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Opportunities and Challenges in Precision Medicine: Improving Cancer Prevention and Treatment for Asian Americans

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Abstract

Cancer is the leading cause of death among Asian Americans, and cancer cases among Asian Americans, Pacific Islanders, and Native Americans are expected to rise by 132% by 2050. Yet little is known about biologic and environmental factors that contribute to these higher rates of disease in this population. Precision medicine has the potential to contribute to a more comprehensive understanding of morbidity and mortality trends among Asian American subgroups and to reduce cancer-related health disparities by recognizing patients as individuals with unique genetic, environmental, and lifestyle characteristics; identifying ways in which these differences impact cancer expression; and developing tailored disease prevention and clinical treatment strategies to address them. Yet substantial barriers to the recruitment and retention of Asian Americans in cancer research persist, threatening the success of precision medicine research in addressing these knowledge gaps. This commentary outlines the major challenges to recruiting and retaining Asian Americans in cancer trials, suggests ways of surmounting them, and offers recommendations to ensure that personalized medicine becomes a reality for all Americans.

Keywords

cancer; Asian Americans; precision medicine; minority health; patient participation

Introduction

The global cancer burden is estimated to rise from 14 million new cases in 2012 to 24 million in 2035.[1] Existing data demonstrate population-based disparities in cancer prevalence and survival rates that will expand as cancer cases increase.[2] In the United States (US), 31% increase in cancer incidence by 2050 is anticipated for whites, as

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compared to a 99% or more increase in cancer cases among ethnic and racial minority groups, including American Indian/Alaska natives, African Americans, Latino/Hispanics, Asian Americans, Native Hawaiians, and Pacific Islanders. [3] Currently, among Asian Americans, Native Hawaiians, and Pacific Islanders, cancer is the leading cause of mortality, accounting for 27% of deaths [4]; and by 2050, cancer cases are expected to rise by 132%. [5]

Precision medicine has the potential to reduce these disparities. By recognizing patients as individuals with unique genetic, environmental, and lifestyle characteristics, precision medicine research aims to identify ways in which these differences impact cancer expression, and to develop tailored disease prevention and clinical treatment strategies.[6] The federal allocation of $215 million to the Precision Medicine Initiative (PMI) signals a national commitment to this emerging area. The PMI will support innovative, patient-centered studies that explore individual variability in cancer expression, develop creative approaches to addressing variability, and rigorously test new strategies for controlling cancer. [7] The initiative's discoveries may ultimately impact public health and clinical practice for a broad range of chronic diseases.

Importantly, the PMI will recruit and retain a research cohort of one million Americans,[8] offering an unprecedented opportunity to expand and diversify clinical trials to include individuals from a broad range of geographic regions, ethnic backgrounds, and lifestyles. [9] As such, not only may the PMI impact clinical cancer treatment by defining and targeting molecular mechanisms of disease, but also help to define effective public health strategies for high-risk populations. [2] In order to realize this promise, however, clinicians, researchers, and public health practitioners must work together to ensure that the recruitment and retention of a diverse million-person cohort is a success. Traditionally, US clinical trial participation has been dominated by whites; furthermore, populations with lower educational attainment and lower socioeconomic status (SES) have been under-represented. [9] As a result, new medicines and technologies that result from these trials may not meet the needs of many Americans. By contrast, the PMI challenges the research community to look beyond a "one size fits all" approach to cancer treatment and prevention, in order to provide the right service at the right time to the right people. [10]

This commentary will describe cancer among Asian Americans, share key findings that suggest deeper inquiry into sociodemographic, cultural, and biologic factors that impact cancer cases among various Asian American subgroups is needed, describe the challenges of recruiting and retaining Asian Americans in scientific research, and suggest ways of surmounting them. The objective is to contribute to the literature informing recruitment and retention of a sufficiently diverse cohort to ensure the PMI's success.

Diversity of the Asian American population

Asian Americans comprise 5.6% of the U.S. population (14 million people), and are the fastest growing racial/ethnic minority group, expected to rise to 38 million people in 2050. [11] The term "Asian American" encompasses a diverse mix of people, including East Asians (e.g., Chinese, Japanese, Korean), Asian Indians (e.g., Bangladeshi, Indian, Pakistani), and Southeast Asians (e.g., Filipinos, Cambodians, Thai, Vietnamese). These groups have distinct genetic traits, environmental exposures, and cultural histories that differentially impact their cancer risk profiles and the epidemiology of cancer expression. Cancer is the leading cause of death for most Asian American adults 25–64 years of age, [12] and for some types of cancers, Asian Americans have the lowest screening rates and the highest proportion of late-stage diagnoses. [13]

Over 60 nationalities that speak over 100 languages may be grouped into one US Census category ("Asian American/Pacific Islander"), masking marked differences in demographic characteristics that are known to be associated with cancer risk factors. For example, low English proficiency (LEP), which is defined as the inability to speak, read, write, or understand English "very well," impacts only 10% of Filipino Americans, but affects 45% of Vietnamese Americans.[14] Poverty rates among Asian American subgroups are similarly disparate. While Japanese Americans have the same 6.6% poverty rate that has been documented among whites, the poverty rate among Southeast Asians is 66.6%. [13] Stark differences in household income, educational attainment, and language ability have also been documented within subgroups. For instance, South Asians -- a diverse subgroup that includes Indians, Pakistanis, Bangladeshis, Sri Lankans, Nepalis, and Bhutanese -- have a median household income of $72,000/year, substantially higher than the US average of $53,000/year. Yet, within that group, Bangladeshi Americans have a median income of only $46,950/year, while Indian Americans have a median income of $95,000. [15]

Factors impacting cancer disparities among Asian Americans

Sociodemographic factors

Poverty, low educational attainment, and LEP are linked to health disparities among racial/ethnic minority groups, in general. [16] Higher cancer mortality rates among immigrant groups, including Asian Americans, have been attributed more specifically to a lack of access to health care, lack of cancer education and awareness, and institutional barriers associated with LEP, low SES, and cultural beliefs that may be at odds with public health messaging about cancer prevention and treatment. [17] For example, research has shown that some Asian Americans believe cancer is a punishment for immoral behavior [17]; and studies have demonstrated that individuals of Asian American descent may resist prioritizing cancer screening and treatment because they viewed their personal well-being as less important than their families' welfare. [5] Furthermore, among some Asian American groups, fatalistic views about health in general – and cancer diagnoses in particular - may conflict with public education campaigns or even provider advice to screen for infectious origin. [18]

This is particularly concerning because Asian Americans experience proportionally more cancers of infectious origin than other racial/ethnic groups, including human papillomavirus (HPV)-induced cervical cancer, hepatitis B virus (HBV)-induced liver cancer, and stomach cancer. [11, 19] The screening programs that have significantly improved detection and treatment of these cancers among the general US population remain underused by Asian American groups due to a lack of linguistically- and culturally-tailored programming for Asian Americans. As a result, Asian Americans have the lowest rates of Pap smear/cervical cancer screening (68%) as well as endoscopy/stomach cancer screening (19%) of any US ethnic/racial group [18] Acknowledging and addressing differences in Asian American care-seeking practices and health beliefs through tailored messaging and education, along with increasing access to preventive care among Asian Americans through the development of linguistically-appropriate, conveniently-located, and affordable services, is imperative to improving these rates.

Biologic factors

Biologic factors also contribute to differences in cancer rates among Asian American subgroups, and between Asian Americans and other racial/ethnic minority groups. Identifying Asian Americans by known genetic differences, and targeting cancer prevention strategies and treatments toward their profiles could vastly improve outcomes. For example, a unique loss-of-function point mutation in aldehyde hydrogenase 2 (ALDH2), referred to as ALDH2*2, affects 560 million people of East Asian descent globally. [20] Studies suggest that ALDH2*2 reduces the ability of ALDH2 to catalyze the oxidation of toxic cellular aldehydes, contributing to an increased risk of oral cancer and gastrointestinal cancer, among other illnesses. Moreover, the presence of ALDH2*2 may compromise the effectiveness of certain medications. Examples include nitroglycerin, which may be less effective in reducing vasodilation among individuals with ALDH2*2 experiencing acute myocardial infarction, and acetaminophen, which may be detrimental to preserving tissue following ischemic injury among patients with ALDH2*2. Thus, screening individuals of East Asian descent for ALDH2*2 using either a simple two-question screener or a rapid genotyping test could help health care providers to develop both personalized preventive care plans as well as treatment plans for their patients who test positive for the mutation. Additional research into the activation of ALDH2*2, leading to treatments based on this genotype, could substantially improve clinical care and cancer outcomes for Asian Americans.

As another example, studies of lung cancer have identified the higher incidence of activated epidermal growth factor receptor mutations among Chinese patients as compared to other groups. [2] This higher incidence may contribute to the higher rates of lung cancer seen in China as compared to the US, particularly among non-smokers and women; it may also explain why Chinese Americans experience the highest lung cancer mortality rate of all Asian American subgroups, despite having lower incidence rates than other groups. However, a lack of sufficiently powered studies has precluded researchers from suggesting how best to test for these mutations and tailor clinical care for Chinese American patients that manifest them. Precision medicine has the opportunity to correct this imbalance by including Asian Americans in studies that aim to identify, understand, and target disease-modifying molecular mutations, as a critical step toward developing therapies for resistant subpopulations of tumors. [10]

Barriers to Asian American Participation in Cancer Research

Despite the passage of the federal Revitalization Act in 1993 to ensure that federally funded clinical research prioritized the inclusion of racial/ethnic minorities and women, less than 2% of 10,000 federally funded cancer clinical trials since that year have met the federal government's own guidelines for diversification of participant cohorts in cancer research.[21] Cancer clinical trials have rarely included sufficient numbers of Asian Americans or other racial/ethnic minority populations to allow scientists to develop a complete picture of the biologic, sociodemographic, and environmental factors influencing cancer expression.[9] For instance, the Multi-ethnic Cohort Study for cancer included only Japanese Americans, excluding all other Asian American groups, and thus limiting the generalizability of findings.[22] The absence of Asian Americans in cancer clinical trials reflects a more generalized challenge facing health research: Asian Americans are the most understudied of all racial/ethnic minority groups, overlooked in national health surveys and, consequently, the clinical research informed by them. [14]

Inadequate data collection strategies and methods

Inaccurate estimations of disease risk for Asian Americans result from biases within data collection methods. Examples include the limited availability of Asian languages for survey administration, which prevents many Asian Americans from participating in surveys due to LEP; and the use of random digit dialing sampling methods, which often include only landlines and thus have been shown to exclude many immigrant communities, including Asian Americans. Additionally, surveys may suffer from a lack of geographic representation, which translates to underrepresentation of Asian Americans in national datasets. For example, the Surveillance, Epidemiology, and End Results (SEER) registry is the only federally-funded national dataset of cancer incidence in the US; but the SEER registry does not conduct data collection in every state, resulting in unbalanced datasets. For instance, New York, a state with one of the largest and most diverse Asian American populations in the country, does not have a SEER registry site. [14]

Some surveys omit Asian Americans from data collection altogether, while others aggregate health data for all subgroups, or extrapolate risk for all Asian Americans from data collected from only one or several subgroups. [22] These practices have led to the systematic underrepresentation of Asian Americans in national and regional surveys, and the minimization of Asian American health disparities. Yet, solutions to these challenges are available. A number of innovative and feasible strategies have been proposed, [14] including:

- Pooling data across years in order to develop a sufficiently large dataset of Asian Americans for analysis;
- Using innovative sampling strategies, such as oversampling, targeted sampling, respondent-driven sampling, cumulations, and add-ons;
- Engaging health plans, disease registries, hospitals, and other providers to create community-based epidemiological data repositories;
- Collecting granular data, including country of birth and number of years in the US, to allow for detailed analysis of epidemiologic trends; and
- Utilizing community-based participatory research models (CBPR) or other community-engaged methods, and developing mixed methods approaches.

Multilevel socioecological barriers to Asian American participation

Barriers at the societal, systemic, provider, and individual level also impact Asian American participation in health research; yet, like data-related issues, these barriers also may be overcome with focused efforts. At the societal level, the pervasive “model minority” stereotype – that is, the misconception that all Asian Americans are highly educated, driven, and successful – causes many healthcare professionals, policymakers, and the public at large to assume that Asian Americans do not experience health-related disparities. [15] This persistent stereotype contributes to a fundamental lack of cultural competency across healthcare institutions, leading to systemic barriers. Medical schools may insufficiently prepare clinicians for the unique health issues of Asian Americans or the cultural contexts in which these issues emerge, while hospitals may routinely overlook the service needs and challenges faced by Asian Americans. [23] Lack of culturally and linguistically tailored services, lack of health insurance, and lack of a usual care provider all pose significant systemic barriers to Asian American health seeking. [18]

In parallel, at the provider level, unconscious bias stemming from this stereotype, as well as from difficulties that providers may experience in communicating with Asian Americans with LEP and low acculturation, impacts screening and treatment recommendations.[18] Despite being aware of higher cancer rates among Asian Americans, providers may neglect to recommend cancer screening and prevention to this population. [24] Communication difficulties may also impact providers’ efforts to inform and educate Asian American patients about clinical trials that could offer novel treatments. Meanwhile, at the individual level, Asian Americans may hold negative views of Western medicine and a fatalistic acceptance of poor health.[18] These views, particularly when combined with some Asian Americans’ low health literacy and lack of familiarity with the health care system, may translate to a lack of skills needed to navigate the health system, or hesitation to ask pointed questions about cancer care and treatment options. Asian Americans have been shown to choose more aggressive treatment methods even when less aggressive options are presented to them. One study demonstrated that Chinese American and Japanese American women with early stage breast cancer chose mastectomies over breast-conserving therapies at higher rates than white American women due in part to the reluctance of Chinese American and Japanese American women to either burden or embarrass their providers by asking additional questions about treatment options. [25] Additionally, Asian Americans, like other racial/ethnic minority groups, may distrust government-administered scientific research.[17]

Strategies to reduce barriers at all levels have been tested and implemented successfully in various settings throughout the US, including small clinical settings as well as larger research environments, and often through partnerships between community-based Asian American providers and larger medical centers or universities. Adapting lessons learned from these interventions will improve cancer prevention and care for Asian Americans in general, and, more specifically, help to ensure the recruitment and retention of a diverse, successful million-person PMI cohort. For example, to improve cancer screening and care, one study found that inserting a prompt within the electronic health record could effectively remind clinicians to screen for HBV among Chinese and Vietnamese patients, thereby providing a pre-emptive solution to overcoming potential provider bias or error.[26] Other studies have introduced culturally and linguistically tailored programming for Asian Americans, demonstrating that engaging and training lay health workers can significantly increase cervical and breast cancer screening rates among Vietnamese Americans, a method that may be even more effective when combined with media-based education.[27] Multi-faceted clinic-based interventions that involve health educators from the community of interest have also been shown to be effective at increasing colorectal cancer screening rates among Chinese Americans. [28]

Recommendations

As precision medicine focuses attention on developing clinical trials and prevention research to explore molecular therapies, pharmaceutical options, and public health strategies to prevent and treat cancer among the groups who most need them, a critical opportunity to include Asian Americans and other racial/ethnic minority groups in the million-person cohort alongside is emerging. However, to realize this inclusive vision, developing innovative partnerships between researchers, clinicians, public health practitioners, policymakers, and the community will be essential, as will targeted efforts to dispel the model minority stereotype at the societal, systemic, and provider levels.

Key recommendations include:

- Improve data collection strategies to recruit sufficient numbers of Asian Americans to ensure a diverse cohort, and employ methods to enhance data analysis for Asian American participants. Previously published recommendations must be incorporated into new trial designs and analysis procedures, such as employing CBPR insofar as possible, recording granular ethnicity data in citywide, regional, and national surveys (including country of birth and years in the US), pooling data across years when necessary, and introducing other innovative methods.
- Improve provider education and training about Asian American cancer rates, as well as the social and cultural factors that impact their cancer risk. Addressing potential unconscious bias among providers, increasing providers' cultural competency, and enhancing the structural competency of the health system overall is essential to effective participant outreach and recruitment. Efforts to advance cultural competency within medical and nursing schools, healthcare institutions, and research centers are critical.
- Ensure that linguistically and culturally appropriate health services, health information, trial recruitment materials, and community-based support are available to the diverse Asian American populations that need them. Strategies must include, but are not limited to, ensuring the development of linkages to community-based organizations serving Asian Americans that can inform recruitment and retention efforts; engagement and training of on-site patient navigators and/or community health workers to facilitate care for Asian American patients; availability of on-demand translation services in multiple

Asian languages; and implementation of changes to the physical medical facility, such as on-site signage, to enhance access for Asian Americans.

Operationalizing these recommendations will help to ensure the design and implementation of meaningful studies that engage Asian American patients in research over the long term. Only through such focused efforts will the PMI impact Asian American health disparities, and, more broadly, achieve its goal of personalized medicine for all Americans.

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