Exploring Asian Indian and Pakistani views about cancer and participation in cancer genetics research: toward the development of a community genetics intervention

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Abstract Cancer is a leading cause of mortality among the three million Asian Indian/Pakistanis (AIPs) in the USA. AIPs have traditionally been underrepresented in cancer-related research, although reasons remain largely unexplored. We sought to understand AIP's awareness and perceptions of cancer to improve their participation in risk assessment and cancer genetics research. Four focus groups, stratified by gender and birthplace (US-born vs. foreign-born), were held at an AIP cultural center. Discussions focused on knowledge and awareness of cancer risk; how AIP culture influences cancer perceptions; access to health care services for cancer screening, diagnosis, or treatment; and willingness to or experiences with participating in cancer genetics research. Sessions were audio-recorded, transcribed verbatim, and content analyzed using NVivo[®]11 for dominant themes. Thirty-two AIP adults participated in a focus group. Information on family cancer history is challenging to obtain due to the desire for privacy, cancer stigma, and loss of medical records. Interest in genetic testing for cancer risk was mixed: some were in favor of

knowing their personal risk, yet many noted that future generations in their family would benefit more by knowing their risk. Participants felt that the AIP community has largely been overlooked in recruitment efforts for research studies. Recommendations for improving recruitment efforts included partnering with community events and festivities, posting culturally and linguistically relevant recruitment materials, and focusing on population-wide health improvement. Understanding the culture and perceptions of AIPs, separate from Asian Americans at large, will allow for more tailored approaches for including this population in cancer genetics research.

Keywords Ethnic minority · Cancer risk assessment · Genetic testing · Participation in medical research

Background

Asian Americans represented 6.3% of the total US population in 2014 and are the fastest growing racial/ethnic group in the USA (Colby and Ortman 2014). Growth in the population is driven dually by immigration as well as native births. Asian Indians and Pakistanis (AIP), considered to be those originating from the Indian subcontinent, are one of the most rapidly growing subpopulations, comprising roughly 16% of the Asian American community (Colby and Ortman 2014). There is extraordinary cultural heterogeneity within the AIP subpopulation by immigration history, region of descent from Indian subcontinent, language, nativity, ethnic origin, acculturation, and socioeconomic status. Despite this diversity, the community remains tight-knit, with ten states in the USA serving as home to roughly 75% of the AIP population (Hoeffel et al. 2012).

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Cancer is the second leading cause of mortality among AIPs in the USA (Palaniappan et al. 2010; ACS 2016). A focused study of cancer trends among AIPs revealed that the most common cancers among males are prostate, lung, and colorectal. Among females, the most common cancers are breast, colorectal, and uterine, with a noted statistically significant 3% annual increase in breast (95% CI = 2.4 to 3.6%) and uterine (95% CI = 0.3 to 5.8%) cancers from 1990 to 2008 (Gomez et al. 2013). Known risk factors for several of these cancers include hereditary factors as indicated by family cancer history and genetic predisposition, as well as lifestyle factors such as obesity, smoking, and hormonal influence (PDQ® Cancer Genetics Editorial Board 2017).

Thus, cancer risk assessment is a key approach to identify cancer risk, address risk factors, and ultimately reduce cancer-related morbidity and mortality. However, AIPs have not historically engaged in cancer risk assessment activities, therefore limiting our understanding of risk factors for cancer development in this subpopulation of Asian Americans. Furthermore, engagement in genetic testing is crucial for uncovering the genetic spectrum relevant to a population. Multigene testing capability has now led to the well-recognized need to discuss the potential to identify variants of uncertain significance (VUS), where interpretation for cancer causation is unclear (Balmaña et al. 2016). VUS do not change management when initially identified, which requires discussion with patients to understand this and to keep in contact with their genetics provider as the interpretation of VUS can change over time with accumulation of scientific evidence. VUS findings and discussions can be particularly relevant for certain populations. For example, African American females have higher rates of VUS when undergoing *BRCA* testing for breast cancer risk compared to Caucasian females (Haffty et al. 2006). Genetic testing in AIPs will likely also lead to a greater need for tailored genetic counseling based on rates of mutations and VUS identified.

Despite cancer being a leading cause of death for AIPs, few studies have investigated AIPs' knowledge and understanding of cancer risk and prevention in the USA. Research conducted with AIPs has predominately involved those living in the UK rather than those living in the USA. A cross-sectional study of AIP men and women living in England found that while 91% of adults could name at least one risk factor for cancer, this was lower than the British white population (Marlow et al. 2012). Similarly, a study examining breast cancer screening rates among 16 ethnic groups in London, UK, found that rates of first screening and subsequent screening were slightly lower in Indian and Pakistani women compared to white British women (Jack et al. 2014). The authors of both studies suggest that campaigns to improve knowledge and screening uptake should be tailored to reflect the unique cultures of the AIP subpopulation within the broader Asian immigrant population.

Reduced levels of cancer awareness and screening may be due to prevalent feelings of cancer fear and fatalism in the AIP population. In previous research, AIP females and those with lower levels of education were found to have higher levels of cancer fear and fatalism (Powe and Finnie 2003; Consedine et al. 2004; Vrinten et al. 2014). Associations with age are less consistent, with higher levels of fear in those who are younger (Kudadjie-Gyamfi et al. 2005; Vrinten et al. 2014) and higher fatalism in those who are older (Powe and Finnie 2003). A recent study investigating fear and fatalism among ethnic minority groups in the UK found that, relative to white British women, Indian women were more fearful of cancer but Pakistani women were more similar to white British women (Vrinten et al. 2016). Cancer fatalism was higher in both Indian and Pakistani women compared with white British women. Among all AIPs, less acculturated women were less likely to worry or feel particularly afraid of cancer but more likely to feel uncomfortable talking about cancer. Lower acculturation and general fatalism were also associated with the belief that cancer is predetermined.

There is little data on AIPs' willingness to or experiences with participating in clinical research studies. A report detailing barriers to clinical research participation among AIPs in the UK found that while psychosocial factors were, in fact, a barrier to participation, a greater barrier was simply not being approached to participate in the research (Hussain-Gambles et al. 2004). The authors found little mistrust in researchers or antipathy in the population, but rather that ethnic AIPs rarely saw research announcements in their native languages or failed to understand the larger benefit to their community. A study involving 15 AIPs who had participated in a clinical study found that one of the strongest motivators for participation was to investigate illnesses that they felt were prevalent and important in their subpopulation (Hussain-Gambles et al. 2004). The author suggested that research opportunities be further tailored to attract interest of diverse subpopulations within ethnic minority populations.

As the literature reflects, only a handful of studies have explored AIPs' knowledge and awareness about cancer risk and prevention or their participation in clinical cancer research. Those that were conducted have almost exclusively been conducted in the UK, where the AIP population, particularly in London, is a greater proportion of the total population than in the USA. However, it is important to investigate these differences within a US population, as AIPs in the UK are exposed to different media and cultural sources than those in the USA. To our knowledge, our study is one of the first to report on cancer knowledge, awareness, and risk perception, as well as barriers to participation in clinical genetics research, among AIPs living in the USA. Using a mixed methods approach, we explored AIPs' thoughts and perceptions about cancer to be able to design a culturally relevant community genetics intervention in the future. As this subpopulation of

Asian Americans continues to grow, it becomes increasingly important to understand their perceptions about cancer and participation in research, to be able to design effective educational and clinical initiatives to meet their needs.

Methods

Four focus groups were conducted in December 2016 at an AIP cultural center in Marlton, NJ, considered to be suburban Philadelphia. Two of the groups were with females and two of the groups were with males. Within each gender, one group was comprised of those who were born in the USA while the other group was comprised of those who were born in India or Pakistan. Prior to the start of the focus group, each participant completed a brief survey to assess cancer risk and awareness as well as to collect demographic data. Focus groups were moderated by a graduate public health student (SM) who is a member of the research team and the AIP community. The study was approved by the Thomas Jefferson University Institutional Review Board. Informed consent was obtained from all participants for being included in the study. Each participant received \$50 for their time and thoughtfulness in being a part of the research study.

Focus group guide

Members of the research team, some who have previous experience engaging members of the AIP community initiatives and others who have expertise in clinical genetics and qualitative research methods, designed a semi-structured script to guide the focus group discussions. The guide primarily explored four broad areas of interest: knowledge and awareness of cancer risk; how AIP culture influences health behavior and cancer perceptions; access to health care services as it pertains to cancer screening, diagnosis, or treatment; and experiences with or willingness to participate in cancer genetics research (Table 1). Questions addressing each area of interest were drafted by members of the team and reviewed for relevance, understanding, and cultural appropriateness.

Eligibility criteria

To participate in a focus group, participants had to be over the age of 30, speak and read English comfortably, and self-identify as a member of the AIP community. We were interested in the views of those older than age 30, as cancer risk becomes increasingly relevant as one ages, and screening guidelines become more pertinent for those over the age of 30. Family or personal history of cancer was neither an inclusion nor exclusion criteria to participate, as we aimed for a diverse participant group to hear a wide range of experiences. Due to the diversity of languages among the AIP community, and

Table 1 Content description of focus groups

Section	Content description
1	Cancer awareness/concerns <ul style="list-style-type: none"> • Knowledge about specific cancers (breast, prostate, colon) • Risk factors for each cancer; the role of lifestyle as a risk factor for cancer • Ability to detect cancer early or prevent cancer • Health information seeking behaviors
2	Beliefs about cancer <ul style="list-style-type: none"> • Knowledge of one's own family history of cancer • Ability to talk openly about cancer with one's family or friends • Perceptions about cancer and/or people who are diagnosed with cancer • The role of spirituality and cancer, particularly the role of prayer • How AIP culture influences beliefs and perceptions about cancer
3	Attitudes toward participating in research and genetic testing <ul style="list-style-type: none"> • Perceptions about medical research; barriers and facilitators to participating in medical research • Understanding and awareness of genetic testing • Sharing the results of a genetic test with physicians or family members
4	Access to medical care <ul style="list-style-type: none"> • Usual source of care and decisions about where to seek care • Barriers to seeking medical care in a timely manner • The role of AIP culture in seeking medical care

that we were limited to conducting four focus groups, we chose our discussions to be in English as a common language. While we realize this may have caused a selection bias, data shows that almost all AIP men and close to two thirds of AIP women can converse in English as a primary or secondary language (Johnson 2000).

Recruitment and participant selection

Information about the focus groups was provided by the research team to the cultural center, who used social media and personal contact to promote the event to its members. An e-mail invitation was also created and distributed to members of the cultural center, who were asked to forward it to friends and family members. Recruitment began roughly 3 weeks prior to the scheduled date of the focus groups. Those who were interested called a central number, where a member of the research team determined which focus group was appropriate for each participant and accepted reservations until all slots were filled. We aimed to recruit up to 12 participants for each focus group.

Data analysis

Each of the focus group discussions were audio recorded and transcribed verbatim by a professional transcription company. All members of the research team reviewed the transcripts and

came to a consensus on major themes that emerged during the discussions. Using those themes as a guide, the transcripts were further analyzed using NVivo 11 to elucidate subtleties within each theme and identify quotes that illustrate the theme. Survey data was analyzed using SPSS 10 to determine frequencies, means, and standard deviations.

Results

Description of participants

Thirty-two adults participated in one of four focus groups. There were seven females and ten males in the two US-born groups, and ten females and five males in the two foreign-born groups. Regardless of gender, all the foreign-born participants immigrated from India or Pakistan. In the two US-born groups, the mean age of participants was 47 years while in the two foreign-born groups, the mean age of participants was 62 years. All participants were well educated, with 100% of men and 55% of women reporting a graduate degree. All but two participants were currently married and all had health insurance. Interestingly, 75% of foreign-born males reported that they were “not at all worried about cancer” and 60% of those same males would “rather not know that they have cancer.” More detailed data from participant surveys can be found in Table 2.

Focus group themes

Through the data analysis and qualitative coding process, seven themes emerged from the focus groups. They were as follows: influence of AIP culture on health, perceptions of cancer, causes of cancer, spirituality, access to health information and medical care, the role of genetic testing in cancer risk assessment, and willingness to or experiences with participating in clinical genetics research. Table 3 summarizes the seven themes and their subthemes. Brief descriptions of each theme follow below, with selected quotes to add depth and meaning to the data.

Influence of AIP culture on health

In this theme, participants talked about how their heritage has influenced their health, both in positive and negative ways. They mentioned how in India or Pakistan, actions are mostly geared toward treating disease while in the USA, there is much more emphasis on preventing disease. One US-born male noted, “My parents’ generation, my uncles and aunties, there they don’t think about it [prevention] because they’re from India. Their culture is different.” Another US-born male astutely explained, “And, you know, they’re just thinking about surviving, not getting heart disease, not getting diabetes, managing the chronic illnesses. And you know what? They’ve already lived longer than their parents have, right? So, at this point, it’s bonus. They’re in bonus territory.”

Also noted within this theme was the level of privacy seen in AIP families that is not traditionally seen in US families.

Table 2 Description of participant characteristics by focus group

	FG #1 US-born	FG #2	FG #3 Foreign-Born	FG #4
Gender	Females	Males	Females	Males
Number of participants	7	10	10	5
Mean age (range)	49 (42–60)	46 (34–64)	59 (37–70)	66 (59–70)
Education—graduate degree	71%	100%	40%	100%
Preferred language—English	100%	100%	70%	100%
Marital status—married	100%	100%	90%	100%
Employment—full time	71%	90%	50%	60%
Need help with medical materials—never	57%	80%	20%	40%
Health—excellent or very good	85%	100%	40%	80%
Motivated for good health—extremely	71%	70%	80%	40%
Last visit to MD within 1 year	71%	50%	100%	100%
Private practice for medical care	100%	100%	100%	100%
Have health insurance	100%	100%	100%	100%
Personal history of cancer	0%	0%	30%	20%
Family history of cancer	51%	70%	80%	60%
Not at all worried about cancer	51%	0%	43%	75%
Would rather not know about cancer	14%	40%	20%	60%

Table 3 Description of major themes and subthemes identified from focus groups

Major theme	Subthemes
1. Culture	Influence on lifestyle behaviors Treatment-based medicine vs. prevention Privacy Optimistic bias
2. Perceptions about cancer	Certainty of death Not talking about cancer
3. Causes of cancer	Documented links to cancer Uncertainty of what causes cancer
4. Spirituality	Its role in predetermination of cancer Its role in helping someone through cancer
5. Health information and medical care	Preventive health information/general awareness of cancer risk and risk assessment is limited Lack of family history documentation Access to cancer screening, diagnostic, and treatment services
6. Genetic testing for cancer risk	Not wanting to know one's own genetic risk Benefits future generations of one's family rather than personal benefits
7. Participating in clinical genetics research	Not being invited to participate Feeling that the research is not relevant to AIPs

This mainly pertained to discussions about family health history, which has an impact in knowing or understanding one's genetic risk for cancer or other diseases. Discussions frequently mentioned that within Indian or Pakistani families, people did not discuss or reveal a family members' true disease status. One of the US-born male participants offered this thought while thinking about his family's medical history: "Do you have any family members with cancer? I had to think about it for a minute. 'Oh yeah, my uncle had some sort of cancer.' I didn't know which one it was. I wrote down prostate, and then when you mentioned colon cancer, I was like, 'Oh, maybe it was colon.' I had no idea what cancer it was because nobody in my family would tell me what was wrong with him. 'Oh, Uncle is sick.'" Privacy may be a way to preserve the status of the family in society or not to burden other family members with disheartening news. This was not something that the participants saw in American culture, where health history is more readily shared among family members.

Perceptions of cancer

When asked to think about cancer, there was a feeling among participants that those in the AIP community almost always associate having cancer with a certainty of death. This may stem from experiences with family members or a reflection on AIP culture at large. Said one of the US-born female participants, "They're not aware that, okay, it is treatable disease.

They assume the worst. Okay, breast cancer your breast will be taken out or you're going to die." It was noted that in American culture, views on cancer tend to be almost the opposite, with many talking about 'fighting cancer' or overcoming the diagnosis to live long into the future.

The second most prominent discussion when asked to think about cancer was about AIPs' reluctance to talk about a cancer diagnosis to their friends or family members. This goes hand-in-hand with being reluctant to talk about health histories in general, but there appeared to be a greater stigma about cancer than most other diseases. One of the groups noted that this is deeply rooted in AIP history, where marriages have typically been arranged and the value of the family lineage plays a distinct role in society. "Marriage was on dowry and your financial transaction. And if there was something wrong with your family, if they found out that there was cancer in the family or somebody was ill, [the] reputation of your family was tarnished, so don't tell anyone," noted one US-born male participant.

It was also mentioned that another reason to not discuss someone's cancer diagnosis was to not burden the family, particularly spouses or children, with worry. This idea is much more prominently seen in AIP than American families. "Half of the patients will not know, especially if they [are the] parents. Children won't tell them that, 'Mom, you have a cancer,' or, 'Dad, you have this and you're going to die from that.' They want to keep the peace. You know, not worry about it," noted one foreign-born female participant. "I don't know if it's stigma or they don't want to burden the rest of the family is more probably," explained one US-born male participant. In addition, those diagnosed with cancer may not want to discuss their diagnosis because they do not know what kind of support they will receive from the community around them. Mentioned one participant, "because when the phone call comes, you don't know whether the phone call will be supporting phone call or whether the phone call will be the negative phone call and putting you down."

Causes of cancer

Across all four groups, participants noted similar causes of cancer. Commonly known causes such as smoking, diet, genetics, and environmental exposures were often cited in each group. Interesting discussions centered on how modernization in the USA has increased AIPs' exposure to chemicals in food preservatives and pesticides in agriculture; things that are not as much of an issue in India or Pakistan. There were also discussions about how much of cancer risk remains unknown or incalculable. Noted one of the US-born men, "You know, you can be healthy. You can do all the right things; but you don't know when you're going to get cancer, right? It could be an occupational exposure. It could be just bad genes."

Spirituality

Spirituality was one of the few themes where differences were seen between US-born and foreign-born AIP participants. It may be reflective of the age of participants, too, as the US-born participants were roughly 15 years younger than the foreign-born participants. Regardless, the foreign-born males and females were much more likely than their US-born counterparts to acknowledge the role of karma in developing cancer. Noted one US-born male about the previous generations in his family, “So my parents actually grew up—and my grandparents, especially—grew up with the notion that whatever is going to happen to me, I deserve; and whatever I do in my life will come back to me one way or another.” Explained one foreign-born female participant, “As Hindus, I think there’s a whole religious component to discussing things. Health is one of them. The Dharma of this person, the karma of this person. He didn’t do enough pooja [prayer], that’s why he has cancer.”

Although there was disagreement about karma in causing cancer, all participants felt that there was a prominent place for spirituality once someone was diagnosed with cancer. In this case, spirituality was calming for those who have cancer and a way to bring people together in support of someone being treated for cancer. “We do this on a regular basis. If we come across somebody who’s going through a lot of physical pain, it could be cancer, it could be any other form of illness or disease. We all get together, be it physical or over the phone... and then we pray or chant together for that person for an allocated time,” explained one foreign-born female participant.

Access to health information and medical care

When discussing access to health information for learning about various types of cancer, all participants agreed that younger generations, particularly those born in the US, have an easier time finding relevant health information. This partially pertains to the pervasiveness of the Internet in American culture and the ease of accessing information. All participants mentioned that younger generations, or those AIPs who were born in the USA, are much more aware of cancer risk factors than older generations or those born abroad. “Here, when you go for a doctor’s visit, they have the chart right there. At this age, you do this. At this age, you do this. So everybody goes for a physical every year. Plus, there’s so much news floating around everywhere. There’s so much available. So I’m sure the younger generation is much more aware and they spread more awareness,” noted one US-born female participant.

There were vibrant discussions across all four groups when talking about accessing medical care. Many noted the socioeconomic disparities within the AIP community that limit options for some. “Poor guy, right. I mean, he’s here illegally,

works 12 hours, 7 days a week. He makes \$10 an hour. Is he going to take that \$10,000 to pay for throat cancer if he gets it? That’s his whole family’s yearly livelihood and he’s sending half that money to India or Pakistan, or Bangladesh, wherever. So it comes down to all those choices, and it’s difficult,” noted one US-born male participant. Staying within the AIP community for medical care was also seen as important, as those physicians would be more likely to understand their culture and views toward health. Also, it was almost seen as the AIP physician’s obligation to treat a fellow community member without charge, regardless of socioeconomic status. “I think Indians, many Indians, feel very entitled to free care because of so many other Indian doctors. I think they feel that, well, why am I paying? I mean I’m Indian, you’re Indian. So how are you as an Indian doctor charging me?” noted one US-born female participant.

Genetic testing for cancer risk assessment

While some participants understood the role of genetics in the development of cancer more than others, most had a basic understanding of genetics and genetic testing. When asked whether they would want to have genetic testing to assess cancer risk, the discussions were surprisingly similar across the four groups. “I don’t know whether I’d want to have it because I think maybe my whole outlook on life might be cloudy. I might feel like, ‘Oh, well I have this,’ and it’ll always be in the back of my mind. Oh, I’m going to get it.’ Sometimes maybe not knowing is a blessing,” said one foreign-born male participant. One of the US-born male participants explained not wanting to know more about their family’s genetic lineage because of the stigma associated with certain illnesses. “Right now, you’d like to think that your family is good, you’re coming from a good family line. Once you find out that your family carries that gene, maybe they’ll be stigmatized.” A third participant, one of the foreign-born women said, “They know genetically, maybe the child will get it, too. So, they don’t want to get married to that child because the parents had cancer.”

Most participants felt that the true benefit of genetic testing would be for their children and future generations of their family, rather than for their own personal gain. Explained one of the US-born female participants, “I’m like, whatever I can do as a team player for my family or my children, even though they may not appreciate, but I’ll do it, take the genetic testing to help somebody else down the line.” One of the foreign-born men agreed, saying, “The only reason I might want to get it done is to see if my children are going to be affected.”

Participating in clinical genetics research

Participants acknowledged that the clear majority of AIPs, including themselves, had not participated in medical research, be it a clinical genetics study or otherwise. While some participants knew of a family member or friend who had enrolled in a clinical trial, they felt that research participation was not common in their community. One of the reasons was simply never being approached to participate in a study, or feeling that most studies were not designed for ‘people like me’. “I don’t know much opportunity is there that they’re declining to do so. I’ve never been solicited outside of this [study],” offered one male foreign-born participant. Another reason was feeling that the research wasn’t for them. “For the older generation, if it [the flyer] was written in Gujarati...and it was explained to them when they came to a cultural function, you probably could have gotten more of the older generation [to participate].” Because the barriers to participation were more logistical than philosophical, there was a strong interest in participating in medical research in the future.

Discussion

To our knowledge, this is the first US-based study to explore knowledge and understanding about cancer, the influence of culture, and barriers to participation in clinical genetics research among AIPs. While many have studied Asian Americans’ views on these topics, this study was the first to dive deeper into the subpopulation of AIPs living in the USA. Specifically, our study identified several important findings from this community as it relates to cancer in general and cancer genetics more specifically: (1) a historically, more emphasis rested on the treatment rather than the prevention of cancer; (2) the influence of family privacy, cancer burden, and community standing on limiting discussions of family and personal cancer history; (3) fatalism and karma reducing interest in seeking genetic evaluation for personal cancer risk; (4) concern regarding access to health care and financial difficulties hindering seeking cancer screening; and (5) lack of participation in research due to not being invited or unclear benefit to the community. While some of these findings are also apparent in the Asian American population at large, involving AIPs in these discussions has uncovered thoughts, experiences, and perceptions that have yet to be documented for this community.

Cancer risk assessment is an integral part of addressing cancer concerns and development, with intake of risk factors such as family history and lifestyle factors being critical to providing individuals with their personal risk for cancer to inform cancer screening and risk reduction (PDQ® Cancer Genetics Editorial Board 2017). Furthermore, if there is suspicion of an inherited risk for cancer in a family, genetic

counseling and genetic testing can provide even more precise estimates of cancer risk for an individual and lead to heightened recommendations for cancer screening and management. These efforts require individuals, families, and communities to communicate about cancer information, such as family cancer history and personal cancer diagnoses, and to engage in cancer screening, genetic evaluation, and risk factor modification as appropriate. Our results show that most AIPs were not aware of their family history of cancer and also did not want to have genetic testing due to fear of the results. There is very little information in the AIP community regarding cancer risk awareness, even though the AIP population comprises a substantial proportion of the Asian American population in the USA. While comparative statistics may show that AIPs have lower rates of cancer incidence and mortality compared to other ethnic groups (ACS 2016), cancer is the second leading cause of death in the AIP population and warrants dedicated efforts to address barriers to cancer risk assessment in this population.

Fear or fatalistic views toward cancer may be one underlying cause of AIPs’ limited participation in cancer research, whether it is in genetics research or therapeutic clinical trials. It is prudent to include ethnic minority populations in research to sustain the generalizability of the findings to the population and to provide opportunities for subgroup analyses to determine if ethnic origin influences the effectiveness of the intervention. Furthermore, exclusion of ethnic minority people from clinical trials and medical research, it has been argued, also denies patients state-of-the-art treatment for diseases, frequent follow-up consultations and closer disease monitoring and management (Heiat et al. 2002). Opportunities to improve recruitment and retention of AIPs in research endeavors include ensuring that study eligibility criteria are wide enough to be inclusive of ethnic minority groups, using recruitment approaches that reach a diverse audience, training study staff to be sensitive to various cultural norms in certain subpopulations, and disseminating results to study participants so that they can see the impact of their participation on their broader community (Hussain-Gambles et al. 2004).

Previous literature has shown that culturally tailored community interventions have been effective in increasing cancer-screening rates, as well as knowledge, perceived risk of cancer and benefits of cancer screening among other racial minority populations (Percac-Lima et al. 2009) (Gotay et al. 2000) (Wang et al. 2008) (Kwok and Lim 2016). In each of the interventions, the authors surmise that the culturally tailored messages and understanding of the social context of the participants’ lives increased the ability to recruit and retain participants. Additionally, by touching on core values unique to the population, researchers are more likely to instill positive behavior change. By uncovering the knowledge, perceptions, and barriers among this sample of AIPs in the USA, we can begin to develop culturally appropriate community genetic

interventions to assist them in understanding their risk for cancer in the future. This may include clinical, educational, or community engagement initiatives to encourage cancer awareness and risk assessment; these interventions would need to be sustainable on a long-term basis and fit the needs of the community.

While this study may be the first to engage AIP adults living in the USA in discussions about participating in cancer genetics research, previous studies predominately carried out in the UK have asked similar research questions. Our results are consistent with UK-based studies, with common themes among the same population separated by geographic distance. In both the US and the UK, studies involving AIP adults report (1) a decreased awareness about cancer and a hesitancy to talk about it among their families, (2) increased perceptions of cancer fear and fatalism, and (3) an openness to enrolling in medical research yet limited opportunities to participate. Similar findings across two continents may suggest the strong role that AIP culture plays, much stronger than the culture of the country in which they live, in shaping attitudes and perceptions about cancer and medical research. Furthermore, as cancer prevention and control initiatives become more widespread in India and Pakistan (Mathur et al. 2014), perceptions, as well as opportunities to participate in research, may improve over time. Increasing the visibility of cancer and genetics research in the AIP culture globally may help to decrease the stigma of cancer that is so widespread in AIP families.

Although there are numerous strengths to our study, some limitations should be noted. The study was conducted in a densely populated community on the East Coast, where the health care needs and perceptions of individuals (such as finances, transportation, access to medical research opportunities, and lifestyle) may differ from rural settings or other areas of the country. A large percentage of our cohort were well educated, and all had access to health insurance, which may have limited uncovering additional social factors important in devising cancer education materials. Everyone in our study could read and speak English, which may have excluded some less-aculturated AIPs from participating. Yet, while we note these limitations, we believe that this study was an important first step in involving AIPs in the discussion about cancer risk and participation in medical research. Future work with an even more diverse population of AIPs is already underway.

In summary, our study has uncovered critical gaps in knowledge and cultural issues influencing engagement in cancer risk assessment in the AIP population—a substantial and growing Asian American population in the USA. These findings are important groundwork in devising culturally competent community interventions in cancer risk assessment, cancer genetic evaluation, and community research to ultimately reduce the burden of cancer in this diverse population.

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Compliance with ethical standards

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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.

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

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