# Breast cancer screening attitudes, beliefs, and behaviors of Zuni Pueblo women: identifying cornerstones for building effective mammogram screening intervention programs 

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#### Abstract

Purpose Breast cancer is the leading form of cancer and has the second highest mortality rate of cancers for American Indian/Alaska Native (AI/AN) women. Early screening is critical. This study examines the breast cancer-related knowledge, beliefs, and behaviors of Zuni women in the Southwest United States (U.S.). Methods In 2020 and 2021, a survey was administered to better understand cancer screening patterns in Zuni Pueblo; 110 women from 50 to 75 years of age were recruited to respond to the breast cancer screening portion. Inclusion criteria included self-identifying as AI, a member of the Zuni tribe, or married to a Zuni tribal member, and meeting the age and gender requirements. Descriptive statistics and bivariate analyses were conducted examining the associations between measures of breast cancer knowledge, beliefs, and behaviors and breast cancer screening status (never, ever/non-compliant, and ever/ compliant). Results Of survey participants, $47.3 \%$ have had a breast cancer screening and are up-to-date, $39.1 \%$ have had a screening in the past but are not up-to-date, and $13.6 \%$ have never been screened. Age was the only statistically significant socioeconomic predictor of breast cancer screening; the median (interquartile range) ages of each group are $62(54,68)$ ever/compliant, 56 $(54,68)$ ever/non-compliant, and $53(51,55)$ never $(p$-value $<0.001)$. Significant differences by health status and access to medical care include having a regular health care provider and going to see a provider for routine check-ups. The survey also shows differences in knowledge about breast cancer risk factors, beliefs, and behaviors. Women across all three screening statuses reported that they would get screened if encouraged by a health care provider. Conclusion While survey respondents report a relatively high rate of ever having had a breast cancer screening, less than half are compliant with screening guidelines, which shows there is an opportunity to improve breast cancer screening rates. With culturally tailored interventions, providers have the potential to improve breast cancer screening for Zuni women.


Keywords Breast cancer screening • American Indian/Alaska Native health • Health equity

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## Introduction

Similar to the wider population of women in the US, breast cancer is the leading form of cancer for American Indian/ Alaska Native (AI/AN) women. As of 2019, breast cancer is the top cancer by the rate of new cancer cases for AI/ AN women (73.1 cases/100,000 women) and is the second highest cancer leading to mortality for AI/AN women [1]. AI/AN women tend to have lower rates of breast cancer and breast cancer mortality compared to non-Hispanic white women [2]. From 2014 to 2018, the breast cancer incidence rate per 100,000 for $\mathrm{AI} / \mathrm{AN}$ women was 81.7 compared to 137.9 for non-Hispanic white women (a ratio of 0.6 ) and the breast cancer mortality rate per 100,000 for AI/AN women was 14.8 compared to 20.1 for nonHispanic white women (a ratio of 0.7) [2]. However, these lower incidence patterns do not minimize the burden of breast cancer for AI/AN communities where breast cancer is still among the most common malignancy and continues to lead to considerable morbidity and mortality [2]. Additionally, tracking statistics over time, from 1999 to 2015, AI/AN women are experiencing a relative increase in new cases of breast cancer compared to non-Hispanic white women [3].

One of the most impactful ways of minimizing the burden of breast cancer is to detect it at the earliest possible stage through guidelines compliant screening, specifically mammography. There is wide variation in information about AI/ AN mammogram patterns based on the source of the data. Self-reported data from the 2019 National Health Interview Survey, indicate that AI/AN women and non-Hispanic white women have similar rates of mammography screening: $65.3 \%$ of AI/AN women compared to $68.0 \%$ of non-Hispanic white women [2]. However, drawing from clinical data from the national Indian Health Service (IHS) performance statistics, the percentage of AI/AN women aged 52-74 who have received mammography screening from the IHS within the previous 2 years is 42.6 in 2018 and 42.0 in 2019 . Of the Albuquerque Area IHS population, $43.0 \%$ (2018) and 38.7\% (2019) of women have received mammography screening within the last 2 years [4]. These clinical figures may point to screening inequities. Additionally, AI/AN breast cancer screening patterns vary based on Tribe and region. While these discrepancies may be partially due to self-report versus clinical data and to some individuals seeking and receiving care outside of the IHS, all sets of figures demonstrate that AI/AN women breast cancer screening percentages fall short of the Healthy People 2020 goal for breast cancer screening of $81.1 \%$ [4]. Early screening is critical for minimizing the burden of breast cancer for AI/AN women.

To improve breast cancer screening in AI/AN women, studies need to prioritize understanding motivators for
and barriers to screening. Access to timely and regular breast cancer screening is key to minimizing the burden of breast cancer and minimizing related health disparities [5]. Studies show that racial and ethnic minority populations including AI/AN have specific factors which both facilitate and hamper breast cancer screening [6-9]. Prior studies have demonstrated an association between breast cancer screening awareness and breast cancer screening behaviors [9]. Studies exploring factors hindering AI/AN breast cancer screening connect lack of knowledge about breast cancer screening and risks, in addition to sociodemographic factors, to lower rates of breast cancer screening. AI/AN women report culturally specific views and beliefs about breast cancer screening like mammography [7, 10].

An additional factor that has been identified as a facilitator and a detractor at times is the IHS provision of services [11]. The IHS provides more accessible care in many ways, but also due to systematic underfunding from the federal government in addition to other factors, the IHS may also prevent or delay access to breast cancer screening services for AI/AN women. AI/AN populations are entitled by treaty to receive healthcare free of charge provided by the US federal government, which for most is healthcare provided by the Indian Health Service (IHS). This universal health care coverage does not result in easily accessible health care services in many cases [12]. Challenges to health care access through the IHS stem from several factors including underfunding, geographic sparsity, and historic trauma leading to current mistrust [12]. While AI/AN populations are entitled to healthcare, the federal funding is insufficient for addressing comprehensive healthcare needs. In 2019, the annual IHS expenditure per user population was $\$ 4,078$ compared to the national average of over $\$ 10,000$ per person [13]. An additional challenge for the AI/AN population in accessing care is geography. While there are over 300 IHS primary health clinics, there are only 46 IHS hospitals, and not all hospitals provide specialty care services [12]. This means that in many cases AI/AN patients and caretakers must travel long distances to receive specialty healthcare services, such as mammograms. Finally, the HIS has a complicated history of healthcare delivery, which included culturally destructive healthcare programs, such as a program in the 1970s which resulted in the sterilization of over $25 \%$ of AI/AN women of childbearing age without adequate consent [14]. While the current leadership and practices and policies aim to center patient autonomy and many efforts have been made to build strong, positive relationships between IHS facilities and Tribal communities, many AI/ AN women are justifiably wary of receiving IHS services due to historic trauma [14]. Engagement with IHS should be further explored to better understand the link between cancer-specific care and reducing cancer disparities [11].

Ultimately, the literature shows that breast cancer studies are not racially, ethnically, nor geographically representative. There is a need for more breast cancer and breast cancer screening research focused on AI/AN women. AI/AN experiences with cancer screening are not uniform; there is a need for more Tribe-specific research. There is great diversity among the 574 federally recognized Tribes, yet the vast majority of research investigates AI/AN health patterns as one group and generalizes findings based on these studies $[10,15]$. This project answers that call for Tribe-specific research and addresses priority goals for Zuni Pueblo to improve cancer outcomes; recent research demonstrates that Zuni Pueblo has unique resources, strengths, and challenges in addressing cancer inequities [15-19]. This study contributes to this growing scholarship by examining the breast can-cer-related knowledge, beliefs, and behaviors of Zuni women in the Southwest. Finding from this study will inform the development, implementation, and resting of interventions tailored to the unique attributes of Zuni women.

## Materials and methods

## Research setting

In 2020 and 2021, a survey was administered in partnership with the Zuni Health Initiative in the Zuni Pueblo, the largest Pueblo Tribe in New Mexico with approximately 11,000 residents, to better understand cancer screening patterns for cervical, breast, and colorectal cancers. While Zuni is a small, rural community, breast cancer screening including mammography is available locally at the IHS-administered Zuni Comprehensive Health Center [20]. This project has received research approval from the Zuni Pueblo Tribal Council, the Southwest Tribal Institutional Review Board (IRB), and UNM Health Sciences Center IRB.

## Sampling strategy and eligibility criteria

The sampling strategy for this community survey includes random sampling of streets, strategic convenience sampling, and snowball sampling. This survey sample is the result of inclusive, broad reaching recruitment efforts; however, this survey is not a systematic, representative random sample. The sampling strategy began with a random selection from all streets in Zuni Pueblo after which all residences located on selected streets were recruited through flyers. Women called the number listed on the flyer and the research team also conducted limited in-person outreach efforts. Research team members would inform potential participants about the study when they went to households to distribute the fliers. COVID-19 restrictions limited most in-person recruitment strategies, but recruiting efforts were supplemented
through outreach at high-traffic community locations and snowball sampling from key community stakeholders and respondents. Inclusion criteria included self-identifying as AI, a member of the Zuni tribe, or married to a Zuni tribal member, and meeting the age and gender requirements for the age/gender-specific survey. To be eligible for the breast cancer screening portion of the survey, in addition to the above criteria, women needed to be at least 50 and up to 75 years of age, resulting in 110 respondents.

## Study implementation

The survey used an observational, cross-sectional design. The Zuni Health Initiative (ZHI) staff conducted surveys between October 2020 and April 2021. The survey varied in length based on the age/gender-specific survey. The survey varied by three groups: women 21-49, women $50-75$, and men 50-75. All groups were asked the same questions about general cancer knowledge, beliefs, and behaviors as well as demographics. Women 21-49 were asked the cervical cancer knowledge, beliefs, and behaviors subset; women 50-75 were asked the cervical, breast, and colorectal cancer knowledge, beliefs, and behaviors subset; and men 50-75 were asked the colorectal cancer knowledge, beliefs, and behaviors subset. All participants received a merchandise card in recognition of their participation in the study. Due to COVID-19 pandemic precautions, surveys were conducted by phone.

## Measures/variables

Dependent variable Breast cancer screening status is determined by self-report of mammograms and the time of last mammogram at the time of the survey based on the breast cancer screening recommendations from the US Preventive Services Task Force (USPSTF): ever screened/compliant includes women who have been screened within the last 2 years; ever screened/non-compliant includes women whose last screening was over 2 years ago; and never screened includes women who have never had a mammogram [21].

Independent variables Variables of interest include a wide range of factors associated with cancer screening and cancer outcomes. Sociodemographic characteristics include age, marital status, language, education, income, and employment. In addition to mammogram status and most recent year of mammogram, breast cancer screening behaviors of interest include the main reason for having most recent mammogram, reasons for not having had a mammogram, and questions about when women should start having mammograms. These questions are adapted from the measures included in the National Cancer Institute Health Information National Trends Survey (HINTS) [22]. Health status and access to medical care measures include self-rated health,
personal and family history of cancer, and multiple questions about personal experiences with healthcare. Breast cancer risk knowledge is measured by asking women to select which of 21 factors ( 10 more medically reasonable, and 11 less medically reasonable) increase a woman's chance of developing breast cancer. These questions were compiled from the risk factors listed by the American Cancer Society, the National Cancer Institute, and the Centers for Disease Control and Prevention and are listed in the results tables [23-26]. These factors have been used in previous research and were updated with the current best evidence [27, 28]. Attitudes and beliefs about cancer in general include general statements about cancer (agree/disagree), measures social network attitudes and beliefs, attitudes and beliefs about healthcare providers and cancer screening, and future screening intentions. Finally, women reported preferences for strategies to improve cancer screening, which include 15 evidence-based strategies designed to increase cancer screening from the Community Preventive Services Task Force's Community Guide (based off recommendations for breast, cervical, and colorectal cancers) [29].

## Data analysis

Descriptive statistics were calculated by mammogram screening status for sociodemographic characteristics, health status and access to medical care, breast cancer risk knowledge, breast cancer screening behaviors, attitudes and beliefs toward cancer in general, and preferences for strategies to improve breast cancer screening. Bivariate assessments of significant differences among the groups were accomplished using the statistical approach appropriate for the data type (i.e., Fisher's exact, Pearson's Chi-squared, or Kruskal-Wallis rank sum tests).

## Results

Sociodemographic characteristics Of Zuni women who participated in the survey, $47.3 \%$ have had a breast cancer screening and are compliant, $39.1 \%$ have had a screening in the past but are non-compliant, and $13.6 \%$ have never been screened. There were few meaningful and statistically significant characteristics associated with breast cancer screening status (Table 1). Age was the only meaningful and statistically significant socioeconomic covariate associated with breast cancer screening; the median [interquartile range $(I Q R)]$ ages of each group are $62(54,68)$ years for the ever/compliant, $56(54,68)$ years for the ever/noncompliant, and $53(51,55)$ for the never ( $p$-value $<0.001$ ). Employment status was also significantly different among the groups ( $p$-value 0.027 ). Noteworthy patterns were identified among non-statistically significant associations: in all
breast cancer screening groups, the vast majority speak a language other than English at home ( $96 \%$ ever/compliant, $86 \%$ ever/non-compliant, and $93 \%$ never) and at least $80 \%$ of respondents report having health insurance across all groups ( $86 \%$ for both ever/compliant and ever/non-compliant and $80 \%$ never).

Breast cancer screening behaviors In addition to mammogram status and compliance with screening guidelines, the results show more precise information about the length of time since the last reported mammogram (Table 2). For those who are compliant with screening guidelines, based on the time of the survey, $58 \%$ have had a screening in the last 12 months and $42 \%$ have had a mammogram over 1 year ago but less than 2 years. For those who have had a mammogram, but are currently not compliant, $47 \%$ of respondents have had a mammogram more than 2 years ago but less than 3 years ago, which means that $53 \%$ of respondents have not had a mammogram in the last 3 years. Both groups of women who have been screened report that the main reason why they did their most recent mammogram was because it was part of a routine exam ( $81 \%$ for ever/compliant and $84 \%$ for ever/non-compliant). For those who have never been screened almost half (47\%) said that they have not been screened because they perceive that a mammogram is too painful, unpleasant, or embarrassing. Answers varied widely to the questions about when women are supposed to start having mammograms and how often women over the age of 50 with no personal or family history of breast cancer should do mammograms.

Health status and access to medical care Analysis of health status measures did not reveal statistically significant differences among the breast cancer screening status groups. However, four measures of access to medical care showed distinct associations for screening (Table 3). The groups varied by the percentage who reported having a regular health care provider ( $81 \%$ ever/compliant, $65 \%$ ever/non-compliant, and $47 \%$ never; $p$-value $=0.022$ ). The percentages of respondents who see health care providers when they are not sick, but to do check-up visits also vary ( $61 \%$ ever/compliant, $37 \%$ ever/non-compliant, and $20 \%$ never; $p$-value 0.007 ). The median (IQR) number of visits to a healthcare provider over the last 12 months for any reason varied significantly ( $p$-value $<0.001$ ): the ever/ compliant group reported $3(2,4)$ visits compared to $2(1,4)$ visits for the ever/non-compliant and $0(0,1)$ visits for the never screened groups. Similarly, when asked how many visits respondents have made to an IHS clinic in the last 3 years, $71 \%$ of the ever/compliant group and $74 \%$ of the ever/ non-compliant group reported having made three or more visits compared to $27 \%$ of the never screened group ( $p$-value 0.02 ). While non-significant, there is a pattern worth noting about how respondents perceived their relationships with their providers. When participants were asked if their health

Table 1 Sociodemographic characteristics of participants by mammogram screening status ( $n=110$ )

|  | Compliant ( $n=52$ ) | Ever had test but not compliant, $(n=43)$ | Never had test ( $n=15$ ) | $p$ value |
| :---: | :---: | :---: | :---: | :---: |
| Age | $62(54,68)$ | $56(54,68)$ | $53(51,55)$ | <0.001 |
| BMI | $29(25,32)$ | $29(26,32)$ | $27(25,32)$ | 0.7 |
| Married/partnered |  |  |  | 0.7 |
| No | 26 (50\%) | 24 (56\%) | 9 (60\%) |  |
| Yes | 26 (50\%) | 19 (44\%) | 6 (40\%) |  |
| Speak non-English at home? |  |  |  | 0.2 |
| No | 2 (3.8\%) | 6 (14\%) | 1 (6.7\%) |  |
| Yes | 50 (96\%) | 37 (86\%) | 14 (93\%) |  |
| Fluency speaking English |  |  |  | 0.13 |
| English only | 2 (3.8\%) | 6 (14\%) | 1 (6.7\%) |  |
| Very well | 22 (42\%) | 23 (53\%) | 9 (60\%) |  |
| Well | 24 (46\%) | 14 (33\%) | 4 (27\%) |  |
| Not well | 4 (7.7\%) | 0 (0\%) | 1 (6.7\%) |  |
| Education |  |  |  | 0.4 |
| High school or less | 29 (56\%) | 18 (42\%) | 8 (53\%) |  |
| More than high school | 23 (44\%) | 25 (58\%) | 7 (47\%) |  |
| Income |  |  |  | 0.3 |
| < \$10,000 | 18 (35\%) | 15 (36\%) | 7 (47\%) |  |
| \$10,000-\$19,999 | 21 (41\%) | 10 (24\%) | 4 (27\%) |  |
| > \$20,000 | 12 (24\%) | 17 (40\%) | 4 (27\%) |  |
| (Missing) | 1 | 1 | 0 |  |
| Employment |  |  |  | 0.027 |
| Employed | 9 (17\%) | 8 (19\%) | 3 (20\%) |  |
| Self-employed | 9 (17\%) | 11 (26\%) | 9 (60\%) |  |
| Not in labor force | 31 (60\%) | 20 (47\%) | 2 (13\%) |  |
| Unemployed | 3 (5.8\%) | 4 (9.3\%) | 1 (6.7\%) |  |
| Insurance |  |  |  | 0.9 |
| Insured | 44 (86\%) | 37 (86\%) | 12 (80\%) |  |
| Uninsured | 7 (14\%) | 6 (14\%) | 3 (20\%) |  |
| (Missing) | 1 | 0 | 0 |  |

Median (IQR); $n(\%)$. Kruskal-Wallis rank sum test; Pearson's Chi-squared test; Fisher's exact test
care providers treated them with respect, the majority of each group agreed or agreed strongly ( $79 \%$ ever/compliant, $78 \%$ ever/non-compliant, and $94 \%$ never), but there are differences in the patterns of which groups disagreed ( $16 \%$ ever/compliant, $4.8 \%$ ever/non-compliant, and $6.7 \%$ never).

Breast cancer risk knowledge Women's knowledge of breast cancer risks was measured by assessing correct knowledge of 21 factors ( 10 more medically reasonable, and 11 less medically reasonable) which increase a woman's chance of developing breast cancer (Table 4). There were two factors that were significantly different among the groups. Those who correctly answered that a family history of breast cancer increases a woman's chance of breast cancer varied by breast cancer screening status ( $88 \%$ ever/compliant and ever/non-compliant compared to $60 \%$ never; $p$-value 0.032 ). In addition, correctly answering that having breast implants increases a woman's chance of breast cancer varied
by breast cancer screening status ( $73 \%$ ever/compliant, $86 \%$ ever/non-compliant, and $40 \%$ never; $p$-value 0.003 ).

While there are not statistically significantly different areas of breast cancer risk knowledge, there are response patterns worth noting. A majority of respondents from all breast cancer screening statuses did not correctly identify the following more medically reasonable risk factors: not having children, giving birth to first child after the age of 30 , and starting menstruation before the age of 12 . More than one third of respondents across all breast cancer screening categories did not correctly identify the following more medically reasonable risk factors: using birth control pills, drinking excessive alcohol, being overweight or obese, and not being physically active. In addition, women across all three breast cancer screening groups incorrectly identified many of the less medically reasonable factors as contributors to a woman's change of developing breast cancer.

Table 2 Self-reported behaviors and knowledge regarding breast cancer screening by mammogram screening status ( $n=110$ )

|  | Compliant $(n=52)$ | Ever had test but not compliant ( $n=43$ ) | Never had test ( $n=15$ ) | $p$ value |
| :---: | :---: | :---: | :---: | :---: |
| Have you ever had a mammogram? |  |  |  |  |
| Yes | 52 (100\%) | 43 (100\%) | 0 (0\%) |  |
| No | 0 (0\%) | 0 (0\%) | 15 (100\%) |  |
| Most recent mammogram |  |  |  |  |
| Less than 12 months ago | 30 (58\%) | 0 (0\%) |  |  |
| 1 to $<2$ years | 22 (42\%) | 0 (0\%) |  |  |
| 2 to $<3$ years | 0 (0\%) | 20 (47\%) |  |  |
| 3 to $<5$ years | 0 (0\%) | 14 (33\%) |  |  |
| 5 to $<10$ years | 0 (0\%) | 7 (16\%) |  |  |
| 10 years or more | 0 (0\%) | 2 (4.7\%) |  |  |
| What was the main reason you had this mammogram done? |  |  |  |  |
| Part of a routine exam | 42 (81\%) | 36 (84\%) |  |  |
| Family history of breast cancer | 2 (3.8\%) | 2 (4.7\%) |  |  |
| My healthcare provider told me I was high-risk | 3 (5.8\%) | 1 (2.3\%) |  |  |
| Other | 3 (5.8\%) | 1 (2.3\%) |  |  |
| Because of a breast problem | 1 (1.9\%) | 2 (4.7\%) |  |  |
| I requested it | 1 (1.9\%) | 1 (2.3\%) |  |  |
| Reasons respondents selected for not having had a mammogram |  |  |  |  |
| Your doctor did not recommend it |  |  | 4 (27\%) |  |
| The test is too painful, unpleasant, or embarrass |  |  | 7 (47\%) |  |
| Too expensive, no insurance, cost |  |  | 2 (13\%) |  |
| Age; thought I was too young to have test |  |  | 2 (13\%) |  |
| I do not have any problems |  |  | 2 (13\%) |  |
| Breast cancer screening not important |  |  | 3 (20\%) |  |
| At what age are women supposed to start having mammograms? Is it... |  |  |  | 0.4 |
| 0-29 years | 11 (21\%) | 8 (19\%) | 1 (6.7\%) |  |
| 30-39 years | 21 (40\%) | 18 (42\%) | 4 (27\%) |  |
| 40-49 years | 10 (19\%) | 11 (26\%) | 4 (27\%) |  |
| 50-59 years | 10 (19\%) | 6 (14\%) | 6 (40\%) |  |
| How often should women 50 years and older with no personal or family history of breast cancer do a mammogram? |  |  |  | 0.2 |
| Every year | 24 (46\%) | 10 (23\%) | 9 (60\%) |  |
| Every 2 years | 17 (33\%) | 18 (42\%) | 2 (13\%) |  |
| Every 3 years | 6 (12\%) | 9 (21\%) | 2 (13\%) |  |
| Every 6 months | 3 (5.8\%) | 3 (7.0\%) | 2 (13\%) |  |
| Every 5 years | 2 (3.8\%) | 2 (4.7\%) | 0 (0\%) |  |
| Every 4 years | 0 (0\%) | 1 (2.3\%) | 0 (0\%) |  |

$n$ (\%); Fisher's exact test

Attitudes and beliefs about cancer Among the items in the measures of attitudes and beliefs about cancer in general, three items had different associations with breast cancer screening status (Table 5). First, a greater percentage of those reporting having ever been screened (compliant and non-compliant) reported that they agreed that they were very likely to get cancer in their lifetime ( $56 \%$ ever/compliant, $44 \%$ ever/non-compliant, and $20 \%$ never; $p$-value 0.047 ). Second, a greater percentage of those reporting having ever been screened (compliant and non-compliant) reported that
they agreed that it seems like almost everything causes cancer ( $31 \%$ ever/compliant, $40 \%$ ever/non-compliant, and $0 \%$ never; $p$-value 0.007). Finally, those who had reported screening were more likely to report having discussed their personal risk of cancer with a provider: $56 \%$ ever/compliant, $37 \%$ ever/non-compliant, and $20 \%$ never ( $p$-value 0.027 ). Answers vary across many items, but no other associations were statistically significant.

Although there are a range of differences in both knowledge and beliefs among these groups, women across all three

Table 3 Health status and access to medical care by mammogram screening status ( $n=110$ )

|  | Compliant, ( $n=52$ ) | Ever had test but not compliant ( $n=43$ ) | Never had test $(n=15)$ | $p$ value |
| :---: | :---: | :---: | :---: | :---: |
| Self-rated Health |  |  |  | 0.1 |
| Fair/poor | 10 (19\%) | 5 (12\%) | 4 (27\%) |  |
| Good | 22 (42\%) | 22 (51\%) | 10 (67\%) |  |
| Very good/excellent | 20 (38\%) | 16 (37\%) | 1 (6.7\%) |  |
| How often do you exercise? |  |  |  | 0.3 |
| Daily or more than three times per week | 15 (29\%) | 11 (26\%) | 8 (53\%) |  |
| One to three times per week | 17 (33\%) | 18 (42\%) | 3 (20\%) |  |
| You do not exercise regularly | 20 (38\%) | 14 (33\%) | 4 (27\%) |  |
| Personal cancer history (yes) | 6 (12\%) | 3 (7.0\%) | 1 (6.7\%) | 0.8 |
| Family cancer history (yes) | 36 (69\%) | 32 (74\%) | 9 (60\%) | 0.6 |
| Do you have a health care provider that you go to regularly? (yes) | 42 (81\%) | 28 (65\%) | 7 (47\%) | 0.022 |
| Where do you usually go for health care? |  |  |  | 0.089 |
| Doctor or other provider in a private clinic | 3 (5.8\%) | 1 (2.3\%) | 0 (0\%) |  |
| Hospital outpatient clinic | 1 (1.9\%) | 1 (2.3\%) | 3 (20\%) |  |
| I do NOT have a usual place for health care | 1 (1.9\%) | 1 (2.3\%) | 1 (6.7\%) |  |
| IHS/tribal clinic or hospital | 47 (90\%) | 40 (93\%) | 11 (73\%) |  |
| Do you ever go to see a health care provider when you are not sick or having any problems, just to get a check-up? (yes) |  |  |  | 0.007 |


| No | $20(39 \%)$ | $27(63 \%)$ | $12(80 \%)$ |  |
| :--- | :--- | :--- | :--- | :--- |
| Yes | $31(61 \%)$ | $16(37 \%)$ | $3(20 \%)$ |  |
| (Missing) | 1 | 0 | 0 |  |
| In the past 12 months, how many times did you visit a health care | $3(2,4)$ | $2(1,4)$ | $0(0,1)$ | $<\mathbf{0 . 0 0 1}$ |
| provider for any reason? |  |  |  |  |

How many times have you been to an Indian Health Services clinic in the past three years? $\mathbf{0 . 0 2}$

| Never | $4(7.7 \%)$ | $2(4.7 \%)$ | $3(20 \%)$ |
| :--- | :--- | :--- | :--- |
| One time | $3(5.8 \%)$ | $4(9.3 \%)$ | $4(27 \%)$ |
| Two times | $8(15 \%)$ | $5(12 \%)$ | $4(27 \%)$ |
| Three times or more | $37(71 \%)$ | $32(74 \%)$ | $4(27 \%)$ |

The hospital or clinic I usually go to provides me with good health care overall. Do you...

| $2(4.7 \%)$ | $1(6.7 \%)$ |
| :--- | :--- |
| $30(70 \%)$ | $10(67 \%)$ |
| $5(12 \%)$ | $1(6.7 \%)$ |
| $6(14 \%)$ | $2(13 \%)$ |
| $0(0 \%)$ | $1(6.7 \%)$ |

The health care providers I usually see treat me with dignity and respect. Do you...

| Strongly agree | $12(24 \%)$ |
| :--- | :--- |
| Agree | $28(55 \%)$ |
| Neither agree nor disagree | $3(5.9 \%)$ |
| Disagree | $7(14 \%)$ |
| Strongly disagree | $1(2.0 \%)$ |
| (Missing) | 1 |


| $6(14 \%)$ | $4(27 \%)$ |
| :--- | :--- |
| $27(64 \%)$ | $10(67 \%)$ |
| $7(17 \%)$ | $0(0 \%)$ |
| $2(4.8 \%)$ | $0(0 \%)$ |
| $0(0 \%)$ | $1(6.7 \%)$ |
| 1 | 0 |

I feel comfortable talking to health care providers when I have a health problem. Do you...

| Strongly agree | $14(27 \%)$ | $11(26 \%)$ | $2(13 \%)$ |
| :--- | :--- | :--- | :--- |
| Agree | $32(62 \%)$ | $26(60 \%)$ | $13(87 \%)$ |
| Neither agree nor disagree | $3(5.8 \%)$ | $2(4.7 \%)$ | $0(0 \%)$ |
| Disagree | $1(1.9 \%)$ | $4(9.3 \%)$ | $0(0 \%)$ |
| Strongly disagree | $2(3.8 \%)$ | $0(0 \%)$ | $0(0 \%)$ |
| Have you ever had a test to check for cervical cancer? (yes) | $44(85 \%)$ | $37(86 \%)$ | $12(80 \%)$ |

[^1]Table 4 Knowledge about breast cancer risk factors by mammogram screening status ( $n=110$ )

| Which of the following things increase a woman's chance of developing breast cancer? (yes) | Compliant ( $n=52$ ) | Ever had test but not compliant $(n=43)$ | Never had test $(n=15)$ | $p$ value |
| :---: | :---: | :---: | :---: | :---: |
| Getting older | 36 (69\%) | 25 (58\%) | 10 (67\%) | 0.5 |
| Giving birth to 1st child after age 30 | 11 (21\%) | 9 (21\%) | 4 (27\%) | $>0.9$ |
| Using birth control pills | 28 (54\%) | 23 (53\%) | 9 (60\%) | $>0.9$ |
| Having breast implants | 38 (73\%) | 37 (86\%) | 6 (40\%) | 0.003 |
| Starting menstruation before age 12 | 16 (31\%) | 8 (19\%) | 4 (27\%) | 0.4 |
| Family history of breast cancer | 46 (88\%) | 38 (88\%) | 9 (60\%) | 0.032 |
| Drinking excessive alcohol | 33 (63\%) | 24 (56\%) | 7 (47\%) | 0.5 |
| Being overweight or obese | 28 (54\%) | 23 (53\%) | 7 (47\%) | 0.9 |
| Not being physically active | 26 (50\%) | 25 (58\%) | 9 (60\%) | 0.7 |
| Not having children | 15 (29\%) | 9 (21\%) | 4 (27\%) | 0.7 |
| A diet low in fruits and vegetables | 25 (48\%) | 17 (40\%) | 8 (53\%) | 0.6 |
| A diet low in fiber | 27 (52\%) | 21 (49\%) | 10 (67\%) | 0.5 |
| A diet high in fat | 43 (83\%) | 34 (79\%) | 12 (80\%) | $>0.9$ |
| A diet high in processed meats | 39 (75\%) | 30 (70\%) | 12 (80\%) | 0.8 |
| Smoking | 43 (83\%) | 39 (91\%) | 10 (67\%) | 0.1 |
| Receiving hits or bruises to the breast | 24 (46\%) | 28 (65\%) | 5 (33\%) | 0.056 |
| Excessive fondling of the breast | 11 (21\%) | 11 (26\%) | 3 (20\%) | 0.9 |
| Being exposed to medical $X$-rays | 31 (60\%) | 28 (65\%) | 8 (53\%) | 0.7 |
| Using preservatives in food | 24 (46\%) | 17 (40\%) | 6 (40\%) | 0.8 |
| Having many sexual partners | 22 (42\%) | 16 (37\%) | 4 (27\%) | 0.5 |
| Breast feeding | 14 (27\%) | 6 (14\%) | 1 (6.7\%) | 0.2 |

$n(\%)$. Pearson's Chi-squared test; Fisher's exact test
Bold text—more medically reasonable risk factors; Italics—less medically reasonable risk factors
screening statuses reported that they would get screened if a health care provider encouraged them to ( $96 \%$ ever screened/ compliant, $93 \%$ ever screened/not compliant, and $93 \%$ never screened). One additional standout difference is that of the women who got screening, most women disagreed or strongly disagreed that with the statement "some people say that they either get cancer or they do not get it. They believe there is nothing that can be done to prevent getting cancer" ( $55 \%$ disagreed/strongly disagreed of ever/compliant and $56 \%$ disagreed/strongly disagreed of ever/non-compliant), but of the women who have never been screened most women agreed or strongly agreed with the statement ( $60 \%$ agreed/strongly agreed of never).

Finally, women reported preferences for strategies to improve cancer screening (Table 6). For women who have been screened (whether compliant or non-compliant), at least $75 \%$ reported a preference for 13 of the 15 strategies suggested to improve cancer screening. The two strategies which were not as highly preferred were the same for both groups [offering childcare services ( $69 \%$ ever/compliant and $72 \%$ ever/non-compliant) and using social media such as Facebook, YouTube, Twitter ( $46 \%$ ever/compliant and $53 \%$ ever/non-compliant)]. However, for women who have never been screened, only 6 of the 15 strategies suggested
garnered the preference of at least $75 \%$ of women. The four highest preferred strategies (all tied at $87 \%$ ) for those who have never been screened were: (1) one-on-one education, (2) having community health representatives (CHRs) or patient navigators help obtain screening, (3) reminders such as postcards, emails, or phone messages, and (4) having flexible clinic hours. The two least preferred strategies were home visits for education and using social media such as Facebook, YouTube, Twitter (both tied at 53\%).

## Discussion

This descriptive study of Zuni women's breast cancer and more general cancer screening attitudes, beliefs, and behaviors and the association with breast cancer screening compliance guidelines shows strengths and areas where interventions may be able to boost breast cancer screening. Zuni women who responded to the survey have a relatively high rate of ever having had a breast cancer screening ( $86 \%$ ), and higher percentages of Zuni women in this study report being compliant with screenings (47\%) compared to the 2019 IHS numbers for all AI/AN women ( $42 \%$ ) and for the Albuquerque Area (38.7\%) [4]. Of

Table 5 Attitudes and beliefs toward cancer in general by mammogram screening status ( $n=110$ )

|  | Compliant ( $n=52$ ) | Ever had test but not compliant ( $n=43$ ) | Never had test ( $n=15$ ) | $p$ value |
| :---: | :---: | :---: | :---: | :---: |
| Agreed that |  |  |  |  |
| If cancer is found early, it can be cured | 48 (92\%) | 38 (88\%) | 15 (100\%) | 0.5 |
| I think I would rather not know if I had cancer | 6 (12\%) | 3 (7.0\%) | 3 (20\%) | 0.3 |
| At my age I do not need to worry about cancer | 9 (17\%) | 6 (14\%) | 6 (40\%) | 0.1 |
| I would undergo cancer treatment that is unpleasant or painful if it would improve my chances of living longer | 46 (88\%) | 41 (95\%) | 15 (100\%) | 0.3 |
| I would be afraid to tell my spouse that I have cancer because I think it would affect our relationship | 6 (12\%) | 6 (14\%) | 1 (6.7\%) | 0.8 |
| There is not much that I can do to prevent getting cancer | 21 (40\%) | 13 (30\%) | 8 (53\%) | 0.3 |
| I am very likely to get cancer in my lifetime | 29 (56\%) | 19 (44\%) | 3 (20\%) | 0.047 |
| Benefits of getting a test to screen for cancer are greater than any inconvenience | 40 (77\%) | 34 (79\%) | 12 (80\%) | >0.9 |
| My family and friends would support me in doing a test to screen for cancer | 51 (98\%) | 38 (88\%) | 15 (100\%) | 0.11 |
| With regards to doing a test to screen for cancer, I want to do what my family and friends think I should do | 32 (62\%) | 32 (74\%) | 10 (67\%) | 0.4 |
| There is not much you can do to lower your chances of getting cancer | 18 (35\%) | 9 (21\%) | 6 (40\%) | 0.2 |
| There are so many different recommendations about preventing cancer that it is hard to know which ones to follow | 41 (79\%) | 31 (72\%) | 14 (93\%) | 0.2 |
| Cancer develops over a period of several years | 37 (71\%) | 31 (72\%) | 12 (80\%) | 0.9 |
| There are ways to slow down or disrupt the development of cancer | 41 (79\%) | 34 (79\%) | 14 (93\%) | 0.5 |
| Cancer is most often caused by a person's behavior or lifestyle | 20 (38\%) | 19 (44\%) | 5 (33\%) | 0.7 |
| It seems like almost everything causes cancer | 16 (31\%) | 17 (40\%) | 0 (0\%) | 0.007 |
| You are reluctant to get checked for cancer because you fear you may have it | 20 (38\%) | 15 (35\%) | 5 (33\%) | >0.9 |
| People with cancer would have pain or other symptoms prior to being diagnosed | 38 (73\%) | 29 (67\%) | 14 (93\%) | 0.14 |
| A person can have cancer without symptoms | 41 (80\%) | 36 (84\%) | 11 (73\%) | 0.7 |
| Yes |  |  |  |  |
| Family or friends have suggested to do a test to screen for cancer | 15 (29\%) | 16 (38\%) | 3 (20\%) | 0.4 |
| Would do a test to screen for cancer if encouraged by health care provider | 50 (96\%) | 39 (93\%) | 14 (93\%) | 0.6 |
| Would be able to request a test to screen for cancer from your health care provider | 42 (81\%) | 39 (91\%) | 13 (87\%) | 0.4 |
| Has discussed personal risk for cancer with friends or relatives | 22 (42\%) | 15 (35\%) | 4 (27\%) | 0.5 |
| Has discussed personal risk cancer with provider | 29 (56\%) | 16 (37\%) | 3 (20\%) | 0.027 |
| How likely are you to do a test to screen for cancer within the next 12 months? |  |  |  | 0.5 |
| Not at all likely | 11 (21\%) | 5 (12\%) | 3 (20\%) |  |
| A little likely | 5 (9.6\%) | 6 (14\%) | 4 (27\%) |  |
| Somewhat likely | 16 (31\%) | 10 (23\%) | 2 (13\%) |  |
| Likely | 14 (27\%) | 12 (28\%) | 3 (20\%) |  |
| Very likely | 6 (12\%) | 10 (23\%) | 3 (20\%) |  |
| Compared to other people your age, how likely do you think it is that you could get cancer? Are you... |  |  |  | 0.5 |
| Much less likely | 6 (12\%) | 2 (4.7\%) | 2 (13\%) |  |
| Less likely | 8 (16\%) | 8 (19\%) | 3 (20\%) |  |
| No difference | 12 (24\%) | 14 (33\%) | 7 (47\%) |  |
| More likely | 20 (41\%) | 15 (35\%) | 2 (13\%) |  |
| Much more likely | 3 (6.1\%) | 4 (9.3\%) | 1 (6.7\%) |  |
| (Missing) | 3 | 0 | 0 |  |

Table 5 (continued)

|  | Compliant $(n=52)$ | Ever had test but <br> not compliant <br> $(n=43)$ | Never had test $(n=15)$ | $p$ value |
| :--- | :--- | :--- | :--- | :--- |
|  |  |  |  |  |
| Some people say that they either get cancer or they do not get it. They believe that there is nothing that can be done to prevent getting <br> cancer. Do you... | 0.5 |  |  |  |
| Strongly disagree | $11(22 \%)$ | $10(23 \%)$ | $1(6.7 \%)$ |  |
| Disagree | $17(33 \%)$ | $14(33 \%)$ | $2(13 \%)$ |  |
| Neither agree nor disagree | $4(7.8 \%)$ | $3(7.0 \%)$ | $3(20 \%)$ |  |
| Agree | $13(25 \%)$ | $11(26 \%)$ | $6(40 \%)$ |  |
| Strongly agree | $6(12 \%)$ | $5(12 \%)$ | $3(20 \%)$ |  |
| (Missing) | 1 | 0 | 0 |  |
| Some people say that a person gets cancer as punishment for something they have done wrong. Do you... |  |  |  |  |
| Strongly disagree | $23(45 \%)$ | $21(49 \%)$ | $4(27 \%)$ |  |
| Disagree | $21(41 \%)$ | $19(44 \%)$ | $7(47 \%)$ |  |
| Neither agree nor disagree | $4(7.8 \%)$ | $2(4.7 \%)$ | $2(13 \%)$ |  |
| Agree | $3(5.9 \%)$ | $1(2.3 \%)$ | $1(6.7 \%)$ |  |
| Strongly agree | $0(0 \%)$ | $0(0 \%)$ | $1(6.7 \%)$ |  |
| (Missing) | 1 | 0 | 0 |  |

$n$ (\%).Fisher's exact test; Pearson's Chi-squared test

Table 6 Preference for strategies to improve cancer screening by mammogram screening status ( $n=110$ )

| Selected the following | Compliant ( $n=52$ ) | Ever had test but not <br> compliant $(n=43)$ | Never had test <br> $(n=15)$ | $p$ value |
| :--- | :--- | :--- | :--- | :--- |
| Printed materials such as letters, brochures, and newsletters | $49(94 \%)$ | $39(91 \%)$ | $12(80 \%)$ | 0.2 |
| One-on-one education | $48(92 \%)$ | $40(93 \%)$ | $13(87 \%)$ | 0.8 |
| Having community health representatives (CHRs) or patient <br> navigators help obtain screening | $48(92 \%)$ | $36(84 \%)$ | $13(87 \%)$ | 0.4 |
| Reminders such as postcards, emails, or phone messages | $47(90 \%)$ | $41(95 \%)$ | $13(87 \%)$ | 0.3 |
| Videos in the clinic waiting room | $45(87 \%)$ | $40(93 \%)$ | $11(73 \%)$ | 0.14 |
| Having flexible clinic hours | $45(87 \%)$ | $35(81 \%)$ | $13(87 \%)$ | 0.8 |
| Offering transportation to the clinic | $44(85 \%)$ | $35(81 \%)$ | $11(73 \%)$ | 0.6 |
| Group education | $44(85 \%)$ | $33(77 \%)$ | $9(60 \%)$ | 0.14 |
| Offering translation or interpretation services at the clinic | $43(83 \%)$ | $39(91 \%)$ | $11(73 \%)$ | 0.3 |
| Offering screening through non-clinical settings such as mailing | $42(81 \%)$ | $33(77 \%)$ | $11(73 \%)$ | 0.8 |
| for colorectal cancer screening | $42(81 \%)$ | $39(91 \%)$ | $10(67 \%)$ | 0.086 |
| Reducing co-payments for testing | $41(79 \%)$ | $36(84 \%)$ | $12(80 \%)$ | 0.8 |
| Public service announcements (PSAs) on the radio | $39(75 \%)$ | $35(81 \%)$ | $8(53 \%)$ | 0.1 |
| Home visits for education | $36(69 \%)$ | $31(72 \%)$ | $10(67 \%)$ | 0.9 |
| Offering child-care services | $24(46 \%)$ | $23(53 \%)$ | $8(53 \%)$ | 0.7 |
| Using social media such as Facebook, YouTube, twitter |  |  |  |  |

$n(\%)$. Fisher's exact test; Pearson's Chi-squared test
course, all of these numbers fall short of the Health People 2020 goal of $81.0 \%$, and all of these numbers mean that there is the potential to improve screening numbers which will reduce the burden of breast cancer for Zuni women and their families. Of the women who had been screened and were not compliant, $47 \%$ were within 12 months of compliance. As this survey was administered during the pandemic, some of these delays may be linked to pandemic
related delays in elective health care. However, as over half reported having had their screening over 3 years prior, there is evidence that interventions should be tailored both for women who have had a screening but are not up-to-date with their screenings and for women who have never had a screening. Having increased clinic hours, which was a highly preferred strategy for improving cancer screening,
would create more opportunities for community members to interact with a healthcare provider on a regular basis.

Healthcare providers matter. Both groups of women who report having been screened assert that the main reason why they did their most recent mammogram was because it was part of a routine exam ( $81 \%$ for ever/compliant and $84 \%$ for ever/non-compliant), and women across all three screening statuses reported that they would get screened if a health care provider encouraged them to $(96 \%$ ever screened/compliant, $93 \%$ ever screened/not compliant, and $93 \%$ never screened). However, only $56 \%$ of women who have been screened and are compliant report having discussed personal risk of cancer more generally with their provider which is a higher percentage than the other groups. This takeaway is reinforced when looking at the fact that a greater percentage of those who were compliant reported having a regular provider than those who had been screened but were noncompliant and those who had never been screened. Regular visits, both for check-ups and specific concerns, also provide connection to healthcare which may be a good opportunity to promote breast cancer screening.

More good news is that the majority of respondents agreed that their healthcare providers treated them with respect, but there is still room for improvement, especially as the group that has the highest reported interactions with providers-those who have ever been screened and are com-pliant-report the highest percentage of disagreement that their providers treat them with respect. With trust and culturally tailored interventions, providers have the potential to improve breast cancer screening for Zuni women.

This study provides a foundation for how to start building culturally tailored interventions. As the most common response for never being screened is that women perceive a mammogram as too painful, unpleasant, or embarrassing, there is an opportunity to educate women about the test and to support them through the vulnerable moments that may come along with mammography. One pathway to help motivate women to be screened is to help them understand the benefits of early screening. Women from all groups had gaps in knowledge about breast cancer and cancer risk factors. Most women did know that family history of breast cancer increased their own risk. This is a great foundation. While most women also knew that breast implants increased a woman's chance of cancer, this may be less impactful as this is relevant to a smaller subset.

An evidence-based intervention building on these results would clearly communicate when women should start having mammograms and how often. It would review how a woman's personal health history including the age of menarche, the age at first childbirth, or not having children all contribute to breast cancer risk. It would also review health behaviors including how using birth control, alcohol consumption patterns, weight, and physical activity all
contribute to breast cancer risk. Building on areas where there are gaps in knowledge may more quickly build capacity for higher rates of breast cancer screening.

Finally, any intervention should support women's belief in themselves to impact their health. While there are many structural and hereditary factors that influence one's risk of breast cancer, early detection can reduce the overall burden by having less invasive and more effective treatment. The result that $37 \%$ and $38 \%$ of women who had been screened and were compliant or non-complaint, respectively, but that $60 \%$ of women who had not been screened agreed or strongly agreed that people either get cancer or they do not and that there is nothing which can be done to prevent it, shows that many women do not believe that they can have an influence over breast cancer's impact in their lives. By building women's knowledge of breast cancer and breast cancer screening, screening's role in reducing the burden of breast cancer, interventions have the potential to impact breast cancer screening beliefs and behavior for Zuni women.

Finally, this survey also establishes a foundation for providers to implement effective cancer screening prevention programs. For this group of women, social media interventions are the least preferred. For the group of women who have never been screened, they would prefer one-on-one outreach, assistance with obtaining screening, multiple reminders, and flexible clinic hours. That said, all groups of women strongly preferred many different intervention program suggestions. By developing programs based on the knowledge and belief findings from this study and combining those with preferred intervention programs, providers and public health educators would have a solid foundation of an evidence-based intervention to improve breast cancer screening for Zuni women.

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Author contributions All authors contributed to the study conception and design presented in this paper. SL was involved in data collection. Initial data analysis was performed by DK with input from $\mathrm{KC}, \mathrm{MK}$, and VSP. Data analysis was refined after input from SIM, JS, and NE. The first draft of the manuscript was written by KC and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability Enquiries about data availability should be directed to the authors.

## Declarations

Competing interests No competing interests for all authors.
Ethical approval This project has received research approval from the Zuni Pueblo Tribal Council, the Southwest Tribal Institutional Review Board (IRB), and UNM Health Sciences Center IRB.

Consent to participate Best practices in informed consent were followed and all participants consented to participate in this study.

Consent to publish Best practices in informed consent were followed and all participants consented for research from this study to be published. In addition, this manuscript was reviewed and received approval for publication by the Zuni Tribal Council and the Southwest Tribal IRB.

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[^1]:    $n$ (\%); Median (IQR). Fisher's exact test; Pearson's Chi-squared test; Kruskal-Wallis rank sum test

