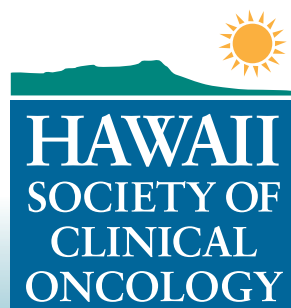


Understanding
& Improving
Lung Cancer
Treatment in
Asian
Americans &
Pacific Islanders
in the
Community
Setting



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INTRODUCTION

Lung cancer is the leading cause of cancer death and the second most common cancer among both men and women in the United States. Moreover, Asian Americans were the first U.S. racial/ethnic group to experience cancer as the leading cause of death.¹ Asian Americans, Native Hawaiians, and Pacific Islanders (AAPIs) represent one of the fastest growing racial groups in the United States. States with the highest AAPI populations include Hawaii, California, and New York.² Given that AAPI patients face disparities in healthcare, the Association of Community Cancer Centers (ACCC), in collaboration with the Hawaii Society of Clinical Oncology (HSCO), launched a project to gain a deeper understanding of the unique cultural, economic, and demographic needs of AAPI patients with lung cancer in order to find ways to improve the diagnosis and treatment of this vulnerable patient population. An Advisory Committee provided oversight over this initiative, which included an online survey of 33 cancer programs in California, Hawaii, Oregon, and Washington (Figure 1). (This number represents 1/3 of the ACCC member programs in those states.) ACCC and HSCO also conducted several interdisciplinary focus groups and a number of in-depth interviews with oncologists in Hawaii to identify key barriers and opportunities for improvement when managing AAPI patients with lung cancer.

SURVEY RESULTS

To gain a better understanding of some of the key issues providers face when treating AAPI patients with lung cancer, ACCC asked about the need for improvement in specific areas. Survey respondents indicated that the greatest needs were around patient education and patient understanding of treatment options, especially regarding end-of-life decisions (Table 1).

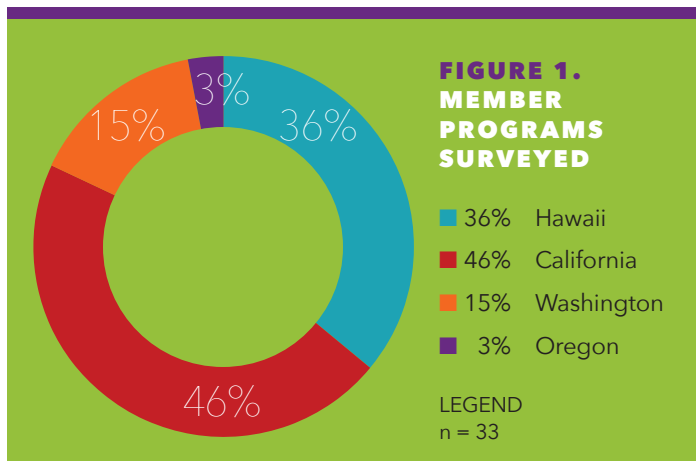


TABLE 1. SURVEY RESULTS OF NEEDS ASSESSMENT

	ASIAN AMERICAN	NATIVE HAWAIIAN	OTHER PACIFIC ISLANDER
Patient's openness and willingness to speak about hospice and end-of-life decisions	■ ■ ■ ■	■ ■ ■ ■	■ ■ ■ ■ ■ ■
Patient's level of understanding about lung cancer and treatment options	■ ■	■ ■ ■ ■	■ ■ ■ ■ ■ ■
Patient's compliance and adherence to treatment recommendations and medical advice	■	■ ■	■ ■ ■ ■
Quality of communication between the patient and the members of the cancer care team	■	■	■ ■ ■ ■

LEGEND
 ■ = Small Need
 ■ ■ ■ ■ ■ ■ = Significant Need

HEALTH DISPARITIES AMONG AAPI PATIENTS

The AAPI population represents over 30 countries and ethnic groups that speak more than 100 different languages.³ In 2011 the population of Asian Americans was estimated at 18.2 million and the largest groups were: Chinese, Filipinos, Asian Indians, Vietnamese, Koreans, and Japanese.² The population of Native Hawaiian or other Pacific Islanders was estimated at 1.4 million in 2011 and the largest groups were: Native Hawaiian, Samoan, Guamanian, and Chamorro.²

AAPI patients may face a host of factors that may threaten their health, including infrequent medical visits, language and cultural barriers, and lack of health insurance.² Among first-generation AAPI patients, 13.2 percent live in poverty and 4.2 percent are unemployed.⁴ Native Hawaiians and other Pacific Islanders have higher rates of smoking, alcohol consumption, and obesity than other minority populations living in the United States.⁵

Specific to lung cancer:⁶

- Lung cancer is 18 percent higher among Southeast Asians than White Americans.
- Vietnamese have the highest rates of lung cancer among all Asian subgroups.
- Chinese have the highest mortality rates of lung cancer among all Asian subgroups.
- Foreign-born Asians have a higher rate of NSCLC (non-small cell lung cancer) than U.S.-born Asians.
- Smoking rates are significantly higher among Southeast Asians.

Oncology clinicians have also noted that Asian American women who have never smoked have a greater risk for lung cancer compared to women in other ethnic groups.⁷ To gain a deeper understanding of why Asian female never-smokers are at greater risk for lung cancer, researchers from the National Cancer Institute (NCI) collaborated with several other countries to form the Female Lung Cancer Consortium in Asia and conducted a Genome-Wide Association Study (GWAS) where they identified three genetic regions that predispose Asian women to lung cancer: loci at 10q25.2, 6q22.2, and 6p21.32.⁸

NCI Community Networks Program Centers (CNPCs) that focus on reducing health disparities among AAPI patients include:⁹

- Asian Community Cancer Health Disparities Center (cah.temple.edu/acchdc)
- Asian American Network for Cancer Awareness Research and Training (aancart.org)
- Weaving an Islander Network for Cancer Awareness, Research, and Training (wincart.fullerton.edu)
- Imi Hale - Native Hawaiian Cancer Network (imihale.org)

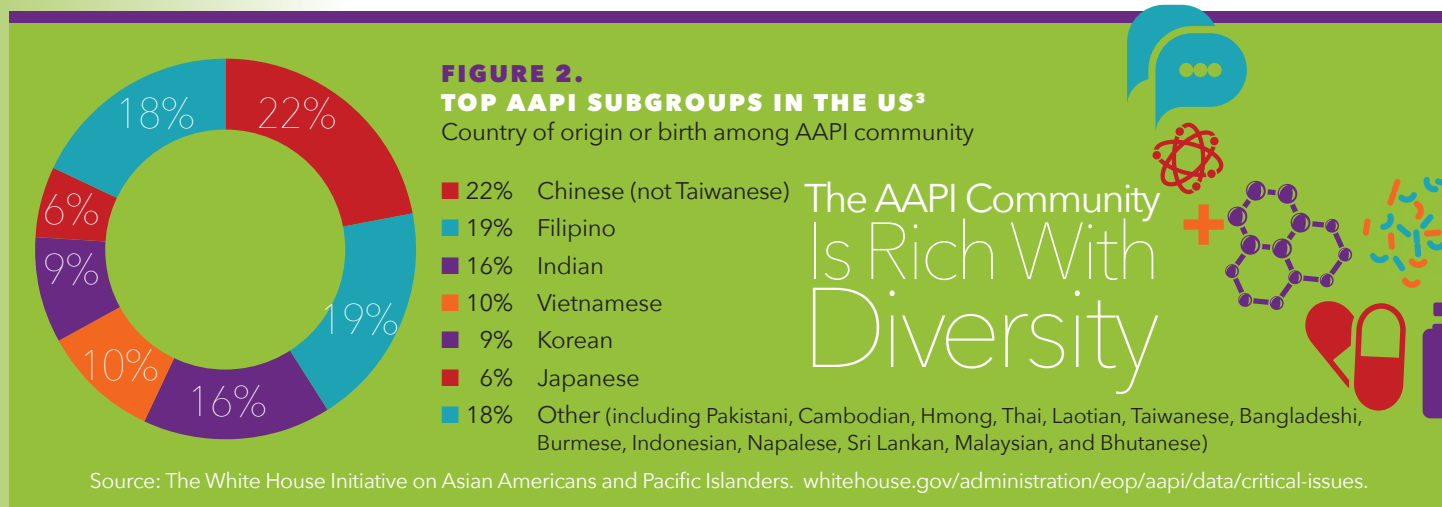
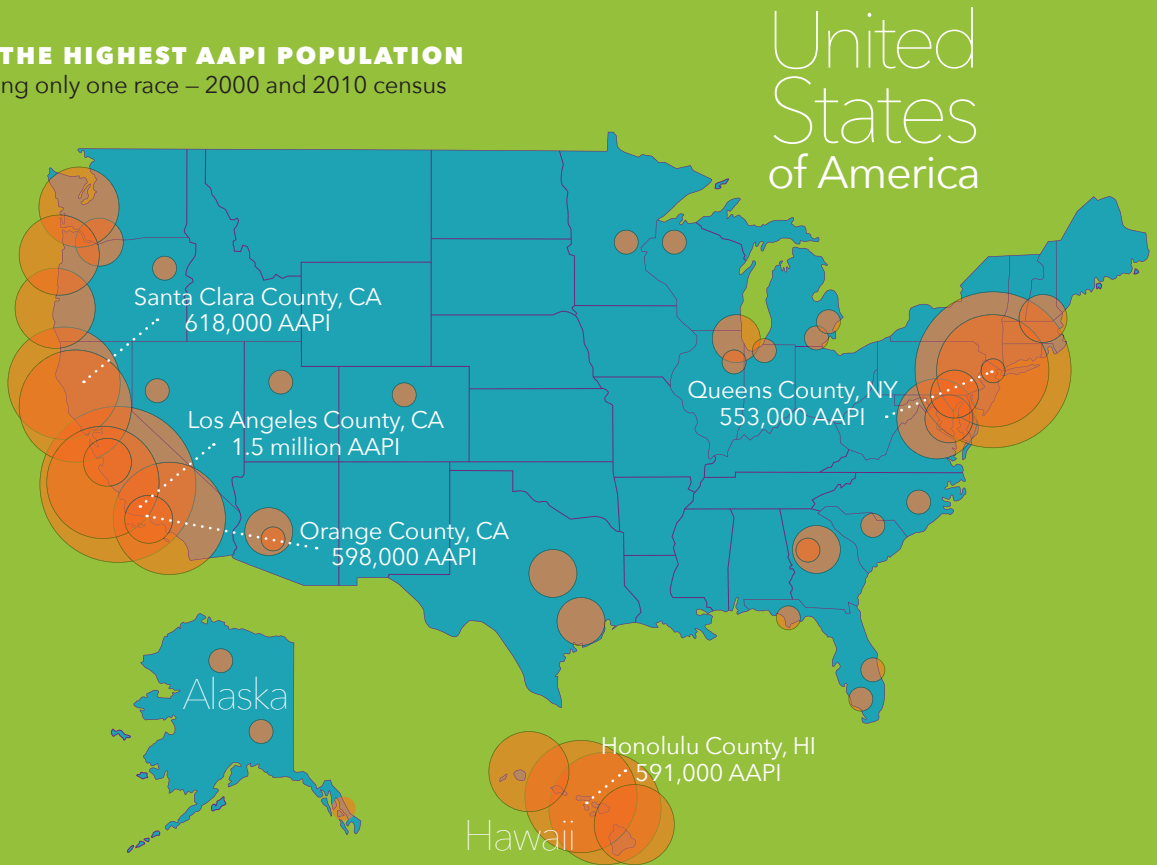
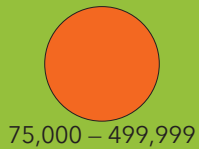
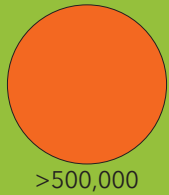


FIGURE 3.
COUNTIES WITH THE HIGHEST AAPI POPULATION

Among people reporting only one race – 2000 and 2010 census

LEGEND



Source: The White House Initiative on Asian Americans and Pacific Islanders. whitehouse.gov/administration/eop/aapi/data/critical-issues.

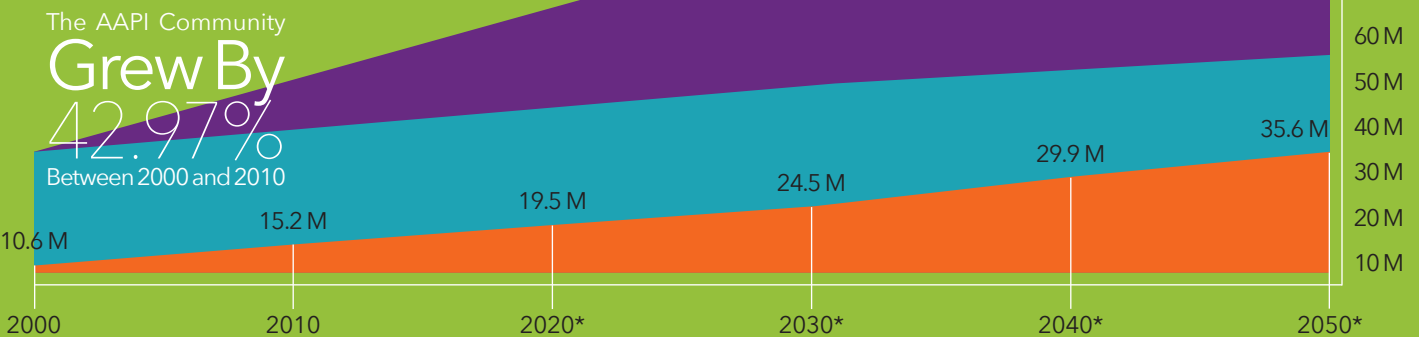
FIGURE 4.
THE AAPI COMMUNITY: DEMOGRAPHICS

U.S. minority population by race

LEGEND

- Asian American, Native Hawaiians and Other Pacific Islanders
- Black or African American
- Hispanic or Latino

The AAPI Community is Projected to Grow Another 134% to Over 35.6 Million Over the Next 40 Years



*Denotes projected estimates

Source: The White House Initiative on Asian Americans and Pacific Islanders. whitehouse.gov/administration/eop/aapi/data/facts-and-figures.

LIMITED ACCESS TO HEALTHCARE

For many decades, AAPI patients faced extreme challenges accessing healthcare because they lacked health insurance and relied on Community Health Centers (CHCs). Although the Affordable Care Act has made it possible for many previously uninsured AAPI patients to receive healthcare coverage, many patients still continue to receive their care from CHCs because the private practice providers in their communities are not accepting new patients, Medicaid patients, or patients covered by other third-party insurance plans.

Cultural and educational barriers can impact how AAPI patients access healthcare. Many are not aware of the importance or availability of screening tests and so they often are diagnosed with advanced lung cancer in an inpatient setting. These patients may present to the hospital emergency department with severe pulmonary symptoms that have progressed over time, and this visit to the hospital may be their first contact with a healthcare provider.

Awareness about lung cancer is growing because of the combined efforts of certain cultural and ethnic groups and religious organizations collaborating with public health departments to offer screening and education. However, these events are limited and often do not reach elderly patients who may avoid leaving their homes. Many AAPI patients also have limited access to reliable transportation during the workday. They often depend on family members who have busy work schedules and public transportation may not be available to take patients to their medical visits. Cancer programs in these communities have found ways to maximize the use of taxi vouchers or other programs like the American Cancer Society Road to Recovery Program.¹⁰

Practical Suggestions for Improvement

- Increase awareness about lung cancer screening programs and insurance coverage for screening tests.
- Leverage community health outreach events to educate patients and their family members about lung cancer, health insurance resources, and ways to improve healthcare access.
- Find ways to engage employer groups that are willing to disseminate health information to their employees.

COMMUNICATION & CULTURAL BARRIERS

The diverse AAPI population who comes from multiple countries speaks more than 100 different languages.³ Hence, language and translation can be especially challenging when encountering patients who come from smaller countries. Although most large hospitals and health systems have reliable access to professional medical translators, oncology providers working in private practice or in smaller hospitals often struggle to find translators when they are needed. In certain AAPI cultures, gender barriers may hinder effective communication between a patient and a translator or a patient and a clinician. These gender-specific cultural issues must be navigated carefully by translators and clinicians if they hope to achieve trust in the patient-provider relationship.

Advances in technology have led to effective video-based translation services in places where live translators may not be available. A leading example is the Language Access Network's (LAN) MARTTI (My Accessible Real-Time Trusted Interpreter), a two-way video and audio medical interpreter service that meets HIPPA data encryption requirements. However, real-world experience with MARTTI remains a challenge in certain areas because of the lack of reliable high-speed Internet connectivity that leads to poor video quality and other user issues.

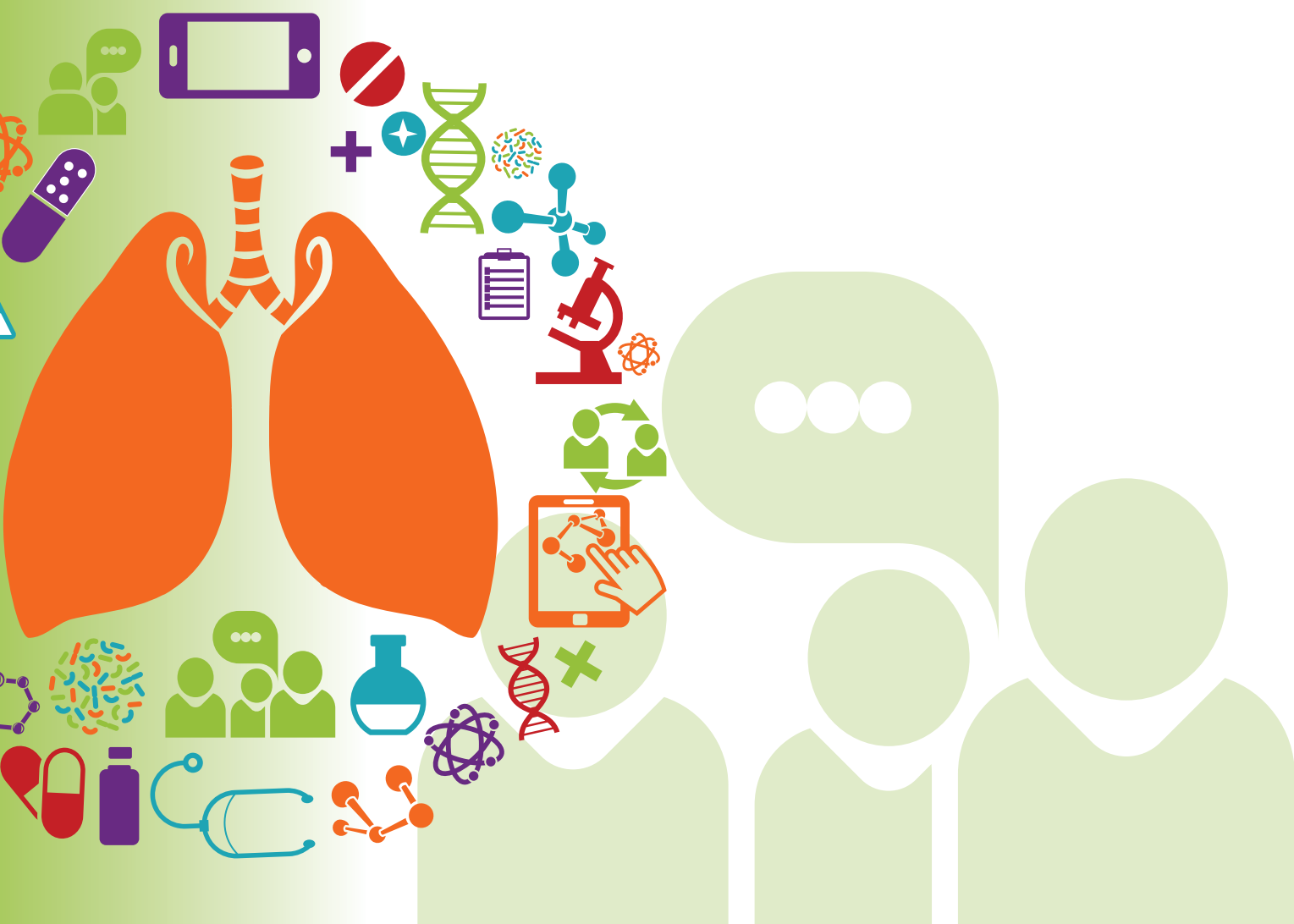
In many areas, medical interpreters often end up playing a significant role in care coordination as they build trust and rapport with patients and family members. For certain AAPI ethnicities, the local community may be very small, so medical translators may end up being related to the patient. These relationships can pose significant challenges around patient privacy and confidentiality.

In some situations, family members may offer to translate, but this may present other types of challenges due to certain AAPI cultural behaviors. For example, adult children may be hesitant and reluctant to give bad news to elderly family members because they fear that the stress associated with the bad news could lead to worse outcomes. Or, due to respect for the elders, the grown children may take a paternalistic approach to shield their parents from bad news. In certain AAPI cultures, the patient's place in the family—both in terms of gender and age—may impact how other family members communicate with the patient about health-related issues. This can also impact the clinical decision-making process among family members who may be struggling with major medical decisions. Studies have also shown that some of the most common causes for medical errors attributed to insufficient patient language proficiency include:¹¹

- Use of family members, friends, or nonqualified staff as interpreters.
- Clinicians with basic foreign language skills who try to communicate without using qualified interpreters.
- Cultural beliefs and traditions that affect healthcare delivery.

End-of-life discussions can be extremely challenging, especially if the topic of death and dying is not a culturally appropriate or acceptable discussion topic. So, although advanced directive documents may be available in different languages, patients need guidance and assistance around sensitive topics. Clinicians and medical translators working in the oncology setting need training on these types of cultural competency communication issues so that they can effectively contextualize their conversations around cultural norms and expectations. For instance, in some cultures, conversations about death and dying may be considered inappropriate. But, if clinicians explain why they must spend time discussing an uncomfortable topic, then patients may be more receptive to and understanding of the dialogue. Several videos covering advanced directives and end-of-life care have been generated in several AAPI languages through the support of grants. However, these valuable resources (kokuamau.org/resources) remain underutilized because some clinicians remain unaware of these tools and others do not make the time to recommend them to patients.





Practical Suggestions for Improvement

- Consider ways to spend more time with patients and family members during their initial visits in order to cultivate trusting relationships.
- Identify ways to increase the usability of video-based translation services, especially in programs that do not have reliable access to translators.
- Find ways to train and equip clinicians and translators to have greater cultural competency when communicating with AAPI patients about treatment options, end-of-life care, and other sensitive topics.

LUNG CANCER MANAGEMENT

In some areas, over 50 percent of AAPI patients are being diagnosed with lung cancer in the inpatient hospital setting because they are not receiving appropriate outpatient care in a timely manner. These individuals often present with severe respiratory symptoms and are admitted from the emergency department. Clinical management and care coordination often require a strong team-based approach that actively involves a medical translator if the patient is not fluent in English.

As more community cancer programs implement a pathology-driven reflexive molecular biomarker testing process for advanced NSCLC, they must also take into consideration the issues that come when patients are diagnosed in the inpatient setting. Because so many AAPI patients are diagnosed as inpatients, the Medicare 14-day rule (which states that CMS will allow independent and hospital-based laboratories to bill separately for certain complex diagnostic laboratory services that are ordered within a 14-day period after a hospital discharge) may cause delays in ordering molecular biomarker tests in patients who have advanced stage NSCLC.¹² Certain actionable mutations, such as EGFR, are found more frequently in AAPI patients, so oncologists are eager to obtain testing information so that they can make informed treatment decisions. In Caucasian patients with NSCLC, EGFR mutations may be found in approximately 20 percent of cases.¹³ However, Chinese researchers found EGFR mutations in 37.5 percent of patients with lung adenocarcinoma.¹⁴ The PIONEER study (NCT01185314) found that the rate of EGFR mutations was 51.4 percent across multiple Asian ethnic groups with lung adenocarcinoma.¹⁵ Lung cancer patients with actionable mutations may also develop treatment resistance to targeted therapies, and researchers are exploring the various mechanisms that may contribute to these specific resistance patterns.¹⁶

Some AAPI patients remain extremely hesitant to accept radiation treatment for lung cancer because they perceive all types of radiation to be harmful. Historic context can be especially important given that certain AAPI ethnic groups experienced significant exposure to ionizing radiation from U.S. nuclear weapons testing.¹⁷

When treating AAPI patients who have limited English proficiency, care coordination becomes a significant challenge. Medical translators often shoulder the responsibility of acting as primary care coordinators, even when they are not formally trained in care coordination. So, it becomes imperative for all the members of the oncology care team to communicate clearly with translators who then serve as the primary point of contact with patients and family members.

NSCLC patients who are treated with oral oncolytic medications need more education, monitoring, and follow-up. Limited health literacy and other communication barriers can make this especially challenging for oncology providers, especially since these patients now have the responsibility of taking their medications at home.

Appropriate monitoring and follow-up with AAPI patients can also be difficult because some patients do not have a reliable phone number and they depend on other family members who have phones. When an oncology provider tries to contact a patient, staff may need to make several phone calls in order to reach the patient. This may complicate communication workflows and create inefficiencies when staff is trying to reschedule patients who missed their appointments.





Practical Suggestions for Improvement

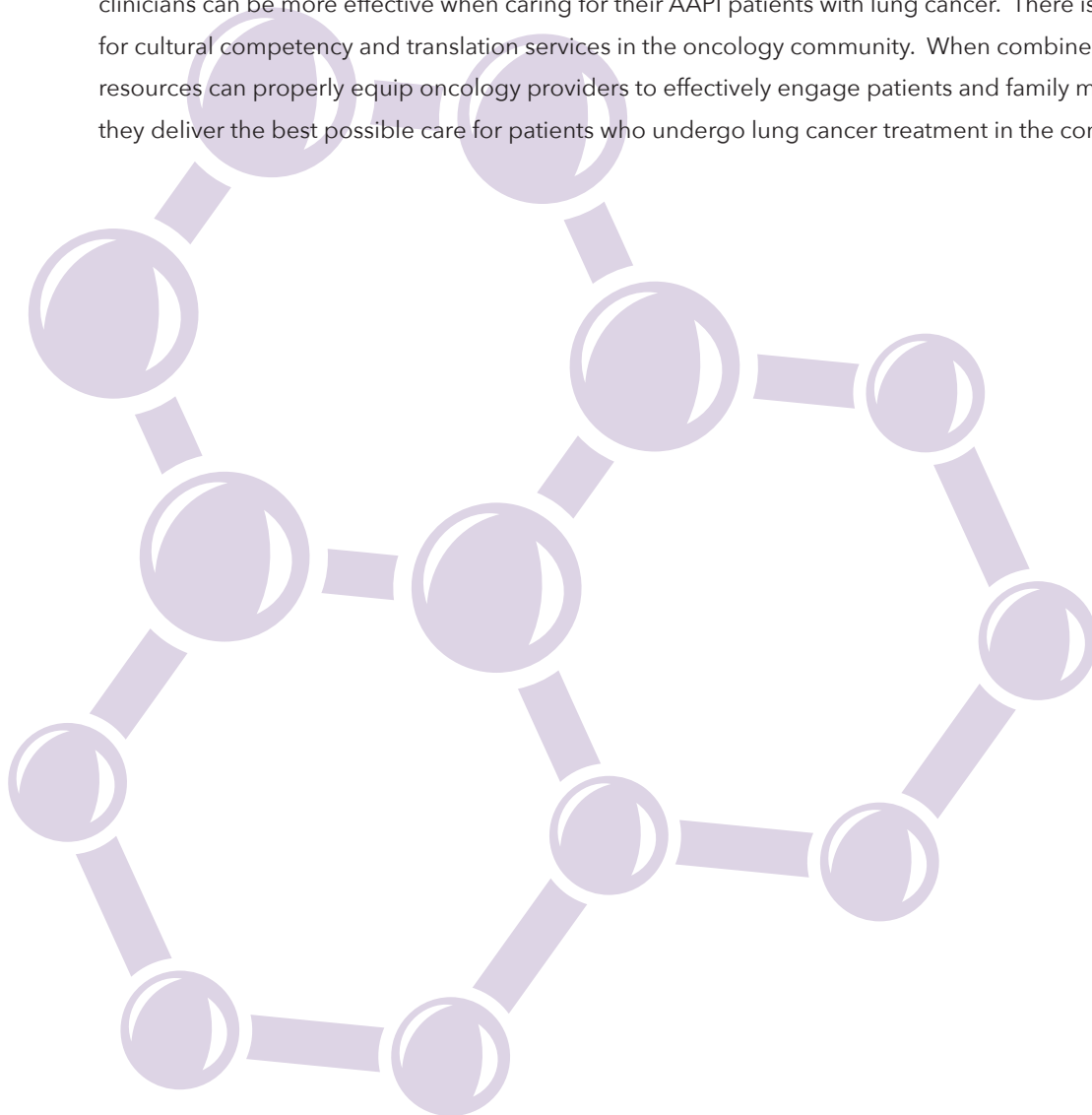
- Educate oncology clinicians about lung cancer characteristics that are unique to AAPI patients and the ongoing research that is actively exploring these issues.
- Ensure that molecular biomarker testing is performed routinely in AAPI patients since they have a higher prevalence of certain actionable mutations, such as EGFR.
- Identify ways to improve care coordination and follow-up, especially when patients are taking oral oncolytic medications at home.

CLINICAL RESEARCH

In our focus groups, clinicians noted that AAPI patients who have limited English proficiency do not have opportunities to enroll in clinical trials because the informed consent forms are often only available in English. In some limited cases, informed consent forms may also be available in Chinese, but they are rarely available in other AAPI languages. The IRB (institutional review board) policies that govern specific clinical trials may require consent forms to be written in native languages to ensure that patients fully understand the risks of participating. Focus group participants agreed that there is a significant need to revise clinical research regulations and policies in order to allow more AAPI patients to participate in studies. Given the unique molecular characteristics found in AAPI patients with lung cancer, more research is needed to explore actionable mutations and patterns of treatment resistance.

CONCLUSION

Asian American and Pacific Islander patients with lung cancer face challenges receiving care, but there are clear opportunities to bridge some of those gaps. This project helped to uncover some key barriers and shed light on practical ways to overcome some of those hurdles so that oncology clinicians can be more effective when caring for their AAPI patients with lung cancer. There is a greater need for cultural competency and translation services in the oncology community. When combined effectively, these resources can properly equip oncology providers to effectively engage patients and family members so that they deliver the best possible care for patients who undergo lung cancer treatment in the community setting.



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The Association of Community Cancer Centers (ACCC) is the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 20,000 cancer care professionals from 2,000 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. Not a member? Join today at acc-cancer.org/membership or email: membership@acc-cancer.org.

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