



Perceptions, Beliefs, and Experiences of Asians and Micronesian Islanders on Family Health History Genetic Cancer Screening Community Outreach

Connie Kim Yen Nguyen-Truong¹ · Andra Davis² · Vananh Minh Nguyen Vuong³ · Kim Quy Vo Nguyen³ · Anthony My Truong⁴ · Jacqueline Leung^{5,6}

Accepted: 29 August 2021 / Published online: 8 September 2021
© American Association for Cancer Education 2021

Abstract

Cancer carries stigma, taboos, and shame including, for diverse communities, who can have difficulty understanding and communicating about family health history genetic cancer screening (GCS). The Oregon Health Authority ScreenWise Program reached out to our academic-community research team to explore Asians and Micronesian Islanders (MI) perceptions on public health education outreach on GCS due to having previously only worked with the Latinx community. The purpose of the qualitative description pilot study was to elicit perceptions, beliefs, experiences, and recommendations from Asian and MI community leaders and community members regarding family health history GCS outreach in communities. Twenty Asians (Chinese and Vietnamese) and Micronesian Islanders (Chuukese and Marshallese) were recruited from the US Pacific Northwest. Nineteen participants are immigrants with an average 21.4 and 18.5 years having lived in the USA, respectively. Individual in-depth interviews were conducted using a semi-structured, open-ended interview guide and analyzed using conventional content analysis. Three main transcultural themes were identified: (1) degree of knowing and understanding cancer screening versus family health history GCS, (2) needing culturally relevant outreach messaging on family health history GCS, and (3) communication and decision-making regarding discussing with family and health care providers about cancer screening and GCS. Culturally relevant messaging rather than generic messaging is needed for inclusive outreach. Healthcare providers are encouraged to assess a client's family health history routinely because Asian and MI clients may not understand the information requested, may be hesitant to offer, or unable to provide information about their personal or family history of cancer.

Keywords Genetic cancer screening · Cancer screening · Family health history · Public health cancer outreach · Culturally diverse communities · Qualitative · Asians · Chinese · Vietnamese · Micronesian Islanders · Chuukese · Marshallese

Although there are technological advances in genetic cancer screening (GCS; i.e., testing) to assess inherited cancer

risk, cancer carries stigma, taboos, and shame, including understanding and communicating about family health history GCS in minoritized communities. Inherited cancer risk assessment and management can help clients (patients) make important decisions about cancer prevention and risk-reducing interventions. Consideration regarding genetic counseling and screening is often warranted when there is a high risk for hereditary cancer [1]. There is little evidence that further evaluates GCS and outreach in different subgroups among Asians and Micronesian Islanders (MI) in the USA and underscores a need for public health education outreach.

Recommendations for cancer screening, GCS, and genetic counseling can be complex and difficult for many to understand and navigate, including Asians and MI. In Hann et al. [2], there is evidence that more Whites were

✉ Connie Kim Yen Nguyen-Truong
c.nguyen-truong@wsu.edu

¹ College of Nursing, Washington State University, Vancouver, WA, USA

² School of Nursing, University of Portland, Portland, OR, USA

³ Asian and Pacific Islander Communities, Seattle, WA, USA

⁴ Asian and Pacific Islander Communities, Portland, OR, USA

⁵ Micronesian Islander Community, Salem, OR, USA

⁶ Health Human Performance, and Athletics with an emphasis in Public Health, Linfield University, Salem, OR, USA

aware of GCS than Asians (in addition to Hispanics and African Americans). Asians may have linguistic barriers and low health literacy impacting their ability to obtain, process, and understand genetic information to make health decisions [3]. Different Asian subgroups also have varying degrees of health literacy that have varying impacts on health outcomes such as cancer [3]. Ineffective communication about genetic information such as content overload, vague discussions on recommendations, as well as complex terminology and concepts have led to elusive, confusing key messages, and inhibited engagement among Chinese patients [4]. Different definitions of family that may extend beyond family who are blood related and not blood related can also create confusion in the attainment of family health history among Asians and MI and impact risk assessment [2, 5]. Culture of shame and social stigma, along with information deficits about cancer, particularly among Asians, can hamper participation in cancer screening [2, 6, 7]. Other barriers include socioeconomic factors in healthcare access, particularly related to cancer care, not having health insurance, and providers without cultural competency training [1, 4, 5]. These widen the gaps in health equity among different subgroups in Asians and MI.

While similar in many of the barriers to engage minoritized groups in cancer screening and GCS, the minimal research representation of Pacific Islanders, and specifically, MI subgroups is a gap in the literature to understand the unique needs and the profound health disparities among this population [8]. The history of trauma, exploitation, and exclusion of Marshallese, including the nuclear weapons testing detonated on their homelands and unethical research, without informed consent, have led to being forced from the homeland and had lasting negative health issues for the community, including cancer [8–12]. There are researchers who are unfamiliar or do not know about this MI community context. When conducting research with MI, researchers must understand the mistrust in research and Western medicine stemming from that historical trauma.

Previous researchers reported barriers to recruitment of minoritized Asian and MI subgroups in research, including access, mistrust, and historical trauma that contributes to varying degrees of willingness to participate in research. Considerations of the complexity illuminate gaps in engaging with Asian and MI subgroups in public health education outreach efforts. Targeting community outreach with culturally relevant and in-language messaging about cancer screening are recommended practices by researchers to recruit minoritized groups in cancer research and shown to increase participation [6, 13, 14]. Researchers working with Chinese and Vietnamese women who were at risk for cervical cancer found that not having time and not convenient due to competing interests were the top barriers to research participation followed by mistrust of institutions, negative experiences of others, and media

portrayal of research [15]. Furthermore, the mere act of interacting with people who are unfamiliar to them was the source of suspicion and mistrust, which is increased with language barrier and dialectal differences between a bilingual recruiter and participant [15]. Chao et al. [16] found that not having access to research such as low levels of education, not having proficiency in English, or not having family support is an underlying issue of underrepresentation of the Chinese community in research, more so than unwillingness to participate. For MI in general, the history of unethical research practices in the Pacific has contributed to MI community members' reluctance to engage with researchers who are not familiar with the community's culture and historical trauma [17, 18]. George et al. [17] systematic review found mistrust, in particular concerns among Asians about signing the informed consent form and negative feelings among Pacific Islanders about the purpose and intention of the research and not having access to information in their preferred language. However, there seemed to be a willingness to participate in research. Earning trust by engaging Asian and MI communities in research and honoring cultures is vitally important to develop authentic relationships. Our diverse academic-community research team recognized this and has fostered trusted relationships with each other as well as in the Asian community and MI community.

The purpose of this academic and community-engaged qualitative description pilot study was to elicit perceptions, beliefs, experiences, and recommendations on GCS outreach from Chinese and Vietnamese community leaders and community members from the Asian community, and Chuukese and Marshallese community leaders and community members from the Micronesian Islander community in the US Pacific Northwest. We described the engagement of participants regarding the family health history GCS postcard outreach, or a public facing educational material, that was developed by the Oregon Health Authority (OHA) Screen-Wise Program. OHA provides the family health history GCS postcard in English and also in other languages upon request. The postcard is intended to be used to facilitate community members to talk with their family and a healthcare provider (HCP) and to visit OHA's Web site for information. OHA reached out to our academic-community research team regarding an essential need to have input from the Asian and MI communities on the family health history GCS postcard as they only previously received input from the Latinx community regarding public health education outreach. Our team consists of two academic nurse scientists, one from Washington State University and another from University of Portland (principal investigator [PI] and Co-PI respectively) with a background in cancer screening inequities, cross-cultural, and community health; the Executive Director from the Micronesian Islander Community organization

(community Co-PI); and three community researchers with a background in community/public health, pharmacy, and family nurse practice respectively.

We used the health belief model (HBM) as a guide for the qualitative descriptive pilot study about health beliefs that includes the concepts of perceived susceptibility, benefits, and barriers [19]. Perceived susceptibility is the “belief about the chances of experiencing a risk or getting a condition or disease” [19]. Perceived benefits are the “belief in efficacy of the advised action to reduce risk or seriousness of impact” [19]. Perceived barriers are the “belief about the tangible and psychological costs of the advised action” [19].

Methods

Setting and Participants

The qualitative description pilot study (#17,800–001) was certified as exempt by the Washington State University Human Research Protection Program. The outreach and recruitment of participants and concurrent data collection and analysis occurred between late August 2019 and May 2020. The study was implemented remotely through virtual means with 100% social distancing during the COVID-19 pandemic that occurred during the middle of the study implementation timeline. The PI (Vietnamese background), community Co-PI, and two community researchers (one Vietnamese-Chinese with a pharmacy background and another Vietnamese with a public health background [VC community researchers]) used a purposive method and recruited community leaders from Asian-based and MI-based organizations as well as community members who are residents from the Chinese, Vietnamese, Chuukese, and Marshallese communities in the United States Pacific Northwest. We used word of mouth, telephone, and email with a study information document to recruit. Participants were included if they were 18 years or older and able to speak and understand English and another language, including Chinese, Vietnamese, Chuukese, or Marshallese.

The VC community researcher reviewed the study consent form with the Chinese and Vietnamese participants and the community Co-PI reviewed it with the Chuukese and Marshallese participants. They provided the study consent form and obtained consent and explained the study’s purpose; the procedures; that there are no known risks, discomforts, or personal benefits; and emphasized that participation was voluntary and confidential where their names would not be revealed with the obtained information. We determined that the participation size was sufficient for codebook stability and for understanding the main themes with a focused scope of the topic, the high quality of data obtained from

participants, and the methodological study by Hennink et al. [20].

Data Collection

We used a semi-structured, open-ended interview guide and included questions related to the HBM concepts described earlier. Questions also included the appearance of and contents of the family health history GCS postcard. This is the same postcard that OHA ScreenWise Program used with Latinx participants. In addition, we asked about perceived susceptibility, barriers, and facilitators for themselves, their families, and with HCPs in talking about GCS related to the postcard. The interview guide was developed by the PI and reviewed by the research team. After the review, additional definitions on family health history, cancer screening, genetic cancer screening, and probing, and follow-up questions were added to the interview guide. The postcard included images, a variety of colors, and written text. The images included two silhouettes of people who varied in height and with varied length of hair, of which one person is holding a heart shaped balloon. Use of colors included blue, light brown, red, white, and black. The written text included, “You are worth the time. Take the time to talk with your family about their cancer health history. Ask 3 key questions: Who in your family had cancer? What type of cancer was it? How old were they when they found out they had it? Share what you learn with your health care provider. Learn more at (OHA web url).” See [Appendix](#) for the semi-structured, open-ended interview guide and a figure of the family health history GCS postcard.

Twenty individual in-depth interviews were completed. Prior to the COVID-19 pandemic, four of the interviews with Chinese and Vietnamese participants were conducted by both the academic Co-PI (White non-Latinx background) and one VC community researcher. The VC community researcher met with the Chinese and Vietnamese participants in their homes, and the academic Co-PI met them by virtual means. The VC community researcher conducted six other interviews with Chinese and Vietnamese participants, of which four were in the participants’ homes, one in an office, and two were by telephone. During the COVID-19 pandemic, the community Co-PI conducted 10 interviews with Chuukese and Marshallese participants by virtual video calls. Participants were shown the English version of the family health history GCS postcard and a translated version in their language provided by OHA. The individual interviews were digitally recorded and were about 30 min in length. The three researchers who conducted the interviews frequently checked-in with participants and verified their understanding of what they had heard. They provided opportunities for participants to verify their perceptions, beliefs, experiences, and recommendations throughout the interviews. They documented impressions of the interviews that included observations. We debriefed as a research

team on all the interviews. Each participant received a \$25 Amazon electronic shopping gift card or a Walmart grocery gift card as an appreciation for their time and contribution.

Data Analysis

We used a team approach for transcription of the interview data and data analysis. The VC community researcher transcribed verbatim each interview with Chinese and Vietnamese participants and reviewed each transcript to verify accuracy. The community Co-PI transcribed verbatim each interview with Chuukese and Marshallese participants and reviewed each transcript to verify accuracy. An Excel spreadsheet was used to manage the data. A conventional content analysis was used for data coding and to identify main themes [21]. The PI and two VC researchers developed and discussed a coding scheme based on the interview guide that included concepts from the HBM. Then as a research team discussed the best codes and achieved consensus. Next, the two VC community researchers independently hand-coded two interview transcripts. The academic Co-PI reviewed the coded transcripts and added variations to the codes. We discussed and clarified as a research team and achieved consensus on the best codes to improve consistency. The two VC researchers independently hand-coded the remaining interview transcripts, documented their reflections and impressions, maintained an audit trail, and met with the PI to discuss and clarify the coding. During this process, the two VC researchers and PI assigned codes representing Chinese, Vietnamese, Chuukese, and Marshallese (i.e., Chi, V, Chu, and Mar, respectively). Then, the two VC researchers sorted codes into potential themes, summarized findings, and discussed with the PI. As a research team, we discussed, clarified, and reached an agreement on the codes for all interview transcripts and, compared across transcripts and identified main themes.

Cultural insights influenced concurrent data collection and analysis and research team findings. Credibility was ensured throughout the interviews with frequent check-ins between the three researchers and participants and our research team debriefing on all interviews and review of the coded transcripts [22]. Our research team approach accommodated for interpretation variances and enhanced credibility. This allowed our research team to discuss and verify that the main themes were understood and aligned with the interviews. Interviewers' field notes of impressions from the interviews, including observations, provided additional depth of understanding. We used reflexivity throughout to address any potential personal biases [23].

Results

Description of Participants

There were 20 participants ($n = 5$ Chinese, $n = 5$ Vietnamese, $n = 5$ Chuukese, $n = 5$ Marshallese). The following were results for Asian participants. The average age was 52.6 years (range = 24–78). The average age was 34.6 years (range = 18–69) when immigrated to the USA. The average was 21.4 years (range = 4–39) having lived in the USA. Most reported ($n = 8$) being female and two being male. The following were results for MI participants. The average age was 41.9 years (range = 28–49). The average age was 22.9 years (range = 17–35) when immigrated to the USA. The average was 18.5 years (range = 1–29) having lived in the USA. Most reported ($n = 7$) being female, two being male, and one preferred not to disclose. See Table 1 for the full display of results.

Three Transcultural Main Themes

Degree of Knowing and Understanding Cancer Screening Versus Family Health History GCS

Although most Chinese, Vietnamese, Chuukese, and Marshallese participants knew the phrase “cancer screening” and understood its meaning, most did not know the term or understand what GCS is within the context of cancer screening. Mar M expressed not knowing what GCS is, “To me, genetic is some kind of a disease that gets into the blood. So it's like, it's like a sickness that affect you.” Although the researchers provided a definition of GCS following participants' responses, most participants still did not understand its meaning. Participants wanted to have more clarification as they were unsure whether there was a difference between the screenings. Of the few participants who know the term GCS, they were unable to describe it in depth. For example, as said by V J, “...I think the genetic like the family history to member to member. From the parent to the children.”

Needing Culturally Relevant Outreach Messaging on Family Health History GCS

Most Chinese and Vietnamese participants expressed that the content and translated postcard were acceptable but needed more clarity on the importance of cancer screening. The headline phrase, “You are worth the time,” seemed to be a confusing message. Participants recommended the important message about family health history GCS needs to be clearly stated and prominent on the postcard. “I think the phrase “you are worth the time”...can change because...

Table 1 Sociodemographic characteristics and background of the participants (N=20)

Sociodemographic characteristics and background	Asians (n=10)			Chinese (n=5)			Vietnamese (n=5)			Micronesian Islanders (n=10)			Chuukese (n=5)			Marshallese (n=5)		
	Average	Range	n	Average	Range	n	Average	Range	n	Average	Range	n	Average	Range	n	Average	Range	n
Age (years)	52.6	24–78	61	36–78	44.2	24–58	41.9	28–49	38	28–44	45.8	42–49	38	28–44	45.8	42–49	38	28–44
Age at immigration (years)	34.6 ^a	18–69	41.2	18–69	26.25 ^a	18–30	22.9	17–35	21.4	18–28	24.4	17–35	21.4	18–28	24.4	17–35	21.4	18–28
Years lived in the USA	21.4	4–39	19.8	4–39	23	11–29	18.5	1–29	15.6	1–22	21.4	8–29	15.6	1–22	21.4	8–29	15.6	1–22
	n	(% n=20)	n	(% n=10)	n	(% n=10)	n	(% N=20)	n	(% n=10)	n	(% n=10)	n	(% n=10)	n	(% n=10)	n	(% n=10)
Race/ethnicity																		
Chinese (Asians)	5	(25)	5	(50)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Vietnamese (Asians)	5	(25)	—	—	5	(50)	—	—	—	—	—	—	—	—	—	—	—	—
Chuukese (Micronesian Islanders)	—	—	—	—	—	—	5	(25)	—	—	—	—	—	—	—	—	—	—
Marshallese (Micronesian Islanders)	—	—	—	—	—	—	5	(25)	—	—	—	—	—	—	5	(50)	—	—
Gender																		
Female	8	(40)	4	(40)	4	(40)	7	(35)	4	(40)	3	(30)	4	(40)	3	(30)	4	(40)
Male	2	(10)	1	(10)	1	(10)	2	(10)	1	(10)	1	(10)	1	(10)	1	(10)	1	(10)
Prefer not to disclose	—	—	—	—	—	—	1	(0.05)	—	—	—	—	—	—	—	—	—	—
Relationship status																		
Single, have never been married	2	(10)	1	(10)	1	(10)	1	(0.05)	1	(10)	—	—	1	(10)	—	—	—	—
Currently married	6	(20)	2	(20)	4	(40)	8	(40)	3	(30)	4	(40)	3	(30)	4	(40)	3	(30)
Not married, living with a partner	—	—	—	—	—	—	1	(0.05)	—	—	—	—	—	—	—	—	—	—
Divorced	1	(0.05)	1	(10)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Widowed	1	(0.05)	1	(10)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Education																		
Some middle school	2	(10)	2	(20)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Some high school	—	—	—	—	—	—	6	(20)	—	—	—	—	—	—	—	—	—	—
Some college	1	(0.05)	—	—	1	(10)	2	(10)	—	—	—	—	—	—	—	—	—	—
Graduated from college	5	(25)	2	(20)	3	(30)	2	(10)	1	(10)	1	(10)	1	(10)	1	(10)	1	(10)
Graduate school	2	(10)	1	(10)	1	(10)	—	—	—	—	—	—	—	—	—	—	—	—
Total household income before taxes																		
Less than \$15,000	1	(0.05)	1	(10)	—	—	2	(10)	2	(20)	—	—	2	(20)	—	—	—	—
\$15,000–30,000	—	—	—	—	—	—	5	(25)	2	(20)	—	—	2	(20)	—	—	—	—
\$50,001–75,000	3	(15)	1	(10)	2	(20)	1	(0.05)	—	—	—	—	—	—	—	—	—	—
\$75,001–100,000	—	—	—	—	—	—	2	(10)	—	—	—	—	—	—	—	—	—	—
\$100,001–150,000	3	(15)	—	—	3	(30)	—	—	—	—	—	—	—	—	—	—	—	—
Not sure	3	(15)	3	(30)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Have health insurance																		
Yes	10	(50)	5	(50)	5	(50)	10	(50)	5	(50)	5	(50)	5	(50)	5	(50)	5	(50)

Table 1 (continued)

Sociodemographic characteristics and background	Asians (n = 10)		Chinese (n = 5)		Vietnamese (n = 5)		Micronesian Islanders (n = 10)		Chuukese (n = 5)		Marshallese (n = 5)	
	Average	Range	Average	Range	Average	Range	Average	Range	Average	Range	Average	Range
Have a regular place of care for non-emergent, healthcare services												
Yes	8	(40)	4	(40)	4	(40)	10	(50)	5	(50)	5	(50)
No	1	(0.05)	—	—	1	(10)	—	—	—	—	—	—
Declined to answer	1	(0.05)	1	(10)	—	—	—	—	—	—	—	—

^aOne Vietnamese participant reported being born in the USA

some people they would say what is that...It doesn't [have] mean[ing]...maybe [due to] the culture or something when...read this...[postcard], thinking...not related to health" (V G). The term family without context generated confusion for Chinese participants. Chi B, "How do you define family? Like my grandma, my nephew, niece, like that how big this family tree is...The Chinese family tree can be huge." Some MI participants talked about how the translated postcard version would hinder them from talking to their family and HCP. Chu S asked, "Why I need to know? What can knowing help me with? I would need to understand why it is important to know." Mar O described that the postcard did not clearly convey that it is about cancer. "When I look at the paper [postcard], I do not see that it is about cancer. It is not until I read it that I realize it is about cancer.

Chinese, Vietnamese, Chuukese, and Marshallese participants described varied understanding of the silhouette images and what they represent. Chi A stated, "Mother, Daughter, Father, Son... Family and not just women's thing." Chu L described the heart in addition, "Family Love. Mom and daughter. Even if you have cancer you are still beautiful. Positive-Loving-Family." Mar N expressed concern that the "Image [is] incomplete, what about dad or family..." V I described, "I like the postcard...looks like a family. But when I think of a family it three, more than two. It looks like there is an older generation and a younger generation. So it means a lot, like what we screening can help the younger generation as well (V I). Some MI participants did not connect with the images. Chu T stated, "Image doesn't represent me. Something that makes it look more like it belongs to me or my people." Some MI participants expressed confusion. "Does not look like a flyer [postcard] for cancer screening" (Mar R). "Looks like a birthday party flyer" (Chu K), or "... why there is an image of a balloon" (Mar Q).

Chinese and Vietnamese participants described the color palette as either standing out or needing to stand out more and concerns about how it might not capture attention. "I don't like the...color background...I don't pay much attention...It don't catch my eye at all" (V G). "Somewhere needs to be seen right away" (V I). Chuukese and Marshallese participants described how the postcard color palette evoked certain feelings or perceptions. Chu L described it as, "Colorful, loving, nice to look at. Blue and Brown represents moods during cancer." Whereas Chu P described it as, "Color is distracting, too dark, make me feel sad. Don't want to look and forget about it." Chu S expressed prior experience with racism and asked, "Why brown? Here in America I get call Brown. Is it brown because I am brown?"

Most Chinese, Vietnamese, Chuukese, and Marshallese participants did not notice the Web site url on the postcard until the researcher brought it to their attention. "It [website url] just didn't stand out much" (Chi E). The phrase "Learn more" above the Web site url seemed to be confusing. Mar

M and Mar N described that the wording in the postcard made it unclear about going to the website to get more information. Two Vietnamese participants and one Chuukese participant said that they would want to read more information on the website due to their searching for things online and reading. “I would go in...I can look for more information because I’m curious...why are they asking about family cancer or something. Maybe I can see some information I don’t know from the website” (V G).

Communication and Decision-Making Regarding Discussing with Family and HCPs About Cancer Screening and Family Health History GCS

Most Chinese, Vietnamese, Chuukese, and Marshallese participants talked about concerns regarding cost or having healthcare insurance as an issue to being able to obtain a GCS. Although most participants showed interest in learning more about family health history GCS, of which some wanted to do the family health history GCS and GCS, there were a range of responses regarding communication and decision-making. Some did not want to talk to anyone about cancer and screening or family health history GCS; others would not talk to family but would talk to a HCP; or some would talk to both their family and HCP. Most participants were concerned that talking about cancer was not their cultural way or “Island” way.

Asian participants, in particular Vietnamese, described a culture of shame regarding cancer. V H talked about a family member, “My father when he was alive, a few years ago he never said he had cancer or...he told me don’t tell anyone that I carry something similar to cancer.” V I described overall experiences in working with community members, “When they have family members who has cancer, some just try to hide it because they don’t want people around to know that there is a family member having cancer.” There seems to be a concern that if people are not willing to talk about their personal or family health concerns, then the postcard may not adequately capture their attention or prompt people to action. As described by V H who works with Vietnamese community members, “If they don’t want to talk about their own problems or family’s problems, they can stop from the beginning while look[ing] at this flyer [post card].” Another person described how family members may not share personal health information, including talking about family history or cancer screening, “...I have some of my friends... [example] she not able to share something with her mother... conversation not open” (V G).

Among Chinese and Vietnamese participants, some expressed that if no one in the family has cancer, then they likely will not discuss it with a HCP about cancer. Some Chinese and Vietnamese participants described the challenges of obtaining a full family cancer health history from

family members who do not live close by, including overseas, and not being ready to talk about their health. Most Chinese and Vietnamese participants either know of a family or friend who has cancer or participants themselves (two) are cancer survivors and described how they would talk about family health history GCS with their family and a HCP after reading the postcard. Chi E described caring for and talking to a family member who has cancer that prompted making an appointment with a HCP. “No[t] specifically about GCS thing [during a visit with a HCP]...I...talk to my provider because my dad has stomach cancer, and then sometimes I have stomach issues too, so I do talk more specific...made me nervous too...”.

MI participants described how difficult it is to talk to the family and community members about cancer because it is a sad subject or because they feel bad about it. It is MI cultural practices not to discuss such topics, and this also included some MI participants who had family members diagnosed with cancer. As stated by Mar R, “Because of culture we cannot just ask [family]. It has to come out of conversation[s] and we do not talk about it in that way [referring to the postcard].” Chu P said, “Sometimes we do not talk about these things. It is our way [referring to Islander way].” Another participant described the specific location of the body being a concern, “Would not discuss a specific type of cancer due to the location on the body – Breast” (Chu K). Two participants described having a fear of talking about cancer. “We don’t talk about these things because they are scary” (Chu S). Some participants, in particular Marshallese, expected the information to come directly from a HCP or from another person who knows about family health history GCS but not from a postcard. “Only if provider started conversation—no postcard. If doctor ask and gave good explanation (Mar Q).” Mar O, “...I would not even talk about it. I would...do research myself, but I would not bring up the subject. It would be up to someone to talk about it.”

Discussion

Engagement of Asian and MI community leaders and community members helped to advance understanding on GCS outreach, including the family health history GCS postcard outreach—a public facing educational material. Our findings align with previous research in which Asians and MI face multiple barriers to screening, including language barriers, lower health literacy, differences in the definition of a family, and financial concerns. Language barriers have led participants to not be able to discern general family cancer screening from assessing inherited risk using GCS [2, 4, 5, 8]. Lee et al. [3] found that among immigrant Asian subgroups, lower health literacy affects health outcomes. In previous research with Pacific Islanders including MI,

researchers reported the need to clarify kinship as family extends to blood or not blood related [5, 8]. In our study, participants did report that the family health history GCS postcard reflected multigenerational importance, yet it was missing the fullness of what is meant by family with the absence of male images on the postcard. The cost of GCS was also raised by participants, an economic stability component of social determinants of health [24]. Financial barriers are a deterrent to GCS [25], and insurance status is associated with referral for genetic screening [1] and is a relevant issue of access raised in our study. Advances in genetic and genomic screening pose the risk of perpetuating cancer susceptibility screening disparities unless systemic education and access inequities are addressed.

Closing the knowledge gap in both cancer screening and GCS is foundational to improving health outcomes; however, educational outreach interventions must pay critical attention to the cultural context and meaning of cancer among Asians and MI. When we asked about whether or not the family health history GCS postcard would encourage discussions with their HCP and/or family members, Chinese, Vietnamese, Chuukese, and Marshallese participants had the most challenges with their family and community cultural influences. In addition, participants have their own differences in how their family and community influenced the discussion surrounding cancer and cancer screening. Our findings underscore that the GCS postcard as a public health education outreach does not consider the complexity of cultural communication with cancer-related topics such as GCS in Asian and MI subgroups. Our cultural contextual findings add to the literature. We found that Chinese and Vietnamese participants had a sense of shame and desire to hide a diagnosis of cancer from family and friends. This is similar to Hann et al. [2] findings. However, we found a few Chinese participants would talk to both family members and a HCP if they cared for a family member who has cancer. This prompted them to make an appointment with a HCP. Our findings support that it is not Chuukese and Marshallese cultural practices or the “Island” way to talk about cancer related topics with family and community members even for those participants who had family members who were diagnosed with cancer. Blocker et al. [5] found privacy is important to the Marshallese community. Emotional expressions of sadness and fear seemed to also deter discussions about such topics. Kim’s [26] report sheds light regarding how Chuukese women are essential in decision making and maintain harmony within social family structures such as respect between a sister and a brother through silence. Kim [26] described having talked with an elder who explained, “that women’s silence has nothing to do with gendered inferiority or superiority. Rather, the aim is to maintain harmony within social family structures, often through reciprocal gestures of respect between a brother and a sister that are often

misunderstood by some Chuukese Islanders and foreign visitors (pp. 149–150).” In a systematic review, McElfish et al. [8] discussed about the importance of honoring the practices of Pacific Islander cultures, and this includes separating activities by sex due to the sensitivity of such topics. Furthermore, having a team member collecting the sensitive data information to be the same sex as the participant or patient would be culturally responsive. Researchers and HCPs need to be cognizant about the Micronesian culture and to facilitate communication spaces while considering the emotional impact of sadness and fear.

Previous researchers found that Chuukese in Hawai’i sought health information from their medical providers, then family and friends, and then from the Internet [27]. We found Marshallese in particular prefer to talk with a HCP. Some reasons for this include having expectations that a HCP would have the knowledge about family health history GCS, be able to discuss this directly with them, and initiate the discussion if they think it is necessary to do so. Another possible explanation is that MI participants are residents from an area where there have been prior public health education outreach efforts on other topics, and they were recruited from a MI-based community organization. Our findings differ from other researchers. Cassel et al. [27] study with Marshallese and Chuukese in Hawai’i on information-seeking practices and cancer screening found that Marshallese and Chuukese were more than twice as likely to trust health information from their religious leaders rather than from their own HCP (physicians), although a HCP were among the first to be consulted regarding health information. Blocker et al. [5] previously found that Marshallese patients would withhold personal and family health information from a HCP who had not yet earned the patient’s trust. In the larger Pacific Islander group, researchers found the sharing of health-related information in family groups, get-togethers, or in a community, particularly by mother and daughter family members [7]. When working with Asians and MI subgroups, it is important for researchers and HCPs to understand the local community context, including prior outreach efforts, and consider the multiple levels of influences on obtaining and processing health information.

Understanding the challenges of not having a cultural way to communicate about cancer as well as the perceived stigma, taboos, and shame of cancer are critical. Our findings underscore the importance of cultural context and can be used to enhance culturally sensitive cancer education in public health education outreach efforts. Cultural context must be considered in intervention design to engage with diverse communities rather than a generic message. In summary, we found cultural context includes consideration of language barriers; lower health literacy; differences in the definition of a family; perceived stigma, taboos, and shame of cancer; and family and community cultural influences.

The Chinese, Vietnamese, Chuukese, and Marshallese participants in our study did not specifically mention trust issues as a barrier. Giralli et al. [15] study with Chinese and Vietnamese suggest that the mere act of interacting with people who are strangers was the source of suspicion and mistrust for participation in research. In our study, both a White non-Latinx academic Co-PI and a VC community researcher co-conducted four interviews with Chinese and Vietnamese participants. We learned in the field that although these four participants could speak in their respective native and English language, they chose to mostly respond to the interview questions first in their respective language with the VC community researcher with whom they trust and know, and then shared what they felt comfortable with the academic Co-PI. The community Co-PI is known as the Executive Director of the Micronesian Islander Community organization, who is a community leader of a trusted organization known for community-engaged research and programming. This can help in part explain why participants in our study did not discuss trust issues in their responses. Community partners serve as gatekeepers, advocates, and health educators in their communities [8]. Prior researchers reported strategies on building trust or overcoming mistrust such as researchers and HCPs engaging with community leaders and community members throughout the research process, including addressing priorities identified by community leaders and community members; co-developing agreements on how partners would like to learn and work together; co-developing and co-implementing the study or program purpose and procedures; sharing to the communities about learned information; and community partners having the time to assess the intentions of the researchers [5, 6, 8, 28–30]. Our findings suggest that current public health education outreach efforts may be impacted even with the best of intentions designed to promote understanding, education, and action due in part to generic messaging. In addition, the written text needed to convey a stronger sense of the importance of screening and use of more culturally relevant language.

We recommend next steps need to further involve community partners as stakeholders in research and programming. Researchers reported successful engagement efforts, including across sectors such as academia, community-based organizations, and community clinics [5, 6, 8, 13, 16, 25, 26, 28–30]. Researchers and HCPs doing community outreach with Asian and MI subgroups need to address community beliefs and behaviors as priorities under the umbrella efforts to help people understand the difference between general and inherited cancer screening. If there is a fundamental perception of shame and secrecy around disclosure, efforts to expand familial conversations of cancer risk will need to be addressed in community outreach. A strength in our qualitative description pilot study is the academic and community-engaged research approach to advance understanding on community education outreach

regarding family health history GCS. Engaging with community partners as stakeholders early in the research design planning can help to amplify their voices throughout the research process [31–33]. In our study, we worked together as academic and community partners and developed the study purpose; outreach and recruitment approach; semi-structured, open-ended interview guide; engaged in concurrent data analysis and interpretation; debriefing; and wrote this article. We recommend researchers and HCPs to authentically engage with community partners early in cancer education research and programming, build a trusting partnership with a shared mission, and co-learn from one another and gain *entrée* and extend further reach in Asian communities and MI communities. We also recommend devoting sufficient time and financial resources to engage with more community partners and expand upon this work with more groups to deepen understanding across cultures. These can help to facilitate community driven public health education outreach efforts in family health history GCS.

Conclusions

Because cancer continues to carry significant stigma, taboos, and shame, culturally sensitive outreach, resources, and education are critical in advancing the discussion about cancer prevention among Asians and MI. Culturally relevant social outreach that engages specific groups with simple language, conveys the importance of screening clearly, acknowledges cultural differences in the definition of family, and promotes meaningful discussions rather than vague ones is needed. Communities will need to consider addressing access inequities, insufficient health care coverage, and limited healthcare resources to promote affordability and access to screening. HCPs need to initiate the discussion on the importance of a family health history to identify those in need of additional screening or surveillance as some may not offer such information. Recognition of the challenges and strengths in the cultural context and family dynamics are important. Clients may not be able to provide a complete family health history and may have a more inclusive definition for a family that can impact risk assessments. Cancer education efforts should consider family participation with the client's permission in the decision-making process given that family often shape cultural values and influence healthcare decisions in collective cultures.

Appendix. Semi-structured, open-ended interview guide includes probing and follow-up questions and a figure of the family health history genetic cancer screening postcard

Introductory Script: Interviewer is a Researcher

“Hello, my name is _____, and I am a team member working on this project who will be interviewing you. (Alternatively: “Hello, my name is _____, and I am assisting with the interviews for this project.”) Thank you very much for your time.”

[If another team member obtained consent besides the Interviewer] “I would like to confirm, you have received information on this study and are agreeing to participate, correct?”

This interview will take about 30 min and to get complete information, the conversation is being recorded. You can take a break or stop the interview if you do not want to continue for any reason. You can skip any question that you are uncomfortable in answering.

Please let me know what questions you might have about anything, and I will try to explain more clearly. There are no right or wrong answers. We want your opinions about this postcard to make it most helpful reaching out to people in our communities. We will ask general questions as well while focusing on the postcard.

“Please let me know what questions you have before we begin.”

[Researcher to provide a participant with time to describe. If the participant expresses not knowing or not understanding the phrase, then to read the following description. Per Centers for Disease Control and Prevention: Cancer screening means checking for cancer before there are signs and symptoms of the disease or used to find the disease.]

3. Can you please describe what the phrase ‘genetic cancer screening’ means to you?

[Researcher to provide a participant with time to describe. If the participant expresses not knowing or not understanding the phrase, then to read the following description. Per Centers for Disease Control and Prevention: Genetic testing looks for changes in your DNA that can inform your medical care. For example, can provide information about your risk to develop cancer.]

4. In general, would you be interested in learning more about what a ‘family health cancer history’ means for you personally?
5. Can you describe any concerns or what might get in the way (susceptibility, barriers)?
6. What might help you to become interested in learning about your personal health cancer history (facilitators – benefits)?

[Researcher shows the postcard from the Oregon Health Authority to elicit participants’ thoughts and recommendations.]

Begin the Interview

1. Can you please describe what the phrase ‘a family cancer health history’ means to you?

[Per Oregon Health Authority, the state of Oregon Medicaid Agency: Family health history is a written or graphic record of the diseases and health conditions present in your family. Family health history is a useful tool for understanding health risks and preventing disease in individuals and their close relatives.]

2. Can you please describe what the phrase ‘cancer screening’ means to you?



Let us look at the postcard. This is a postcard designed by and from the Oregon Health Authority, the State of Oregon Medicaid Agency, that will be used to outreach to people in the communities about family health history genetic cancer screening.

1. Can you describe what you think of the overall appearance of the postcard? (*images [graphics] or way it is designed*) (*Follow-up: Please tell me more about...*)
 - a. Is there anything that you notice about the appearance that gets in the way (barriers) of learning about family cancer health history or this cancer screening—genetic?
 - i. Is there anything that you notice about the appearance that gets in the way (barriers) of talking about this cancer screening—genetic with your family/family member?
 - ii.or with your healthcare provider?
2. Can you describe what you think of the message or content of the postcard? (*the questions or phrases*) (*Follow-up: Please tell me more about...*)
 - a. Is there anything that you notice about the message or content that gets in the way (barriers) of getting this cancer screening—genetic for yourself if you are able to?
 - b. Is there anything you notice about the message or content that gets in the way (barriers) of talking about cancer health history and this cancer screening—genetic with your family/family member?
 - c. ...or a healthcare provider?
3. Would you consider getting a cancer health history and this cancer screening—genetic?
 - a. Does this postcard help you to go visit the website listed on the postcard to learn more about family cancer health history or this cancer screening—genetic (facilitators—benefits)? Please explain.
 - b. Can you describe any concerns or what might get in the way (susceptibility, barriers)?
4. Have you ever considered talking to your **family/family member** about *cancer health history*?
 - a. In general, would this postcard help or encourage you to consider talking to your **family/family member** about cancer health in your family (facilitators—benefits)? Please explain.
 - i. Can you describe any concerns or what might get in the way (susceptibility, barriers)?
 - b. What might help you to talk to your **family/family member** about a *cancer health history* (facilitators—benefits)?
5. Have you ever considered talking to your **healthcare provider** about your *cancer health history or this cancer screening—genetic*?
 - a. In general, would this postcard help or encourage you to consider talking to your **healthcare provider** about cancer health in your family or this cancer screening—genetic? Please explain.
 - i. Can you describe any concerns or what might get in the way (susceptibility, barriers) of talking to your **healthcare provider** about cancer health in your family or this cancer screening—genetic?
 - b. What might help you talk to a **healthcare provider** about your *cancer health history or this cancer screening—genetic* (facilitators—benefits)?
 - c. What would you like to do (prefer) if your **healthcare provider** recommended conducting a *genetic cancer screening*?
 - i. Can you describe any concerns or what might get in the way (susceptibility, barriers) of your obtaining a genetic cancer

- screening (test)?
- ii. What might help you to consider this option if it was recommended (facilitators–benefits)?

At the End of the Interview:

We are finished with our questions but are there other things you might suggest that we talk about for the postcard that we have not asked?

We are completed with the interview, and I will turn off the recorder now. Thank you very much for sharing and for your time. We value your contributions.

Acknowledgements The authors are appreciative of the Centers for Disease Control and Prevention [# 1NU58DP006701-01-00] that funded in part the study. The authors thank the ScreenWise Program Access Coordinator Paulina Almaraz, MPH, and the ScreenWise Program Genetics Coordinator Summer Lee Cox, MPH, at the Oregon Health Authority Public Health Division for their review of the study design. The authors thank Dr. Kandy S. Robertson, PhD, Scholarly Professor, Program Leader in English, and Writing Center Coordinator at Washington State University Vancouver, for editing assistance. The authors are also appreciative of the anonymous peer reviewers for assistance.

References

1. Manriquez E, Chapman JS, Mak J, Blanco AM, Chen L-M (2018) Disparities in genetics assessment for women with ovarian cancer: Can we do better? *Gynecol Oncol*. <https://doi.org/10.1016/j.ygyno.2017.10.034>
2. Hann KEJ, Freeman M, Fraser L, Waller J, Sanderson SC, Rahman B, Side L, Gessier 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* <https://doi.org/10.1186/s12889-017-4375-8>
3. Lee HY, Rhee TG, Kim NK, Ahluwalia JS (2015) Health literacy as a social determinant of health in Asian American immigrants Findings from a population-based survey in California. *J Gen Intern Med*. <https://doi.org/10.1007/s11606-015-3217-6>
4. Joseph G, Pasick RJ, Schillinger D, Luce J, Guerra C, Cheng JKY (2017) Information mismatch: Cancer risk counseling with diverse underserved patients. *J Genet Couns*. <https://doi.org/10.1007/s10897-017-0089-4>
5. Blocker K, Hallford HG, McElfish P, Danylchuk NR, Dean LW (2020) Eliciting culturally and medically informative family health histories from Marshallese patients living in the United States. *J Genet Couns* 29(3):440–450
6. Nguyen-Truong, CKY, Pedhiwala, N, Nguyen, V, Le, C, Le, TV, Lau, C, Lee, J, Lee-Lin, F (2017) Feasibility of a multi-component breast health education intervention for Vietnamese American immigrant women. *Oncol Nurs Forum*. <https://doi.org/10.1188/17.ONF.615-625>
7. Pokharel M, Elrick A, Canary HE, Clayton MF, Sukovic M, Champagne M, Hong SJ, Kaphingst KA (2020) Health communication roles in Latino, Pacific Islander, and Caucasian Families: A qualitative investigation. *J Genet Couns*. <https://doi.org/10.1002/jgc4.1177>
8. McElfish PA, Yeary K, Sinclair IA, Steelman S, Esquivel MK, Aitaoto N, Kaholokula K, Purvis RS, Ayers BL (2019) Best practices for community-engaged research with Pacific Islander communities in the US and USAPI: A scoping review. *J Health Care Poor Underserved*. <https://doi.org/10.1353/hpu.2019.0101>
9. Barker HM (2012) Bravo for the Marshallese: Regaining control in a post-nuclear, post-colonial world. Wadsworth Cengage Learning, California
10. Nguyen-Truong, CKY, Leung, J, Micky, K (2020) Development of a culturally specific leadership curriculum through community-based participatory research and popular education. *Asian Pac Isl Nurs J*. <https://doi.org/10.31372/20200502.1086>
11. Simon SL, Bouville A, Land CE, Beck HL (2010) Radiation doses and cancer risks in the Marshall Islands associated with exposure to radioactive fallout from Bikini and Enewetak nuclear weapons tests: Summary. *Health Phys*. <https://doi.org/10.1097/HP.0b013e3181dc523c>
12. Van Dyne EA, Saraiya M, White A, Novinson D, Senkomago V, Buenconsejo-Lum L (2020) Cancer mortality in the US-Affiliated Pacific Islands, 2008–2013. *Hawai'i J Health Soc Welf*. 79(6 Suppl 2):99–107
13. Aitaoto N, Braun KL, Estrella J, Epeluk A, Tsark JoAnn (2012) Design and results of a culturally tailored cancer outreach project by and for Micronesian women. *Prev Chronic Dis*. <https://doi.org/10.5888/pcd9.100262>
14. Alexander J, Kwon HT, Strecher R, Bartholomew J (2013) Multi-cultural media outreach: Increasing cancer information coverage in minority communities. *J Cancer Educ* 28:744–747
15. Giarelli E, Bruner DW, Nguyen E, Basham S, Marathe P, Dao D, Huynh TN, Cappella J, Nguyen G (2011) Research participation among Asian American women at risk for cervical cancer: Exploratory pilot of barriers and enhancers. *J Immigr Minor Health*. <https://doi.org/10.1007/s10903-011-9461-x>
16. Chao SZ, Lai NB, Tse MM, Ho RJ, Kong JP, Matthews BR, Miller BL, Rosen HJ (2011) Recruitment of Chinese American elders into dementia research: The UCSF ADRC experience. *Gerontologist*. <https://doi.org/10.1093/geront/gnr033>
17. George S, Duran N, Norris K (2014) A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. <https://doi.org/10.2105/AJPH.2013.301706>
18. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D (2010) More than Tuskegee: Understanding mistrust about research participation. *J Health Care Poor Underserved*. <https://doi.org/10.1353/hpu.0.0323>
19. Champion VL, Skinner CS (2008) The health belief model. In: Glanz K, Rimer BK, Viswanath K (eds) *Health behavior and health education: Theory, research, and practice*. Jossey-Bass, California, pp 45–65
20. Hennink MM, Kaiser BN, Marconi VC (2017) Code saturation versus meaning saturation: How many interviews are enough? *Qual Health Res*. <https://doi.org/10.1177/1049732316665344>
21. Hsieh H-F, Shannon SE (2005) Three approaches to qualitative content analysis. *Qual Res*. <https://doi.org/10.1177/1049732305276687>
22. Lincoln YS, Guba EG (1985) Establishing trustworthiness. In: Lincoln YS, Guba EG (eds) *Naturalistic Inquiry*. Sage, CA, pp. 289–331
23. Rae J, Green B (2016) Portraying reflexivity in health services research. *Qual Health Res*. <https://doi.org/10.1177/1049732316634046>

24. HealthyPeople.gov (2020) Social determinants of health. <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>. Accessed 5 December 2020
25. Miguel-Majors S, Sandra L, Whitaker DE, Davis BC, Bailey LO, Springfield SA (2020) Education on cancer risk assessment and genetic counseling to address cancer health disparities among racial/ethnic groups and rural populations: Implementing culturally tailored outreach through community health educators. *J Genet Couns*. <https://doi.org/10.1002/jgc4.1272>
26. Kim MM (2020) Nesor anim, niteikapar (good morning, cardinal honeyeater): Indigenous reflections on Micronesian women and the environment. *Contemp Pac*. <https://doi.org/10.1353/cp.2020.0007>
27. Cassel K, Willingham M, Lee H-R, Somera LP, Badowski G, Pagano I (2020) Acculturation and cancer risk behaviors among Pacific Islanders in Hawaii. *Ethn Dis*. <https://doi.org/10.18865/ed.30.4.593>
28. Nguyen-Truong, CKY, Hassouneh, D, Lee-Lin, F, Hsiao, C, Le, TV, Tang, J, Vu, M, Truong, AM (2018) Health care providers' perspectives on barriers and facilitators to cervical cancer screening in Vietnamese American women. *J Transcult Nurs*. <https://doi.org/10.1177/1043659617745135>
29. Nguyen-Truong, CKY, Leung, J, Micky, K, Nevers, JI (2020) Building safe didactic dialogues for action model: Mobilizing community with Micronesian Islanders. *Asian Pac Isl Nurs J*. <https://doi.org/10.31372/20200501.1066>
30. Saw A, Stewart SL, Cummins SE, Kohatsu ND, Tong EK (2018) Outreach to California Medicaid smokers for Asian language quit line services. *Am J Prev Med*. <https://doi.org/10.1016/j.amepre.2018.08.008>
31. Billan J, Starblanket D, Anderson S, Legare M, Hagel MC, Oakes N, Jardine M, Boehme G, Dubois E, Spencer O, Hotomani M, McKenna B, Bourassa C (2020) Ethical research engagement with Indigenous communities. *J Rehabil Assist Technol Eng*. <https://doi.org/10.1177/2055668320922706>
32. Dill LJ, Gousse Y, Huggins K, Fraser MA, Browne RC, Stewart M, Salifu M, Joseph MA, Wilson TE (2020) Adjourment in community HIV prevention: Exploring transitions in community-academic partnerships. *Health Promot Pract*. <https://doi.org/10.1177/1524839919839361>
33. Hoekstra F, Mrklas KJ, Khan M, McKay RC, Vis-Dunbar M, Sibley KM, Nguyen T, Graham D (2020) A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: A first step in synthesising the research partnership literature. *Health Res Policy Sys*. <https://doi.org/10.1186/s12961-020-0544-9>

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