon SW, Nadel MR, Breen N, Seeff LC, Brown ML. Barriers to colorectal cancer screening: a comparison of reports from primary care physicians and average-risk adults. Med Care. 2005;43(9):939–944. [PubMed: 16116360]

[71]. Honda K (2004). Factors associated with colorectal cancer screening among the US urban Japanese population. Am J Public Health. 2004;94(5):815–822. [PubMed: 15117706]

[72]. Hay JL, Ford JS, Klein D, et al. Adherence to colorectal cancer screening in mammography adherent older women. J Behav Med. 2003;26(6):553–576. [PubMed: 14677212]

[73]. Meissner HL, Breen N, Taubman ML, Vernon SW, Graubard BI. Which women aren't getting mammograms and why? (United States) Cancer Causes Control. 20072;18(1):61–70. [PubMed: 17186422]

[74]. Schueler KM, Chu PW, Smith-Bindman R. Factors associated with mammography utilization: a systematic quantitative review of the literature. J Womens Health (Larchmt). 2008;17(9):1477–1498. [PubMed: 18954237]

[75]. DuBard CA, Schmid D, Yow A, Rogers AB, Lawrence WW. Recommendation for and receipt of cancer screenings among Medicaid recipients 50 years and older. Arch Intern Med. 2008;168(18): 2014–2021. [PubMed: 18852404]

[76]. Gallaudet Research Institute. Stanford Achievement Test, 9th Edition, Form S, Norms Booklet for Deaf and Hard-of-Hearing Students (including conversion of raw scores to scaled score and grade equivalent and age-based percentile ranks for deaf and hard-of-hearing students). Washington, D.C. Gallaudet University 1996.

[77]. Holt JA, Traxler CB, Allen TE. Interpreting the scores: A user's guide to the 9th edition Stanford Achievement Test for educators of deaf and hard-of-hearing students. (Gallaudet Resesarch Institute Technical Report No. 97–1).Washington D.C.Gallaudet University1997 n 9.

Table 1.

Demographic, deafness, breast cancer, and family characteristics (*n*=197)*

Demographic Characteristics	***n* %**
Age	(*n*=193)
< 50	(63) 32.6
< 50–59	(45) 23.3
60–75	(57) 29.5
> 75	(28) 14.5
Marital Status	(*n*=196)
Married/Living with a partner	(78) 39.8
Separated/Widowed/Divorced/Never Married	(118) 60.2
Race/ethnicity	(*n*=193)
White	(100) 51.8
African American or Black	(23) 11.9
Latino (Hispanic)	(43) 22.3
Asian or Pacific Islander	(12) 6.2
Multi-Racial or Other	(15) 7.8
Level of Education	(*n*=190)
Less than High School	(61) 32.1
High School Diploma/GED/Certificate	(78) 41.1
Some college, community college, vocational, business, trade school	(51) 26.8
Employment Status	(*n*=189)
Working full time	(10) 5.3
Receiving SSI/SSD	(110) 58.2
Working part-time	(8) 4.2
Not working	(61) 32.3
Income	(59) 34.1
Less than $10,000	(58) 33.5
$10,000-$20,000	(28) 16.2
More than $30,000	(28) 16.2
Health Insurance Coverage	(*n*=190)
Medicare	(84) 44.2
Medicaid or Medi-Cal	(67) 35.3
Private/Other	(28) 14.7
Do not have insurance	(11) 5.8
Body Mass Index	(*n*=187)
Less than 25 (Underweight-Normal)	(65) 34.8
25–29.9 (Overweight)	(53) 28.3

Demographic Characteristics	***n* %**
≥30 (Obese)	(69) 36.9
Deafness Characteristics	
Deaf or Hard of Hearing:	(*n*=195)
Deaf	(169) 86.7
Hard of Hearing	(26) 13.3
Reported age of onset of deafness:	(*n*=189)
≤3 years old	(158) 83.6
4 – 28 years old	(31) 16.4
Have a hearing adult in household	(*n*=193)
	(102) 52.8
Breast Cancer and Family Characteristics	
Ever diagnosed with cancer other than breast cancer	(*n*=185)
	(17) 9.2
Have female blood relative with breast cancer	(*n*=189)
	(55) 29.1

* Percentages are determined by total number of responses (in parentheses) to each question.

Table 2.

Health communication patterns, decision making preferences, sources of health information (*n*=197)*

Health Communication	***n* %**
Seen a doctor in past year	(*n*=191)
	(159) 83.2
Satisfaction with communication with doctor	(*n*=191)
Satisfied	(139) 72.8
Decision Making	
Would rather have doctor and nurses make decisions for me than make me choose what is best	(*n*=190)
	(108) 56.8
A deaf or hard of hearing woman should insist on a Sign Language interpreter if it is not something that the doctor wants	(*n*=190)
	(170) 89.5
Sources of Information	
Sources of health information (May choose more than 1)	(*n*=197)
Doctor	(115) 58.4
Friends or family	(105) 53.3
Television	(64) 32.5
Internet	(42) 21.3
I don’t get health care information	(16) 8.1
Nurse	(30) 15.2
Deaf/HH agency	(58) 29.4
Books, magazines, newspapers	(78) 39.6
Hearing agency	(6) 3.0
Need help from family/friends to make appointments, get to doctor, or make important health decisions?	(*n*=193)
	(106) 54.9
In past year, asked doctor for information or suggestions about how to protect your health?	(*n*=190)
	(115) 60.5

*Percentages are determined by total number of responses (in parentheses) to each question.

Table 3.

Selected breast cancer knowledge and screening practices (n=209) *

Breast Cancer Knowledge	
Percentages are in parentheses following the number of respondents selecting each item	***n* %**
Age women are supposed to start having mammograms:	(n=182)
<35	(37) 20.3
35	(14) 7.7
36 –39	(1) .6
40	(84) 46.2
41 – 49	(9) 4.9
50	(13) 7.1
>50	(7) 2.8
Don't Know	(17) 9.3
Once women start having mammograms, how often should they have them?	(n=188)
Every year / Every 1–2 years	(161) 85.6
Every 3 years or more	(27) 14.4
Which of following increase risk of getting breast cancer: (May choose more than 1)	(n=197)
Early period – before age 10	(15) 7.6
Older age	(81) 41.1
Exercising a lot/jumping around	(16) 8.1
Late menopause – after age 55	(53) 26.9
Being a woman	(54) 27.4
Being obese	(29) 14.7
Not getting enough exercise	(42) 21.3
Drinking a lot of alcohol	(40) 20.3
Having big breasts	(27) 13.7
Wearing tight bras and other clothing	(27) 13.7
Breast feeding	(21) 10.7
Hitting or bumping breasts	(65) 33.0
Breast Cancer Screening Practices	
Mammography	
Time since last mammogram:	(n=185)
In past year	(69) 37.3
1–2 years ago	(37) 20,0
More than two years ago	(59) 31.9
Never got test	(20) 10.8
Reason for no mammogram in past year among non-adherent women † (May choose more than 1):	(n=79)
Doctor didn't order	(34) 43.0

Breast Cancer Knowledge	
Percentages are in parentheses following the number of respondents selecting each item	***n* %**
No symptoms	(7) 8.9
Psychological barriers[≠]	(17) 21.5
Logistical barriers[≠]	(13) 16.5
Cost too much/No insurance	(11) 13.9
Intentions to be screened in coming year among women due for screening[ǂ]	(*n*=115)
Yes[≠]	(75) 65.2
Maybe	(23) 20.0
No	(17) 14.8
Clinical Breast Examination	
Time since last CBE:	(*n*=180)
In past year	(61) 33.9
1–2 yrs ago	(38) 21.1
More than two years ago	(65) 36.1
Never got test	(16) 8.9

[*] Percentages are determined by total number of responses (in parentheses) to each question.

[≠] Psychological barriers include any concern about pain, embarrassed, fear (afraid of finding cancer), and procrastination.

[≠] Logistical barriers include transportation problems, communication problems, difficulty in making an appointment.

[†] Non-adherent women never had a mammogram or had a mammogram more than two years in the past

[ǂ] Due for screening are women who never had a mammogram or had a mammogram more than one year in the past

Table 4.

Associations with age, education, race/ethnicity and income for selected breast cancer knowledge and screening practice questions

	Over-	Age		Education		Race/Ethnicity		Income		
	All	**< 60**	**≥60**	**< HS**	**≥HS**	**White**	**Other**	**<10k**	**10–20k**	**>20k**
Breast cancer knowledge Percent answering correctly*										
The earlier you find cancer the better the chance of cure.	72.0	64.7	80.0	65.5	75.2	84.0	58.4	58.9	67.3	90.7
	(186)	(182) $p = .023$		(180) $p = .179$		(183) $p < .001$		(172) $p = .001$		
A tumor is not cancer until it is large enough to be felt by a doctor.	51.6	53.8	48.1	62.3	48.0	45.3	59.3	52.7	55.6	46.3
	(184)	(181) $p = .441$		(178) $p = .081$		(181) $p = .059$		(163) $p = .614$		
Women only need a mammogram if there is a lump in the breast.	46.6	50.0	42.2	58.6	43.0	38.4	56.7	52.6	45.6	44.6
	(193)	(189) $p = .284$		(186) $p = .048$		(189) $p = .012$		(170) $p = .649$		
If a woman was screened in the past and was OK does she have to worry about getting breast cancer in the future?	61.2	70.5	50.0	47.4	66.4	56.8	65.6	66.7	60.0	61.8
	(188)	(185) $p = .005$		(182) $p = .015$		(185) $p = .224$		(164) $p = .751$		
Excess weight can increase the risk of cancer.	38.8	38.5	39.5	29.1	42.5	44.7	31.1	30.0	31.6	46.3
	(188)	(185) $p = .885$		(182) $p = .087$		(184) $p = .058$		(166) $p = .167$		
The only way to get rid of breast cancer is to remove the entire breast.	43.2	50.5	32.9	46.4	43.0	35.6	51.1	49.1	43.6	39.6
	(183)	(180) $p = .018$		(177) $p = .667$		(180) $p = .035$		(161) $p = .618$		
The goal of a mammogram correctly answered.	64.3	64.5	64.6	53.3	69.3	70.4	58.7	58.6	64.9	67.9
	(193)	(189) $p = .983$		(187) $p = .034$		(190) $p = .091$		(171) $p = .576$		
The goal of a biopsy correctly answered.	51.8	49.1	58.0	41.4	57.9	64.3	39.3	31.6	55.4	69.6
	(191)	(187) $p = .223$		(184) $p = .037$		(187) $p = .001$		(169) $p < .001$		
The goal of chemotherapy correctly answered.	34.5	29.0	42.2	20.3	40.6	45.5	22.8	20.3	32.8	53.7
	(194)	(190) $p = .058$		(187) $p = .007$		(191) $p = .001$		(171) $p = .001$		
Breast cancer screening practices: Mammography and clinical breast examination										
Ever received a mammogram.	89.2	82.5	97.4	84.2	91.7	95.8	81.2	76.8	92.5	96.4
	(185)	(181) $p = .002$		(178) $p = .129$		(181) $p = .002$		(164) $p = .003$		
Received a mammogram in past two years.	57.3	51.5	64.1	40.4	64.5	69.8	43.5	46.4	52.8	69.1
	(185)	(181) $p = .089$		(178) $p = .002$		(181) $p < .001$		(164) $p = .047$		
Received a clinical breast exam (CBE) in past two years.	55.0	55.6	52.6	26.4	66.7	61.9	46.8	48.1	44.4	72.2

Disabil Health J. Author manuscript; available in PMC 2019 June 10.

	Over-	Age		Education		Race/Ethnicity		Income		
	All	< 60	≥60	< HS	≥HS	White	Other	<10k	10–20k	>20k
	(180)	(177) $p = .692$		(173) $p < .001$		(176) $p = .046$		(162) $p = .007$		

*Denominators for displaying percents are given in parentheses.