Exploring Asian Indian views about cancer and participation in cancer research: an evaluation of a culturally tailored educational intervention

Veda N. Giri¹ · Preethi Selvan¹ · Salini Mohanty^{2,3} · Ray Lum⁴ · Samantha Serrao⁵ · Amy E. Leader¹

Received: 14 December 2018 / Accepted: 29 August 2019 / Published online: 14 September 2019
© Springer-Verlag GmbH Germany, part of Springer Nature 2019

Abstract

Asian Indians (AIs) are a growing population in the United States (US) with increased cancer incidence and mortality. However, screening rates among this population are low, and the population has been underrepresented in clinical research. This pilot study aims to address gaps in the literature in order to understand if a culturally tailored educational intervention will improve knowledge, risk perceptions, and awareness of cancer risk assessments among AIs. We delivered an educational intervention comprised of culturally tailored case studies describing risk factors for developing cancer in both males and females. We assessed knowledge gaps about cancer risk and genetic testing, cancer risk perceptions, and willingness to participate in medical research studies, pre- and post-intervention. Among 23 participants, knowledge of genetic testing use and screening recommendations significantly improved post-intervention, with increased willingness to discuss cancer with family members, participate in medical research, and undergo genetic testing for cancer risk assessment. However, findings at the 1-month follow-up time did not show significant changes, except for one knowledge item. Culturally tailored educational interventions, delivered in a community setting, can influence knowledge and risk perceptions about cancer risk and genetics among AIs. Our findings lay the groundwork to continue educational efforts in the area of cancer risk and genetic testing in the AI population, a growing population that has been understudied in the US.

Keywords Cancer risk assessment · Asian Indian · Educational intervention · Culturally tailored · Ethnic minority · Participation in medical research

Background

As of 2014, the Asian American population is the fastest-growing population in the United States (US), representing 5.4% of the population and accounting for 17.5 million individuals (Colby and Ortman 2014; United States Census Bureau 2016). By 2060, it is estimated that the population will double (Colby and Ortman 2014). Within this population, cancer is a leading cause of mortality (Hastings et al. 2015). Asian Americans are defined as those who have emigrated from more than 20 countries making up East and Southeast Asia and the Indian subcontinent (Lopez et al. 2017). The population encompasses wide variability in immigration patterns, socioeconomic backgrounds, cultural practices, cuisine, and disease occurrence (Hastings et al. 2015). Among the Asian American subgroups, the Asian Indian (AI) population has increased by 50% since 2000, accounting for 11.8% of the Asian American population (Hastings et al. 2015; Hossain et al. 2008). The AI community is close-knit, with ten states

✉ Veda N. Giri
Veda.Giri@jefferson.edu

¹ Division of Population Science, Department of Medical Oncology, Sidney Kimmel Cancer Center, Thomas Jefferson University, Philadelphia, PA 19107, USA

² Department of Community Health and Prevention, Dornsife School of Public Health, Drexel University, 3141 Chestnut St, Philadelphia, PA 19104, USA

³ Department of Family and Community Health, University of Pennsylvania School of Nursing, 418 Curie Blvd, Philadelphia, PA 19104, USA

⁴ Department of Management and Health Policy, Dornsife School of Public Health, Drexel University, 3141 Chestnut St, Philadelphia, PA 19104, USA

⁵ Department of Epidemiology and Biostatistics, Dornsife School of Public Health, Drexel University, 3141 Chestnut St, Philadelphia, PA 19104, USA

in the US serving as home to roughly 75% of the population including Pennsylvania and New Jersey (Hoeffel et al. 2012; Zong and Batalova 2017).

Cancer is the second leading cause of mortality in both males and females in the AI population (Hastings et al. 2015). A study using Surveillance, Epidemiology, and End Results (SEER) data from 1990 to 2008 found that the age-adjusted incidence rate for cancer among AIs has increased more than threefold compared with that for other subgroups in the Asian population (Gomez et al. 2013). In the US, the most common cancers in AI males are prostate, lung, and colon while among AI females, the most common cancers are breast, vaginal, and colon (Hossain et al. 2008). This differs from the types of cancers most prevalent in Asian Indians living in India, such as oral cancer, and highlights the important differences that geography and culture may play in incidence and prevalence of cancer (Hossain et al. 2008). The leading cancers of AIs in the US are primarily screen-detectable cancers, rendering the need for educational interventions that increase awareness of cancer risk and screening practices, including genetic testing.

Screening rates among Asian Americans, including AIs, are still significantly lower than other racial groups in the US (Klabunde et al. 2012; Siegel et al. 2016). For example, in the US, Whites (59.8%) are more likely to have screened for colorectal cancer than Asians (46.9%). Reasons for this have been largely unexplored, particularly among AIs in the US, who are often incorporated into the ethnic designation of “Asian” and likely misrepresents the impact of cultural, genetic, and environmental risk factors unique to this population. Along with screening practices, genetic testing may help to assess cancer risk and aid in prevention efforts. Many Asian Americans are unaware and have low knowledge that genetic testing and counseling can be used as a way of assessing cancer risk (Hann et al. 2017). While inherited genetic mutations account for a smaller fraction of cancer predisposition and risk, carrier rates are not inconsequential as 5–10% of all cancer diagnoses in the US are related to inherited genetic mutations (National Cancer Institute 2017). Furthermore, the lifetime risk for cancer in an individual with a genetic mutation can be substantially higher than the general population. For example, women with BRCA1 gene mutations have a significantly higher risk for breast cancer (72% lifetime risk for female BRCA1 carriers compared with 12% lifetime risk for the general population) along with several other cancers (National Cancer Institute 2018). To address this substantially increased breast cancer risk, national guidelines state that women with BRCA1 gene mutations should consider bilateral prophylactic mastectomy or enhanced screening starting at much younger ages (such as in the late 20s compared with starting at age 40 in the general population) (National Comprehensive Cancer Network 2018). These types of genetically informed screening discussions apply to multiple cancer

types impacting men, women, and families, therefore, widening the population impact of genetic testing to significantly reduce cancer risk and is an integral part of cancer risk assessment along with behavioral factors and access to cancer screening. Moderated discussions with members of the AI population have revealed that individuals were unaware of family disease history and that they could benefit from genetic testing to assess risk. Reasons for hindrance to cancer risk discussions among AIs in our prior work included not wanting to cause stress to family members, fear of damage to family status in society with impact on marriage prospects, and cancer-related stigma (Leader et al. 2017).

Furthermore, the AI population is largely underrepresented in clinical research, limiting information and progress regarding cancer risk factors, screening needs, and behavioral interventions unique for this population (Hussain-Gambles et al. 2004). In addition, of the few studies involving the AI population, most have been conducted in other countries limiting our knowledge of the AI population in the US. A recent study with 720 women in minority ethnic groups across England showed that for cancer screening, AIs often relied upon a strong recommendation from a provider that the test was needed before they would be screened for cancer (Marlow et al. 2017). Indeed, an assessment of breast cancer screening rates among 16 ethnic groups in the UK reported lower rates of attendance by AIs compared with their Caucasian counterparts (Jack et al. 2014). A cross-sectional study of men and women living in England found that while 91% of AI adults could name at least one risk factor for cancer, this was lower than the British white population (Marlow et al. 2012). Researchers concluded that breast cancer screening uptake varies between ethnicities, and engagement with specific communities needs to be considered to improve uptake (Jack et al. 2014). It is widely known that culture and acculturation have a strong impact on cancer risk perceptions, beliefs, and behaviors. A cross-sectional study of 720 British, Caribbean, African, Indian, Pakistani, and Bangladeshi women in the UK assessed cancer fear, fatalism, and general fatalism (Vrinten et al. 2016). The study concluded that while AI women showed more fear and fatalism than British white women, the details influencing these emotions were unable to be explored.

It is important to understand the role that culture has on their views of health and well-being to prevent morbidity and mortality. Compared with other groups categorized as “Asian American,” AIs have a higher proportion of late-stage cancer diagnosis (Yi et al. 2012). By bringing educational efforts to improve early preventive practices, late-stage diagnoses due to lack of knowledge or cultural barriers may be prevented (Rao et al. 2011). Due to the lack of literature about cancer risk perceptions, beliefs, and behaviors in AIs living in the US, our team attempted to close gaps through a comprehensive study using qualitative data to inform the design of an intervention.

In one of the first US-based studies, our team conducted 4 focus groups to explore knowledge, attitudes, and beliefs about cancer risk and prevention among the AI population in the greater Philadelphia area (Leader et al. 2017). Results from the focus groups showed that (1) historically, more emphasis was placed on the treatment rather than the prevention of cancer, (2) cancer is highly stigmatized and family privacy and community standing greatly limit discussions of family and personal cancer history, (3) fatalism and karma reduced interest in seeking genetic evaluation for personal cancer risk, and (4) concern regarding access to health care services and financial difficulties hinders cancer screening. Findings from the focus groups emphasized the importance of understanding AIs' perceptions about cancer and participation in research, such as a medical research study or clinical trial, to inform the design of effective educational and clinical initiatives to meet their needs (Leader et al. 2017).

Among minorities in the US, studies have shown that tailored educational interventions can increase cancer awareness regarding risk factors, screening, and prevention (Larkey et al. 2009; Gotay et al. 2000; Percac-Lima et al. 2009). In the Asian population, culturally tailored intervention through education has shown to be effective in reducing cancer health disparities (Chen et al. 2018). In a study that aimed to improve colorectal cancer screening rates among Latina women, those that received a culturally tailored educational intervention were more likely to get an endoscopy and had increased awareness and accurate risk perception of colorectal cancer compared with those who received the standard intervention (Larkey et al. 2009). In this study, they used “promotoras” or community health advisors who were culturally competent and have commonalities with the target audience. Similar interventions were conducted among populations of native Hawaiian women and patients in low-income communities with similar conclusions (Gotay et al. 2000; Percac-Lima et al. 2009). The literature on AIs has shown that a culturally tailored intervention can reduce risk factors for Type II diabetes (Patel et al. 2017); however, work in cancer risk and awareness is limited. There is a need for community-based educational intervention studies of cancer awareness, risk factors, genetic testing, and research participation for the AI population in the US tailored to the cultural needs of this population.

Since prior data have begun to reveal that the AI population has cultural and perceived barriers to considering cancer risk and genetic testing (Jack et al. 2014; Vrinten et al. 2016), this study addresses a major gap for this population regarding tailoring educational delivery of cancer risk information and genetic testing awareness to the AI community to ultimately motivate behaviors for cancer risk assessment and screening. The objective of this pilot study was to develop and implement a culturally tailored intervention for the AI population and evaluate the following aims: (1) the impact of the intervention regarding the participants' knowledge of cancer and

screenings; (2) the impact of the intervention on risk perceptions; (3) the impact of the intervention on health communication and willingness to talk about cancer; (4) the impact of the intervention on willingness to participate in research; and (5) behavioral changes, such as lifestyle modifications (i.e., increasing physical activity and decreasing alcohol intake) to reduce risk for cancer, post-intervention. To our knowledge, this is the first culturally tailored cancer awareness intervention for AI adults in the US.

Methods

Participants

Participants were recruited, using venue-based sampling (Muhib 2001), in March 2017 at a community-based cultural center in Philadelphia, where they were attending an International Women's Day celebration. Recruitment at the venue was done by the study team, which included those of AI decent. Male and female participants were eligible if they were 18 years of age or older, of AI descent, and could either speak English or had someone that was able to translate for them at the event and during the 1-month post-intervention survey. For this pilot study, cancer risk and eligibility to attend cancer genetic services were not included in the eligibility criteria.

Survey measures

Surveys were administered at three time points: prior to the intervention (baseline), immediately after the intervention (endpoint), and 1-month post-intervention by telephone (follow-up). Drawing from our formative work with this population and the Health Information and National Trends Survey (HINTS) (Leader et al. 2017; Kobayashi and Smith 2016), we developed the baseline survey to include the following domains: (1) knowledge about cancer, genetic testing, and screening practices; (2) perceptions about cancer; (3) preferred language and channels for health information; (4) participation in genetic testing and clinical research; and (5) demographic information (Giri et al. 2018). For the endpoint and 1-month follow-up surveys, we asked the same baseline questions, minus the demographic section, and added questions about behavioral change and receptivity to the intervention. All surveys were administered in English.

Knowledge

To assess knowledge about cancer risk and screening, we used seven true/false statements. Topics included the link between personal behavior and cancer risk; the implications of genetic mutations; and the purpose of genetic testing for cancer (Giri

et al. 2018). A knowledge score was created for each participant by summing the total number of items answered correctly (1 point for the correct answer; 0 points for the incorrect answer). The seven knowledge questions and the mean scores of respondents can be seen in Table 2.

Knowledge about the appropriate age to begin breast, prostate, and colon cancer screening was assessed through free-response questions. Although equally important, cervical cancer screening knowledge was not included because of the variations in the recommendations. Answers to the questions were recorded in a number format, 1–100. If more than one number was recorded, the two answers were averaged to create one response (Table 2).

Perceptions

Cancer and risk perceptions were assessed through 8 statements about participants' understanding about being diagnosed and surviving cancer; ways to prevent cancer; their perceptions about family history as a risk of cancer. The specific wording of items and the response options can be found in Table 3.

Health communication and health information

We assessed participants' willingness to talk to family members or their doctor about their family history, as well as their interest in seeking more information about cancer risk. The specific wording of items and the response options can be found in Table 3.

Participation in medical research and genetic testing

Prior participation in research and genetic testing was assessed through questions with "yes/no" responses. Willingness to participate in research and genetic testing in the future was assessed through questions with a 5-point Likert scale. For questions with "yes/no" responses, qualitative answers were recorded to collect more detailed information. Items pertaining to participation in genetic testing and medical research, as well as the response option for each item, can be found in both Tables 3 and 4.

Behavioral changes

We asked participants whether, because of the intervention, they would talk to their family, friends, or doctor about what they learned; research more about what they learned; explore their family history; or change their lifestyle behaviors. The survey items, as well as the response options, can be found in Table 4.

Demographics

Demographic questions were ascertained at baseline, which included age, gender, number of years living in the US, country of birth, preferred language, needing help reading medical materials, educational level, employment status, and personal or family history of cancer (Table 1).

Intervention

Based on the results of our focus groups (Leader et al. 2017), we used the constructs of the Theory of Planned Behavior to develop this pilot intervention (Ajzen 1985). The group-based educational intervention, approximately 30 min in length, consisted of an oral presentation delivered by a physician of AI decent, with expertise in clinical cancer genetics. Three mock patient cases, one each of breast, prostate, and colon cancer, were presented. Each case included a discussion about cancer risk, when to begin preventive screenings, and a scenario when genetic testing would be applicable. Information about non-modifiable and modifiable lifestyle changes, such as diet, exercise, lifestyle, obesity, and smoking/drinking were also presented. Each case study was tailored based on the perceptions discovered in prior AI focus groups. The presentation included the following information: genetic testing to reduce gaps in knowledge about family health history; the importance of discourse in order to spread awareness about cancer and decrease hesitation to share results with family and friends; modifiable behaviors to decrease thoughts of fatalism; and importance of support to overcome fear that a cancer diagnosis has on family status.

Human subjects protection

The home institution's IRB approved the intervention and all study materials. We obtained informed consent from each participant prior to administering the baseline survey. All surveys were answered anonymously using only unique ID numbers given to participants at the beginning of the study. Participants were compensated up to \$40 (\$20 for participating in the intervention and \$20 for completing the 1-month follow-up telephone survey) for their time and participation.

Data analysis

All variables were analyzed descriptively for frequencies and percentages as well as means and standard deviations, among all three time points (baseline, endpoint, and follow-up). Paired *t* tests were used to analyze differences in means from baseline to endpoint and baseline to follow-up. Statistical significance ($p < 0.05$, $\alpha = 0.05$) was evaluated using SPSS. Only those participants that completed surveys at all three

Table 1 Demographic characteristics of participants

		N (%)
Participants		23 (100%)
Age	Mean (SD): 46.11 ($\pm$ 11.93)	–
Number of years living in the US	Mean (SD): 19.35 ($\pm$ 11.16)	–
Gender*	Female	12 (52.2%)
	Male	10 (43.5%)
Country of birth*	India	22 (95.7%)
Marital status*	Married or partnered	19 (82.6%)
Education	Less than a college degree	8 (34.8%)
	College degree or higher	15 (65.2%)
Employment	Full or part-time	21 (91.3%)
	Retired or unemployed	2 (8.7%)
Have health insurance	Yes	22 (95.7%)
	No	1 (4.3%)
Preferred language when discussing medical issues*	English	12 (52.2%)
	Hindi or other	2 (8.7%)
Need help with medical material*	Never or some of the time	15 (65.2%)
	Most of the time or always	7 (30.4%)
Health (very good)	Fair	5 (21.7%)
	Good or very good	18 (78.3%)
Motivated for good health*	Somewhat motivated or moderately motivated	11 (47.8%)
	Extremely motivated	11 (47.8%)
Participant diagnosed with cancer	Yes	0 (0%)
	No	23 (100%)
Family member diagnosed with cancer	Yes	5 (21.7%)
	No	18 (78.3%)

*Missing responses not included

time points were included in the analysis. Missing responses to individual items were not included in our analysis.

Results

Demographics

Among the 29 participants that consented to participate, 23 participants (79.3%) completed surveys at all three time points (Table 1). All of the participants were born in India and lived in the US an average of 19.4 ($\pm$ 11.2) years. Twelve were female and 10 were male (1 participant did not report gender), and mean age was 46.11 years ($\pm$ 11.93). Most participants, 19 (83%) were married or partnered. Fifteen participants (65%) had a college degree or higher and 21 (91%) were employed full or part-time. Most participants, 22 (96%) reported having health insurance, 18 (78%) reported good or very good health, and 11 (48%) were extremely motivated to have good health. When asked about their health and healthcare needs, 12 (52%) of participants preferred materials to be in English, while 15

(65%) reported never or sometimes needing help with medical material. None of the participants have or had been diagnosed with cancer, while 5 (22%) reported that a family member had been diagnosed with cancer.

Knowledge

Participants answered, on average, 4.30 ($\pm$ 1.26) out of 7 knowledge questions correctly at baseline, 4.43 ($\pm$ 1.16) at endpoint, and 4.48 ($\pm$ 1.28) at follow-up time points. There was no significant improvement in overall knowledge over the course of the study period nor were there significant differences by gender or age of participants. However, significant changes were observed in specific questions regarding the transfer of genetic mutations ($p < 0.05$) and method of genetic testing ($p < 0.05$). The question addressing genetic testing and the prediction of cancer in the future also showed a significant difference ($p < 0.01$); however, the means indicated more responses towards the incorrect answer over time. Knowledge changes over time can be seen in Table 2.

Knowledge was also assessed by asking participants at what age they should be screened for certain cancers (Table 2). For breast cancer, which guidelines recommend screening at age 40 for the general population (Smith et al. 2018), participants answered with a mean age of 34.9 years (± 7.5) at baseline, 39.2 years (± 4.2) at endpoint, and 38.9 years (± 4.9) at follow-up and showed a statistically significant improvement from baseline to follow-up ($p < 0.05$). When asked about the ideal age to begin screening for prostate cancer, which is recommended to begin at age 50 for the general male population, participants answered with the average age of 42.9 years (± 7.34) at baseline, 44.5 years (± 5.0) at endpoint, and 43.2 years (± 5.7) at follow-up. Lastly, for age at which a healthy person should begin colon cancer screening, which was previously recommended starting at age 50 for the general population but was recently changed to age 40 (Smith et al. 2018), participants answered 42.9 years (± 8.3) at baseline, 45.0 years (± 6.1) at endpoint, and 42.7 years (± 8.8) at follow-up. The responses for prostate and colon cancers showed no significant improvement between time points.

Perceptions and attitudes

Participants initially indicated they felt that (1) “everything causes cancer,” (2) “it’s hard to know which guidelines to follow,” and (3) “there’s not much you can do to lower your chances of cancer.” However, after the intervention, attitudes about the causes of cancer and the ability to exert some form of control over it became less fatalistic. By the end of the study, 18 (78%) participants responded that their culture had an interest in prevention, despite only 12 (54.5%) responding the same way at endpoint (directly after the intervention). It should be noted that while we saw improvements in attitudes over time for most items, none of the changes were statistically significant. Additionally, while perceptions were improved at follow-up from baseline, the effect of the intervention was lessened compared with endpoint results. These data can be found in Table 3.

Participation in medical research and genetic testing

Participants generally improved their attitudes about talking with their family members about cancer, participating in a medical research study, or getting a genetic test to evaluate cancer risk, but there was some slight reduction in positive sentiment at the 1-month assessment (Table 3). None of the participants had ever undergone genetic testing to assess their risk for cancer. From baseline to endpoint, we saw statistically significant improvements in willingness to participate in medical research ($p < 0.05$) or get a genetic test ($p < 0.01$).

Behavioral change

On the endpoint survey, participants were asked about actions they planned to take as a result of the intervention; on the follow-up survey, they were asked whether they had taken action on those plans (Table 4). At endpoint, all of the participants ($n = 22$) planned to talk to their family member or friends about what they learned; as well as change their daily lifestyle behaviors and habits. Most ($> 90\%$) also planned to talk to their doctor about what they learned and research more about what they learned. When asked again 1 month later, there was variability in the extent to which they had taken action on what they had intended. For example, 91% of participants reported talking with a family member about what they learned and 56% talked with their friends about what they learned or researched more information. Only 26% had spoken with their doctor about what they learned. Sixty percent reported that they had taken steps to explore their family health history.

Discussion

To our knowledge, this is the first study to assess a culturally tailored educational intervention within the AI community in the US aimed to improve cancer risk awareness and screening knowledge. While many studies in the UK have assessed knowledge, attitudes, and perceptions in the AI community, this has not been reported in the US. Informed by focus group results in the AI community (Leader et al. 2017), our study showed that a culturally tailored educational intervention was able to improve knowledge in specific topics, increase willingness to talk about cancer, and increase willingness to participate in research and genetic testing. Numerous cultural holidays and community gatherings are an extremely important part of AI culture and serve as potential avenues for health professionals to engage members of this community (Herdağdelen et al. 2016).

Although we did not see a significant change in overall knowledge, the culturally tailored intervention showed an improvement in knowledge about what age to begin screening for breast cancer. Low screening rates in the AI population could be attributed to lack of knowledge of preventative screening measures and when they should begin. Age to begin breast cancer screening can be impacted by age of breast cancer diagnoses in a family and genetic information. Therefore, it is important that this population continues to receive and benefit from cancer risk education so that not only knowledge but the use of preventative screening measures is improved (National Comprehensive Cancer Network (NCCN) 2018). Significant improvements in knowledge were also seen for specific questions about genetics and genetic testing. As was learned from prior focus group discussions in the AI

Table 2 Knowledge by time points ($n = 23$)

	Baseline	Endpoint	Follow-up
	% Correct	% Correct	% Correct
¹ Factors such as personal behavior (diet, exercise) and environmental conditions (exposures) can raise the risk of getting cancer. (true)	90.9%	87%	82.6%
¹ Even if someone has a family history of cancer, he or she may not get cancer. (true)	47.8%	31.8%	43.5%
¹ A parent cannot pass down genetic mutations (a mistake in the DNA that is associated with disease such as cancer) to their child. (false)*	60.9%	82.6%	69.6%
¹ Genetic mutations can be tested from a blood sample. (true)*	78.3%	100%	69.6%
¹ Genetic mutations that we inherit can change as we get older. (false)	34.8%	36.4%	39.1%
¹ A genetic test can tell if someone will definitely get cancer in the future. (false)**	60.9%	27.3%	60.9%
¹ Patients with one cancer can be at risk for getting other cancers if the patient has a genetic mutation. (correct answer: true)	65.2%	86.4%	82.6%
Total knowledge score (out of 7): mean (SD)	4.30 (± 1.26)	4.43 (± 1.16)	4.48 (± 1.28)
Age to begin screening for breast cancer in years (correct answer = 40)***	34.76 (± 7.50)	39.21 (± 4.17)	38.91 (± 4.93)
Age to begin screening for prostate cancer in years (correct answer = 50)	42.86 (± 7.344)	44.52 (± 4.97)	43.18 (± 5.68)
Age to begin screening for colon cancer in years (correct answer = 50)	42.86 (± 8.302)	45 (± 6.07)	42.74 (± 8.76)

* $p < 0.05$; baseline to endpoint change.

** $p < 0.01$; baseline to endpoint change.

*** $p < 0.05$; baseline to follow-up change.

¹ Response options: true = 1, false = 2, do not know = 3

population (Leader et al. 2017), illnesses are often taboo to speak of and familial disease history is virtually unknown in many cases. The study intervention's focus on genetics as well as interest in knowing family history may have led to better retention of the genetics information that was presented. Unfortunately, the question focused on genetic test results and informing cancer development ("A genetic test can tell if someone will definitely get cancer in the future") saw a significant decrease in understanding after the intervention. This is a common misunderstanding of genetic test results and deserved focused attention to enhance understanding of the benefits and limitations of genetic testing.

One reason that we may not have seen a significant improvement in overall knowledge or perceptions may be the setting in which our intervention was delivered. We chose to deliver our intervention during a primarily female-focused event, an International Women's Day Celebration, at a community center. The event also featured other speakers and was celebratory in nature, which may have impacted the effectiveness of our intervention. As seen in the results, the intervention had a lasting effect even at the follow-up time period; however, the effect was decreased from the endpoint (Tables 3 and 4) and may suggest that a more pointed intervention in a focused environment, not as a part of a larger community event is needed. One presentation may not be enough to sustain knowledge and attitudes over a longer period of time and maybe the reason for the decrease in effect seen at the follow-up time period (Kempgowda et al. 2018). In a larger study of the Chinese and Vietnamese population in

Boston, MA, similar results were found, with only significant differences in 2 knowledge questions from pre- to post-test (Berger et al. 2017). Unlike Philadelphia, they attributed this lack of change to higher baseline knowledge because Boston is home to one of the National Cancer Institute's Patient Navigation Research Program, which supports the Asian American community specifically (Berger et al. 2017). In a smaller study of Chinese Americans ($n = 40$), researchers found they were able to increase knowledge through a culturally tailored education intervention; however, their focus was only on breast cancer and along with the use of multimedia as their method of delivery their intervention may have had a different effect on participants (Wang et al. 2008). Similar results were seen in an interactive intervention using a kiosk in the Latino population; however, knowledge in the Latino population was lower at baseline compared to our study population (Valdez et al. 2018).

One of the aims of our study was to improve willingness to consider genetic testing, in which our intervention was successful. An assessment of breast examination predictors in the Chinese population found that more acculturated women might be more willing to partake in screening practices due to the constant exposure to advice telling them to do so (Chen 2009). Our population, despite being born in India, have been in the US for almost 20 years and therefore acculturation may have made them more receptive towards considering genetic testing. A study of direct-to-consumer personal genetic testing within an Asian population reported a major reason for wanting to partake in genetic testing was an interest in knowing the

Table 3 Participant perceptions and attitudes towards cancer, risk, and risk assessment ($n = 23$)

Perceptions and Attitudes	Baseline	Endpoint	Follow-up
	Mean (SD)	Mean (SD)	Mean (SD)
¹ It seems like everything causes cancer these days.	2.65 (± 0.89)	2.61 (± 0.72)	2.43 (± 0.73)
¹ There are so many recommendations about how to prevent cancer, it is hard to know which ones to follow.	2.70 (± 0.70)	2.57 (± 0.79)	2.65 (± 0.78)
¹ People with cancer would have pain or other symptoms prior to being diagnosed.	2.35 (± 0.89)	2.09 (± 0.87)	2.26 (± 0.92)
¹ There is not much you can do to lower your chances of getting cancer.	2.04 (± 0.71)	1.87 (± 0.69)	1.87 (± 0.70)
¹ It is important to talk with your family about their history of cancer.	3.26 (± 0.86)	3.50 (± 0.74)	3.30 (± 0.88)
¹ When I think of cancer, I automatically think of death.	2.43 (± 0.95)	2.09 (± 0.79)	2.09 (± 0.73)
¹ I'd rather not know my chance of getting cancer.	1.74 (± 0.86)	1.87 (± 0.87)	1.78 (± 0.67)
² How open is the communication in your family about cancer?	3.57 (± 1.31)	3.86 (± 1.46)	3.91 (± 1.08)
³ How willing are you to talk with your family members about cancer?*	4.23 (± 1.15)	4.82 (± 0.50)	4.17 (± 1.15)
² In the future, if asked to participate in a medical research study, how open would you be to participating?*	3.50 (± 1.10)	3.82 (± 0.96)	3.83 (± 1.07)
² In the future, if asked to get a genetic test to assess your risk of cancer, how open would you be to getting one?*	3.73 (± 1.03)	4.55 (± 0.83)	4.00 (± 0.85)
⁴ How helpful was the information that you learned today (at the intervention)?	–	4.76 (± 0.77)	4.29 (± 1.05)

* $p < 0.05$; baseline to endpoint change.

** $p < 0.01$; baseline to endpoint change.

¹ Response options: strongly disagree = 1, disagree = 2, agree = 3, strongly agree = 4

² Response options: not open at all = 1, somewhat limited = 2, neutral = 3, somewhat open = 4, very open = 5

³ Response options: not willing at all = 1, somewhat hesitant = 2, neutral = 3, somewhat willing = 4, very willing = 5

⁴ Response options: not helpful at all = 1, somewhat helpful = 2, neutral = 3, somewhat helpful = 4, very helpful = 5

personal risk for specific disease (Landry et al. 2017). As previously stated, the lack of known family history and the heightened risk perception after the intervention may have led to an increased interest in partaking in both genetic testing and medical research in our participants. While it is noted that inherited genetic mutations account for a smaller portion of cancer risk, the impact of identifying a genetic mutation for

cancer screening, cancer risk reduction, familial impact, and ultimately population impact is increasingly being recognized and is important to address in the AI population.

The AI population is underrepresented in research, with a limited number of studies that have explored reasons for this (Hussain-Gambles et al. 2004). Our study found that most of the participants had not been a part of any medical research

Table 4 Cancer communication, pre- and post-intervention ($n = 23$)

	Baseline	Endpoint	Follow-up
	Yes (%)	Yes (%)	Yes (%)
Do you think your culture has interest in cancer prevention?	65.2%	54.5%	78.3%
Have you ever been in a medical research study (clinical trial) where you got one of two treatments, such as medicines or surgery procedures?	4.3%	–	–
Have you known someone, a friend or family member, who has participated in a medical research study?	13%	–	–
Have you ever gotten a genetic test to assess your risk of cancer?	0%	–	–
Based on what you learned today, do you plan to/did you:			
Talk with your family members about what you learned.	–	100%	91.3%
Talk with your friends about what you learned.	–	100%	56.5%
Talk with your doctor or health care provider about what you learned.	–	90.9%	26.1%
Go look up or research more about what you learned.	–	90.5%	56.5%
Change any of your daily lifestyle behaviors or habits.	–	100%	43.5%
Do you plan to explore or look into your family health history?	–	–	60.9%

study and only a few knew someone who had participated in one. However, by the end of our intervention, willingness to participate in both a medical research study and genetic testing was significantly higher, showing that we may be able to increase participation in this population with the right recruitment strategies.

The results 1 month after the intervention showed that fewer participants had actually followed through and made behavior changes they intended to make at an endpoint. However, 1 month after our intervention, more than 90% of participants shared information with their family, and over 50% shared information with friends. Although only 26% talked to their doctor, the timing may not have allowed enough opportunity for participants to do so. More than half our participants researched more about what they learned and 44% made changes to their daily lifestyle and behavior. Focus groups brought to light that cancer was not discussed in AI families (Leader et al. 2017); however, our intervention resulted in a significant increase in willingness to discuss cancer with family, similar to a study of Chinese women (Wang et al. 2008).

While there were numerous strengths to our study, including recruiting a community-based sample of participants not generally involved in research, there are some limitations to consider. Because this was a pilot study, we were only able to focus our intervention on one AI community in Philadelphia. Therefore, our results need to be further studied to enhance the generalizability of our findings. The small sample size may have limited the ability to detect statistically significant changes in the variables of interest, and therefore larger studies in the AI population are needed to confirm and extend our findings. Our recruitment strategy limited our sample population to those that participated in the event who for the most part consisted of AIs that originated from one southern Indian state, Kerala. This is only one of the many cultures that make up India. Our study design did not enable us to have a control group to compare our results with. Even though we conducted focus groups prior to designing our intervention, due to the lack of existing research on AIs in the US, we cannot be sure that we were able to address all cultural factors and barriers in our educational intervention. In the creation of our educational intervention, we may have missed topics such as cost and insurance coverage of screenings and genetic testing, which may be barriers to preventative screening measures. Another limitation is that our sample of participants was mostly well educated and most had health insurance, while current data confirms our findings (Pew Research Center 2017), this may not apply to all AI individuals. All of our participants were born in India and may have different attitudes compared with those that were born in the US, supporting further study.

Conclusion

Educational interventions can be successful in improving knowledge and attitudes in minority communities, even in those that are well educated or not typically considered underserved communities. By engaging members of these communities in educational intervention, we may be able to dispel many misunderstandings and improve participation in research as well as increase the use of preventative cancer risk assessments. As the AI population continues to grow in the US, it is important to understand and develop interventions that will reach these communities and ultimately decrease morbidity and mortality from cancer in minority populations.

Acknowledgments We are grateful to the Indian Cultural Center of South Jersey and the Malayalee Association of Greater Philadelphia for their support and community partnership of this study.

Funding information This study was funded, in part, by a Sidney Kimmel Cancer Center Consortium Award.

Compliance with ethical standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

- Ajzen I (1985) From intentions to actions: a theory of planned behavior. In: Kuhl J, Beckmann J (eds) *Action control*. SSSP Springer Series in Social Psychology. Springer, Berlin
- Berger S, Huang C, Rubin CL (2017) The role of community education in increasing knowledge of breast health and cancer: findings from the Asian breast cancer project in Boston, Massachusetts. *J Cancer Educ* 32(1):16–23. <https://doi.org/10.1007/s13187-015-0911-3>
- Chen MS Jr, Chow EA, Nguyen TT (2018) The Asian American Network for Cancer Awareness, Research, and Training (AANCART)'s contributions toward reducing Asian American cancer health disparities, 2000–2017. *Cancer* 124(Suppl 7):1527–1534. <https://doi.org/10.1002/cncr.31103>
- Chen WT (2009) Predictors of breast examination practices of Chinese immigrants. *Cancer Nurs* 32(1):64–72. <https://doi.org/10.1097/01.NCC.0000343366.21495.c1>
- Colby SL, Ortman JM (2014) Projections of the size and composition of the US population: 2014 to 2060. *Current Population Reports* P25–1143. US Census Bureau, Washington, DC
- Giri VN, Obeid E, Hegarty SE, Gross L, Bealin L, Hyatt C, Fang CY, Leader A (2018) Understanding of multigene test results among males undergoing germline testing for inherited prostate cancer:

- implications for genetic counseling. *Prostate* 78:879–888. <https://doi.org/10.1002/pros.23535>
- Gomez SL, Noone AM, Lichtensztajn DY, Scoppa S, Gibson JT, Liu L, Cyllene M, Kwong S, Fish K, Wilkens LR, Goodman MT, Deapen D, Miller BA (2013) Cancer incidence trends among Asian American populations in the United States, 1990–2008. *JNCI J Nat Cancer Instit* 105(15):1096–1110. <https://doi.org/10.1093/jnci/djt157>
- Gotay CC, Banner RO, Matsunaga DS, Hedlund N, Enos R, Issell BF, DeCambia H (2000) Impact of a culturally appropriate intervention on breast and cervical screening among native Hawaiian women. *Prev Med* 31(5):529–537. <https://doi.org/10.1006/pmed.2000.0732>
- Hann KEJ, Freeman M, Fraser L, Waller J, Sanderson SC, Rahman B, Side L, Gessler S, Lanceley A, for the PROMISE study team (2017) Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Public Health* 17:503. <https://doi.org/10.1186/s12889-017-4375-8>
- Hastings KG, Jose PO, Kapphahn KI, Frank ATH, Goldstein BA, Thompson CA, Eggleston K, Cullen MR, Palaniappan LP (2015) Leading causes of death among Asian American subgroups (2003–2011). *PLoS ONE* 10(4):e0124341. <https://doi.org/10.1371/journal.pone.0124341>
- Herdagdelen A, State B, Adamic L, Mason W (2016) The social ties of immigrant communities in the United States. Proceedings of the 8th ACM Conference on Web Science - WebSci. ACM Press, New York, New York, USA, pp 78–84
- Hoeffel EM, Rastogi S, Kim MO, Shahid H (2012) The Asian population: 2010. 2010 census briefs: U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau
- Hossain A, Sehbai A, Abraham R, Abraham J (2008) Cancer health disparities among Indian and Pakistani immigrants in the United States: a surveillance, epidemiology, and end results-based study from 1988 to 2003. *Cancer* 11:1423–1430. <https://doi.org/10.1002/cncr.23686>
- Hussain-Gambles M, Leese B, Atkin K, Brown J, Mason S, Tovey P (2004) Involving south Asian patients in clinical trials. *Health Technol Assess* 8(42):1–109
- Jack RH, Möller H, Robson T, Davies EA (2014) Breast cancer screening uptake among women from different ethnic groups in London: a population-based cohort study. *BMJ Open* 4(10):e005586. <https://doi.org/10.1136/bmjopen-2014-005586>
- Kempegowda P, Chandan JS, Hutton R, Brown L, Madden W, Webb J, Doyle A, Trembl J (2018) Focused educational intervention improves but may not sustain knowledge regarding falls management. *BMJ Open Quality* 7(3):e000222. <https://doi.org/10.1136/bmjopen-2017-000222>
- Klabunde CN, Brown M, Ballard-Barbash R, White MC, Thompson T, Plescia M, Coleman King S (2012) Cancer screening—United States, 2010. *MMWR Morb Mortal Wkly Rep* 61(03):41–45 from https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6103a1.htm?s_cid=mm6103a1_w. Accessed 13 Dec 2017
- Kobayashi LC, Smith SG (2016) Cancer fatalism, literacy, and cancer information seeking in the American public. *Health Educ Behav* 43(4):461–470. <https://doi.org/10.1177/1090198115604616>
- Landry L, Nielsen DE, Carere DA, Roberts JS, Green RC, the PGen Study Group (2017) Racial minority group interest in direct-to-consumer genetic testing: findings from the PGen study. *J Commun Genet* 8(4):293–301. <https://doi.org/10.1007/s12687-017-0325-5>
- Larkey LK, Lopez AM, Minnal A, Gonzalez J (2009) Storytelling for promoting colorectal cancer screening among underserved Latina women: a randomized pilot study. *Cancer Control* 16(1):79–87
- Leader AE, Mohanty S, Selvan P, Lum R, Giri VN (2017) Exploring Asian Indian and Pakistani views about cancer and participation in cancer genetics research: towards the development of a community genetic intervention. *J Community Genet* 9:27–35. <https://doi.org/10.1007/s12687-017-0312-x>
- Lopez G, Ruiz NG, Patten E (2017) Key facts about Asian Americans, a diverse and growing population. Pew research center. From <http://www.pewresearch.org/fact-tank/2017/09/08/key-facts-about-asian-americans/>. Accessed 28 Mar 2018
- Marlow LA, Robb KA, Simon AE, Waller J, Wardle J (2012) Awareness of cancer risk factors among ethnic minority groups in England. *Public Health* 126(8):702–709
- Marlow LAV, Meisel SF, Wardle J (2017) Ethnic minority women prefer strong recommendation to be screened for cancer. *BMC Public Health* 17(164):164. <https://doi.org/10.1186/s12889-017-4093-2>
- Muhib FB, Lin LS, Stueve A, Miller RL, Ford WL, Johnson WD, Community intervention trial for youth study team (2001) A venue-based method for sampling hard-to-reach populations. *Public Health Rep (Washington, DC: 1974)* 116(Suppl 1):216–222. <https://doi.org/10.1093/phr/116.S1.216>
- National Cancer Institute (2017) The genetics of cancer. Accessed August 11, 2019 from <https://www.cancer.gov/about-cancer/causes-prevention/genetics>
- National Cancer Institute (2018) BRCA mutations: cancer risk and genetic testing. Accessed August 11, 2019 from <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet#how-much-does-having-a-brca1-or-brca2-gene-mutation-increase-a-womans-risk-of-breast-and-ovarian-cancer>
- National Comprehensive Cancer Network (2018) NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®): genetic/familial high-risk assessment: breast and ovarian (Version 1.2018). Accessed July 21, 2018 from https://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf
- Patel RM, Misra R, Raj S, Balasubramanyam A (2017) Effectiveness of a group-based culturally tailored lifestyle intervention program on changes in risk factors for type 2 diabetes among Asian Indians in the United States. *J Diabetes Res* 2017:2751980. <https://doi.org/10.1155/2017/2751980>
- Percac-Lima S, Grant RW, Green AR, Ashburner JM, Gamba G, Oo S, Richter JM, Atlas SJ (2009) A culturally tailored navigator program for colorectal cancer screening in a community health center: a randomized, controlled trial. *J Gen Intern Med* 24(2):211–217. <https://doi.org/10.1007/s11606-008-0864-x>
- Pew Research Center (2017) Indians in the U.S. fact sheet. Accessed August 3, 2018 from <https://www.pewsocialtrends.org/fact-sheet/asian-americans-indians-in-the-u-s/>
- Rao M, Khan AJ, Moran MS, Hirshfield KM, Ganesan S, Haffty BG, Goyal S (2011) Clinicopathologic presentation of Asian-Indian American (AIA) women with stage 0, I & II breast cancer. *J Immigr Minor Health* 13(1). <https://doi.org/10.1007/s10903-010-9359-z>
- Siegel RL, Miller KD, Jemal A (2016) Cancer statistics, 2016. *CA Cancer J Clin* 66:7–30. <https://doi.org/10.3322/caac.21332>
- Smith RA, Andrews KS, Brooks D, Fedewa SA, Manassaram-Baptiste D, Saslow D, Brawley OW, Wender RC (2018) Cancer screening in the United States, 2018: a review of current American cancer society guidelines and current issues in cancer screening. *CA Cancer J Clin* 68:297–316. <https://doi.org/10.3322/caac.21446>
- United States Census Bureau (2016) Selected population profile in the United States. From <https://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf>. Accessed 13 Aug 2018
- Valdez A, Napoles AM, Stewart SL, Garza A (2018) A randomized controlled trial of a cervical cancer education intervention for Latinas delivered through interactive, multimedia kiosks. *J Cancer Educ* 33(1):222–230. <https://doi.org/10.1007/s13187-016-1102-6>
- Vrinten C, Wardle J, Marlow LA (2016) Cancer fear and fatalism among ethnic minority women in the United Kingdom. *Br J Cancer* 114(5):597–604. <https://doi.org/10.1038/bjc.2016.15>

- Wang JH, Liang W, Schwartz MD, Lee MM, Kreling B, Mandelblatt JS (2008) Development and evaluation of a culturally tailored educational video: changing breast cancer-related behaviors in Chinese women. *Health Educ Behav* 35(6):806–820. <https://doi.org/10.1177/1090198106296768>
- Yi M, Liu P, Li X, Mittendorf EA, He J, Ren Y, Nayeemuddin K, Hunt KK (2012) Comparative analysis of clinicopathologic features, treatment, and survival of Asian women with a breast cancer diagnosis residing in the United States. *Cancer* 118(17):4117–4125. <https://doi.org/10.1002/cncr.27399>
- Zong J, Batalova J (2017) Indian immigrants in the United States. Online J Migr Policy Instit from https://www.migrationpolicy.org/article/indian-immigrants-united-states#Distribution_by_State_and_Key_Cities. Accessed 7 Nov 2018

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.