2022 Advancing the Science of Cancer in Latinos

Conference Proceedings

ADVANCING
THE SCIENCE OF CANCER
IN LATINOS

UT Health
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Dr. Amelie G. Ramirez of the Institute for Health Promotion Research at UT Health San Antonio partnered with the Mays Cancer Center at UT Health San Antonio to create the *Advancing the Science of Cancer in Latinos* biennial conference. The 2022 event on Feb. 23-25 in San Antonio, Texas, welcomed over 250 prominent researchers, physicians, healthcare professionals, patient advocates, and students from across the globe to address cancer health disparities among Latinos. The following “conference proceedings” summarizes presentations and discussions.

Conference sponsors included major supporters Genentech and Bristol Myers Squibb; contributors Gilead Sciences and Novartis; donors Adaptive, Pfizer, and AstraZeneca; and exhibitors Caris, Pfizer, AstraZeneca, Sobi NA, Texas Society of Clinical Oncology, Regeneron, Genentech, Bristol Myers Squibb, Bayer, Immudex, National Alliance for Hispanic Health, and Merck & Co. Inc.

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INTRODUCTION

Healthcare inequity in the Latinx community

The United States healthcare system is rife with systemic inequities affecting the Latinx community, the largest ethnic minority in the country with a population of 60.6 million [Estrada]. Health disparities include higher rates of infant mortality, stroke, cancer, heart disease, diabetes, hypertension, and COVID-19, and are often rooted in systemic racism and unconscious bias. [Webb Hooper, Duma] Latinx patients, especially those who are uncomfortable discussing care in English, are often stereotyped as unintelligent and non-compliant. In a meta-analysis of 15 studies, 13 found that healthcare professionals showed statistically significant moderate levels of bias against people of color. [Duma]

In the COVID-19 pandemic, cases among the Latinx population have been 1.3 times higher than in the White population, with 3.2 times more hospitalizations and 2.3 times higher death rates. [Del Rio] Furthermore, among high-risk patients, such as pediatric cancer patients, those of Latinx ethnicity were disproportionately affected compared with other racial and ethnic groups and experienced more symptomatic illness. [Flatt] Such disparities are often due to social determinants of health (SDoH), which account for at least 60% of the variance in health outcomes, a much greater percentage than the pure effects of biological and genetic factors. [Nunez-Smith] Misinformation is another challenge affecting the Latinx community, with social media misinformation even more prevalent in Spanish posts than in English. [Goddard]

SDoH include spatial patterns of poverty, lack of access to nutritious food, environmental toxins, educational disadvantage, health literacy, and more. [Nunez-Smith] One of the more important SDoH, socioeconomic status, shows a startling association with mortality. US residents in a household of four with an income less than $25,000 show a mortality ratio of 3:1 when compared to those with a household income of greater than $115,000. [Perez-Stable] In Texas, Latinx men and women are the least likely to have health insurance of any major racial or ethnic group. Among those 18 to 64 years of age, 26% of Latinx individuals were uninsured, compared to 9% of White individuals in 2017-2018. [Estrada]

Cancer inequity

Cancer is the leading cause of mortality in the Latinx population, accounting for 20% of deaths. [Estrada] In fact, 1 in 3 Latinx men and women will be diagnosed with cancer in their lifetime, with 1 in 5 men and 1 in 7 women dying from the disease. [Estrada] From 1999 to 2016, cancer cases increased by 106.0% in the Latinx community, compared to a 17.5% and 50.0% increase in White and Black communities, respectively. [Sáenz]

Lung cancer is the leading cancer killer in Latino men, and breast cancer is the leading cancer killer in Latina women. [Taverna, Velazquez] Latinx lung cancer patients die earlier than White patients, with 5.2 years of potential life lost compared with just 4.3 years for White patients. [Cress] Latino ethnicity and living in the lowest-income neighborhoods are associated with a higher risk of gastric cancer diagnosis, and Latino populations have the highest incidence rates of liver cancer compared with other ethnic groups. [Long Parma, Setiawan] B-Cell acute lymphoblastic leukemia (B-ALL), the most common childhood malignancy, disproportionately affects Latinx children, who are 1.2-1.75 times more likely to develop ALL than their White counterparts; and Latinx adolescents are 2.09 times more likely. [Dovat]

The cancer care continuum

These inequities affect Latinx cancer patients across the entirety of the cancer care continuum. Obesity, for example, has been shown to increase cancer risk, cause delays in diagnosis, alter treatment plans, and increase complications associated with comorbidities. [Bandera] The obesity rate for Latinx adults in the United States is 44.8%, second only to Black adults at 49.6%. [Bandera, Rodriguez-Rodriguez] Cardiometabolic comorbidities are also higher in Latinx populations, which are often found in ethnic enclaves, or areas of ethnic density based on language and birthplace. [Maras, Diaz] These ethnic enclaves are associated with higher obesity rates, and can often be food deserts, have high poverty rates, lack green spaces, and be areas of high stress due to violence. [Diaz]

Another part of the cancer continuum affecting Latinx patients is stress management and mental health. [Costas-Muniz] End-of-life care is another concern, with Latino patients less likely to complete do-not-resuscitate orders, have living wills, or have designated health care proxies. [Maciejewski] This results in a higher likelihood of aggressive EoL care, including increased ICU admissions and chemotherapy use. [Tergas]

Disparity in clinical trial representation

Despite representing 18% of the population, Latinx participants only represent 4-8% of clinical trial participants. [Lynce, Fashoyin-Aje, Trevino] In a recent study of almost 6000 precision oncology trials, all minority groups were underrepresented, with Latinos showing the greatest disparity. [Lynce]] In trials for oncology drugs approved by the FDA from 2008 to 2018, only 630 of the 70,201 patients who reported their racial background were Latinx. [Rodriguez] When comparing participants in clinical trials from 1996-2002 with participants from 2003-2016, Latinx participation has decreased, with 3.1% Latinx participation prior to 2002 compared with 2.6% Latinx participation after 2003. [Rivera] The Cancer Genome Atlas (TCGA) program, a large publicly available genomic database, also has a very low number of Latinx participants with only 3% of participants identifying as Hispanic or Latino. [Ziv, Dutil]

Practical steps for addressing inequity

Advancing the Science of Cancer in Latinos, a conference held from February 23rd to 25th, 2022, brought together leading Latinx healthcare voices in San Antonio, TX to discuss these inequities and share practical approaches for moving forward. Presenters included physicians, researchers, survivors, policy makers, and industry leaders from across the US and Latin America. It was agreed that dismantling racial disparities in the healthcare system must involve diversity at every level, from educators to physicians to administrators to legislators. A diversity of voices always leads to a broader understanding of patient experience. [Santos, Winn]

Intervention in Latinx populations must also begin with an understanding of language and culture, and these communities should be engaged with sincerity and a willingness to listen to those affected by the issues being studied. [Sanchez-Johnsen] Successful health care interventions are often driven by multi-layered community networks through the identification of root causes and solutions, as well as community resources. [Molina, Tortolero-Luna] Community-based health workers can provide education, screen for social determinants of health, schedule screenings, and follow patients until screenings are complete. [Jones]

Latinx participation in clinical trials must also be increased through more purposeful study design, more flexible inclusion criteria, and fewer economic barriers to participation. [Duma, Dovat, Rodriguez, Trevino, Penedo, Perez, Kuri] Through greater Latinx participation and more diversified genomic testing, Latinx presentations across all diseases can be better understood. [Ziv, Lynce, Dutil, Cress, Dovat] In this way, more individualized treatment plans with fewer side effects can be implemented. [Taverna]

Cooperation between research programs, especially across borders, is another necessary strategy moving forward. Many initiatives can be emulated in this regard, including the Latin American Cancer Research Network (LACRN), the Mexican National Institute of Public Health, the Puerto Rico Breast Cancer Genetics and Genomics Study (PUR-BCGG), and the Leading Pathways study. [Lajous, Llera, Dutil, Penedo]

The presentations outlined below discuss the findings of Latinx leaders in the areas of cancer research, healthcare disparity, COVID policy, clinical trial inequity, international cooperation, community intervention, end-of-life care, and social justice. The information presented, however, merely represents a beginning, with the hope that dialog and collaboration will continue into the future, providing new solutions for the elimination of health disparities among Latinx populations.

1. ADDRESSING SYSTEMIC INEQUITIES BEHIND CANCER DISPARITIES

Addressing Systemic Inequities and Structural Racism to Advance Health Equity for Latinos

Dr. Marcella Nunez-Smith is an internal medicine physician, the Associate Dean for Health Equity Research at Yale School of Medicine, and the Associate Director for Community Outreach and Engagement at the Cancer Center. Dr. Nunez-Smith served as chair of the Presidential COVID-19 Health Equity Task Force, and is one of the nation's foremost experts on disparities in healthcare access.

Health Disparities Affecting Marginalized Communities

Dr. Nunez-Smith spoke on health disparities affecting marginalized communities and communities of color, both in regard to the COVID-19 pandemic and beyond. The discussion began by emphasizing the impact of structural racism on health equity and overall patient care. The COVID-19 pandemic, although more challenging than anyone predicted, brought many such fundamental problems into public consciousness. This prompted important conversations, long overdue, addressing inequities in the structures and systems that affect individual and collective health. Throughout the pandemic, the burden of disease was found to be unequally distributed across populations, with infection rates, hospitalizations, and loss of life falling along familiar lines of social inequity. In order to combat this trend, the Presidential COVID-19 Health Equity Task Force prioritized equitable access to vaccinations, PPE, treatments, and testing.

Dr. Marcella Nunez-Smith

Although COVID-19 brought such disparities to the forefront of public consciousness, inequity is rampant in many other areas, including cancer rates and survivorship in underserved and marginalized communities. Such disparities are rooted in spatial patterns of poverty, lack of access to nutritious food, environmental toxins, educational disadvantage, health literacy, and more. These social and structural drivers of health account for at least 60% of the variance in health outcomes, a much greater percentage than the pure effects of biological and genetic factors.

Communities of color are at a particular disadvantage in regard to living conditions that promote health, as well as access to affordable healthcare before and after illness. Despite recent research into understanding these trends, more knowledge is needed, especially in regard to how government policy and economics affect and exacerbate pervasive racism and health disparities. For example, nearly half of Latino workers report no paid time off of any kind. This lack of access to sick leave or vacation days disproportionately prevents access to life-saving cancer screening, treatment, and care.

Health is also compromised by general stress, and more research is needed in regard to overall health in communities that experience stressful living conditions. It is important to understand the mechanisms by which social determinants affect physiology. Dysregulation of physiological systems, epigenetic modifications, and immune and inflammatory responses have all been proposed as areas of research addressing the effects of chronic social stress.

Social Inequities and Impact on Cancer

In cancer specifically, the fact that upstream social inequities are responsible for disparities in risk, incidence, and outcome indicates the need to engage in policy outside of the healthcare system. Advocating for and implementing legislative strategies that counteract racism and inequity are paramount, ensuring that current and future policies do not have an adverse impact on marginalized communities.

Throughout the pandemic, the COVID-19 Health Equity Task Force found that communities themselves were the best resource of insight into their own needs. They began by engaging community leaders and working with individuals who had proven trustworthy to the community. Meeting people where they were was also important, and building mechanisms of community support empowered positive outcomes. By listening to and relying on generational wisdom, the task force observed health behavior changes, increased access to care, and the closing of many inequity gaps.

Dismantling Discrimination in Healthcare

Dr. Nunez-Smith ended by emphasizing that both patients and providers experience discrimination in healthcare, which disrupts the trust that is so fundamental to the patient-provider relationship. Currently, only 5.8% of practicing physicians identify as Latino, compared to 18% of the overall US population.

It is therefore important that healthcare professionals practice self-interrogation, acknowledging the structural racism in healthcare systems, and ensuring that instead, diversity and anti-racism are the norm. Furthermore, as the burden of cancer increases both for the Latino population and other communities of color, solutions that are proactive and anticipatory, and not merely reactionary, are needed.

Paying Respects and Con Respeto: Economic Considerations of Community-driven Interventions

Dr. Yamilé Molina

Dr. Yamilé Molina is Associate Professor at Community Health Sciences at the University of Illinois Chicago (UIC), and Faculty Affiliate at the Center for Research on Women and Gender at UIC. Dr. Molina also serves as Associate Director of both Community Outreach and Engagement at University of Illinois Cancer Center.

A History of Breast Healthcare Interventions in US-Based Latinas

Dr. Molina discussed the power and value of community-driven interventions in breast healthcare, both updating information on previously used interventions, as well as sharing a new study empowering Latinas to obtain breast cancer screenings. Economic considerations for socially just and sustainable scalability were also addressed.

Since 1990 there have been more than 49 community-driven interventions addressing breast healthcare in the US, 25% of which targeted Latinas. Most of these interventions were focused on screening, but others were centered on diagnostic care and treatment as well. The success of these studies was driven by multi-layered community networks. Such networks are composed of community nonprofits, such as health and social services; community venues, such as churches and businesses; community media, such as radio and kiosks; and community members, such as family and friends. Interventions were conducted through cooperation between these community networks and academic-based staff, health workers, and community navigators.

A New Way to Increase Breast Cancer Screenings

Despite success with such previous interventions, questions remain regarding scalability and sustainability, especially when considering cost. In pursuit of these questions, a quasi-experimental pilot study was conducted, comparing two approaches for encouraging Latinas to obtain breast cancer screenings.[1] The first approach, Educate, addressed participants' breast cancer prevention and screening behavior. The second approach, Empower, addressed participants' and their social networks' breast cancer screening.[1] Of participants in the Empower group, 72% received mammograms within 6 months of the intervention, while only 48% of the Educate group received mammograms.[1] Furthermore, 41% of participants in the Empower group engaged more than seven family or friends, communicating the message about breast cancer. In contrast, only 20% of the Educate group did the same.[1] Finally, 70% of the Empower participants communicated with a community member specifically about mammography, while only 48% of the Educate group did so.[1] These results reveal the importance of focusing on individuals' social networks as well as the individuals themselves when designing interventions.

The Challenges of Scaling

While community non-profits, venues, and media may be the most effective way to reach individuals in small numbers, scaling comes with several difficulties. First, these institutions typically have limited access to funding, prioritizing relationships over raising money. Also, they often do not know about systems such as the Data Universal Numbering System (DUNS), which would allow them to apply for or renew federal grants, or the indirect cost reimbursement process through which nonprofits receive compensation for qualified expenses when they provide services to governments using federal funds. Finally, they might not have the time or resources to wait for “net-30” or other payment schedules.

One possible solution to this difficulty in scalability is for the academic sector to step in, becoming employers, and giving a more robust infrastructure. However, academic investment in community staff can lead to less support of community non-profits themselves. Also, academic investment can result in competition, meaning fewer resources and benefits for community-based non-profit staff. Community-based staff could even be paid significantly less than academic-based staff for doing the same work. Other factors to consider when attempting to scale these interventions are that community health workers currently are underpaid and have to work multiple jobs, even paying for their supplies out of pocket. These disparities must be addressed and not forgotten in the excitement of large-scale endeavors. Certification and recertification can also be a concern when scaling interventions, since many community health workers have limited time, money, education, and language training for certification while working. Some may even be ineligible for certification and formal payment.

Dr. Molina concluded by expressing that the goal of any intervention, especially one that seeks to be scalable, is to increase inclusion, opportunity, and flexibility, while maintaining compensation and obligations to community health workers. There is momentum demonstrating the power of community-driven interventions, but socially just implementation requires consideration of the evidence as well as social context.

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Two Tales, One Goal: Equity

Dr. Narjust Duma is a thoracic oncologist at the Lowe Center for Thoracic Oncology at the Dana-Farber Cancer Institute, and serves as Associate Director of the Cancer Care Equity Program at Dana-Farber, as well as Assistant Professor of Medicine at Harvard Medical School.

The Pervasive Nature of Subconscious Bias

Dr. Duma began by leading the audience through a visualization activity, challenging each listener's biases and stereotypes. All people have unconscious biases, and, as evidenced by the tragedies of George Floyd, Breonna Taylor, Tamir Rice, Ahmaud Arbery, and others, these biases can be fatal. Unconscious biases – defined as negative associations that can lead people to see danger, underqualification, and faults where they do not exist – are also prevalent in healthcare, and almost always have negative consequences. Since stereotypes and unconscious biases are worse in times of high stress, the pandemic has exacerbated the problem even further.

Dr. Narjust Duma

Latinx patients, especially those who are uncomfortable discussing care in English, are often stereotyped as unintelligent and non-compliant. In a meta-analysis of 15 studies, 13 found that healthcare professionals showed statistically significant moderate levels of bias against people of color. These physicians were shown to be less likely to provide appropriate treatment for pain and blood clot events. Another study found that women of color were less likely to receive a follow-up call after breast cancer treatment. Further, in a review of the last 14 years of oncological research, a decline was seen in the recruitment of minorities and women in clinical trials.

Several strategies could help reverse this trend of underrepresentation in clinical trials. First, inclusion/exclusion criteria need to be examined for unconscious bias. Next, target accrual goals could ensure that minorities are accurately represented, and the FDA should not approve medications that have not been tested in populations that mirror US demographics. Cost and coverage barriers to participation should also be addressed. Most importantly, however, physicians need to ask people of color to participate, practicing cultural humility, and not assuming that participation will be too difficult. Patients who lack understanding, or who show “poor compliance,” are often simply victims of inadequately used language resources, with physicians relying on rudimentary Spanish skills instead of using a fluent Spanish translator to explain complex treatment instructions.

Consequences of Inequity in the Workforce

Another major area of concern is equity in the workforce. Patients often show bias, preferring doctors that look and sound like them, and requesting an “American doctor,” or a male doctor, or a doctor without an accent. These microaggressions against racial minorities, as well as the LGBTQ+ community, lead to feelings of isolation and exclusion. In fact, there has been no increase in Latinx and Hispanic medical students over the last 10 years.

There has, however, been an exodus of Latinx and Hispanic doctors from academic medicine to practice due to the hostile work environment for those who do not look and sound like the majority. Dr. Duma shared a personal story of clinical depression while in academic training. Comments such as “Oh, you’re so Latina” or “I didn’t know Latinas could be doctors” reinforced this exclusion. For many in this situation, microaggressions lead to either quitting the program, or migrating out of academia into practice.

Approaches to Counteract Historical Bias

One non-profit organization fighting this bias is called #LatinasInMedicine. Dedicated to telling stories of Latinas in Medicine, this organization seeks to overcome the feelings of isolation and exclusion that can be so pervasive. While the Latinx community represents 18% of the US population, only 1.8% of doctors are Latinx, a fact that underscores the importance of organizations such as #LatinasInMedicine.

Dr. Duma, along with Dr. Gladys Rodriguez, established the Conquer Cancer Foundation Young Investigator Award for Latinas in medicine, in order to address financial challenges. This endeavor needs funding, as their goal is to provide financial support for two Latinas in medicine every year. The Duma research group is also spearheading several research studies that hope to bring unconscious biases and workforce inequity to the forefront. They are addressing issues regarding safe mentors for women of color, and even have a Medscape column addressing difficulties for women of color in medicine and the reasons people of color are leaving academic medicine.

The presentation ended with a challenge: can each person use his or her privilege to create equity? One person has a lot of power, Dr. Duma emphasized, and even seemingly trivial privileges such as electricity, internet, and speaking the language can be used to affect change. Use the privileges you have to be an advocate for change in your specific environment.

Obesity Through the Cancer Continuum: Current Evidence and Guidelines for Cancer Prevention and Control

Dr. Elisa Bandera is Professor and Chief of Cancer Epidemiology and Health Outcomes and co-Leader of the Cancer Prevention and Control Program and a member of the Cancer Health Equity Center of Excellence at the Rutgers Cancer Institute of New Jersey.

The Obesity Epidemic and Cancer

The high prevalence of obesity defined as body mass index (BMI) ≥ 30 kg/m^2 is a major public health concern, with alarming increasing prevalence rates, going from 30.5% of American adults in 1999-2000 to 39.6% in 2015-2016.[1]

Although about half of the population is unaware of the link between obesity and cancer, there is strong evidence that obesity increases risk in at least 13 cancer sites (esophagus: adenocarcinoma; gastric cardia; colon and rectum; liver; gallbladder; pancreas; breast: postmenopausal; uterine endometrial; ovary; kidney: renal cell; meningioma; thyroid; and multiple myeloma).[2] Overall, an estimated 5% of all cancers in men, and 11% in women are attributed to excess body weight.[3]


Dr. Elisa Bandera

The impact of obesity on cancer is multifaceted and spans the entire cancer continuum from increased risk, delays in diagnosis, suboptimal treatment, more treatment complications, higher prevalence of patient reported outcomes (e.g, sleep disturbance, severe cancer-related fatigue, and poorer physical and functional well-being), and worse prognosis.[4] Several interrelated pathways have been proposed as underlying biological mechanisms by which adiposity leads to metabolic dysregulation, disrupting hormonal pathways, and increasing chronic inflammation which affects immune function. Obesity is also associated with several comorbidities, which further impact the risk of mortality and complicate treatment.[5]

Recommendations Regarding Obesity

Dr. Bandera, who served in the World Cancer Research Fund/American Institute for Cancer Research Expert Panel for the Third Expert Report on Diet, Nutrition, Physical Activity and Cancer, presented the current guidelines for cancer prevention.[6] These guidelines emphasize a more holistic approach for cancer prevention, with the general recommendation of following a healthy lifestyle pattern, rather than focusing on individual factors, such as certain foods or nutrients. This lifestyle pattern includes maintaining a healthy weight and an active lifestyle; eating a healthy dietary pattern that emphasizes whole grains, vegetables, fruit, and beans; minimizing red and processed meat, fast foods and other processed foods high in fat, starches or sugars; and avoiding sugary drinks. For cancer prevention, alcohol consumption and vitamin supplements are not recommended.

Given the strong evidence linking obesity to cancer, maintaining a healthy weight is crucial for cancer prevention and a top recommendation. A healthy weight is defined as keeping weight within the healthy range and avoiding adult weight gain. These recommendations mirror those suggested by the American Heart Association and the American Diabetes association, showing that a healthy lifestyle reduces risk across a range of chronic diseases.

Relevance of the Obesity-Cancer Link to the Latinx Community

While obesity prevalence is high in general in the United States, it disproportionately affects non-Hispanic Black and Hispanic men and women. Obesity prevalence rates are 46% for Hispanic men and 44% for Hispanic women.[1] Body Mass Index (BMI) is widely used and its high correlation with adiposity makes it a useful public health tool, but it has limitations as it cannot capture body fat distribution or body composition.[7] Central obesity is also of interest, as a proxy of higher intra-abdominal visceral fat, which is more metabolically active and more strongly associated with insulin resistance and metabolic syndrome than subcutaneous fat.[7] Prevalence of central obesity (defined as a waist circumference of more than 88 cm in women) is also highest in Hispanic (75%) women, with a striking increasing trend in prevalence among Hispanic women.[8] Weight gain during adulthood is also more common among Hispanic women[9], which primarily results in abdominal accumulation of adipose tissue, resulting in central obesity and negative metabolic effects.[10] As a consequence, metabolic syndrome, insulin resistance, diabetes, and dyslipidemia are common among Hispanics[11,12], with rates varying by Hispanic origin. For example, Puerto Ricans had the highest prevalence of obesity, and associated comorbidities, such as diabetes, hypertension, and hypercholesterolemia, while South Americans had the lowest rates. Mexican men and women had the highest rates of diabetes.[13]

Place of residence in the United States within the Hispanic subgroup also seems to matter.[14] For example, Puerto Ricans living in the Bronx were more likely to have obesity and extreme obesity than those living in Chicago. This suggests that the built environment may also play a role in the obesity epidemic. Further evidence of the importance of the environment is that risk for obesity is higher among Hispanics/Latinos born in the United States, who had lived longer in the U.S., or who arrived in the U.S. at an early age.[14]

While clearly obesity, central obesity, and related-comorbidities are a major public health issue among Hispanics in the United States, few studies have been focused on addressing the impact of obesity and related factors on risk of cancer, survivorship, and prognosis among Hispanic women.[15]

Important Areas of Further Study

Despite the wealth of data on obesity and cancer, Dr. Bandera emphasized, several unresolved questions remain. First is how the different obesity phenotypes based on metabolic health (e.g., metabolically healthy obesity and metabolic obesity in the normal weight impact cancer risk and survival), and how body composition and body fat distribution affect cancer and cancer subtypes. Furthermore, whether these associations differ by race and ethnicity and underlying biological mechanisms need further investigation.

Summary

There is strong evidence linking excess body weight to increased risk and poorer outcomes among cancer survivors. Current national and international nutrition and physical activity guidelines promote maintaining a healthy weight for prevention of cancer and other chronic conditions. However, obesity remains prevalent among Hispanic populations in the United States, with obesity being more strongly associated with longer residence in the United States than with acculturation or country of origin. To counteract the obesity epidemic, interventions at the neighborhood, health system, and individual levels are needed.

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Genetic Ancestry, BMI and Tumor Genomic Alterations Among Latinx - Increasing Data Complexity

Dr. Lorna Rodriguez-Rodriguez is Professor and Vice-Chair of the Department of Surgery at the City of Hope Division of Gynecologic Oncology.

Dr. Lorna Rodriguez-Rodriguez

Cancer, BMI, and the Latinx Community

Dr. Lorna Rodriguez-Rodriguez began by challenging the audience to examine why cancer health disparities exist in the USA, directly tying these disparities to structural and systemic racism. Many factors contribute to health inequity, including environmental factors, social factors, psychological factors, and more. However, for this presentation Dr. Rodriguez-Rodriguez chose to focus on body weight and genetic factors as they relate to cancer.

A prospective trial was conducted at City of Hope in which every new patient diagnosed with cancer over a two-year span was given the opportunity to participate through informed consent. After a wealth of demographic information was obtained, each patient's germline DNA and tumor DNA were sequenced, and this data was assessed with respect to patient outcomes and clinical care. First, patients with homologous recombination deficiency (HRD) tumors were considered. These patients had either breast cancer, prostate cancer, ovarian cancer, or pancreatic cancer. Participants were also asked to self-identify as having one or more of five ancestries: African ancestry, European ancestry, South Asian ancestry, East Asian ancestry, or Native ancestry. Latinx patients almost exclusively self-identified as a mix of European and Native ancestry.

Among patients with African ancestry, 87.7% had BMI values that were overweight or obese, which was the highest percentage of all the groups. Those with European and Native ancestry, the Latinx group, had the second highest value at 79.7%. The East Asian group had the lowest percentage of participants with overweight or obese BMI values, at 51.3%.

When compared to the European group, Latinx breast cancer patients had a higher percentage of tumors that were homologous recombination deficiency (HRD)-positive. The average age of diagnosis was also nearly ten years younger than the average age among those of European ancestry. Previous studies have similarly reported a younger average age of breast cancer diagnosis among Latinx women, suggesting that this group may benefit from starting breast cancer screenings at an earlier age.

When considering all cancers, no difference was found in prevalence of pathogenic or likely pathogenic variants between Latinx and European individuals. However, recurrent germline variants of uncertain significance in ATM and RAD50, which are rarely found in the global population, were found in the Latinx population. This illustrates the need to expand the available genomic databases to aid in classification and interpretation of germline events in diverse ancestry groups.

Metabolic Versus Mutation Cancer Mechanisms

Dr. Rodriguez-Rodriguez also set out to discover if obesity can lead to the activation of tumor-inducing pathways, since it is known that hyperinsulinemia can activate metabolic pathways that block growth inhibition and enhance cell proliferation. Endometrial cancer patients of European ancestry who were obese were found to have more alterations in phosphoinositide 3-kinase (PI3K) pathways when compared to obese Latinx patients. This could mean that tumors in the Latinx cohort are more metabolically driven, whereas tumors in the European cohort are typically driven by mutations.

Patients with a BMI under 25 were found to have a higher recurrence/progression of endometrial cancer when compared to those with a BMI of 25 or more, a trend that was exaggerated in the Latinx cohort. This could be because those with a lower BMI had tumors that were driven by mutation, leading to poorer outcomes. Those with a higher BMI, on the other hand, may have had tumors that were metabolically driven and, therefore, less aggressive.

Guidelines for the Future

In closing, healthy weight is a key factor in avoiding cancers, such as breast cancer, which is prevalent in Latina women. Although HRD variants are common among Latina women with breast cancer, there may be other more rare pathological variants that could be uncovered with more extensive sequencing, and tumor and germline genomic sequencing should be prioritized to further understand the prevalence of these variants among Latinx patients. Although more information is needed to better understand metabolic versus mutation cancer pathways, initial results indicate that metabolic mechanisms may be more prevalent in Latinx endometrial cancer patients. If this proves to be true, lifestyle changes could be even more effective in this population.

Obesity and Severe Obesity: Opportunities for Culture-Based Cancer Risk Reduction in Latinxs

Dr. Lisa Sanchez-Johnsen is the Vice Chair for Research and Associate Professor in the Department of Family Medicine at Rush University Medical Center in Chicago.

Recommendations for researching obesity in the Latinx community

Dr. Sanchez-Johnsen's presentation drew on her wealth of experience both in practice and in academic research to outline eleven recommendations when researching obesity in the Latinx community. The first recommendation is to learn about Latinx culture and the local groups and their history. This can be a complicated endeavor. Even the words that describe this population can vary from Hispanic, to Latino, to Latin@, to Latinx.

Dr. Lisa Sanchez-Johnsen

Each community may have a different preference for how they prefer to be identified.

Race is also important when researching obesity in the Latinx community, and allowing individuals to choose more than one racial background can be helpful. Among US Latinos, 25% identify as Afro-Latino, Afro-Caribbean, or of African descent with roots in Latin America. Other terms can be population-specific, such as Chicanos, Tejano, Mexicano, Mexican-American, Boricua, Nuyorican, or La Raza. It is always best to ask the patient or research participant what word they use to describe their background.

The second recommendation is to engage Latinx communities with sincerity when developing research, clinical, or educational and training activities. Any new inquiry should proceed with the collaboration of those affected by the issues being studied in order to effect social change.

Third, it is important to learn about Latinx worldviews, cultural values, and gender roles, and how these relate to research, education, and clinical practice. This understanding is especially vital when learning about health issues such as obesity, weight, diet, and physical activity. Values such as familism (family values) or personalism (personal relationships), for example, can greatly impact health decisions. Machismo (culturally prescribed ways for a man to behave) and marianismo (culturally prescribed ways for a woman to behave) are also important values to understand.

The importance of statistics

The fourth recommendation is to learn about Latinx obesity-related disparities statistics. For example, Puerto Rican men and women have the highest rates of obesity among Latinx populations, while South American men and women have the lowest rates. Latinxs in general have a rate of severe obesity (BMI ≥40) of 7.1%, compared to the overall US population rate of 7.7%. Bariatric surgery can be an effective treatment for severe obesity, and is known to reduce cancer risk, but there are disparities in weight loss across ethnic groups after bariatric surgery. Clearly, these and others are important statistics to know.

Dr. Sanchez-Johnsen also advises, as recommendation number five, learning about health risk behaviors such as dietary intake, physical activity, and body image in Latinxs and encouraging healthy behaviors. For example, 93% of Mexican and Puerto Rican men eat fewer than five fruits and vegetables per day, and Latino men engage in more occupational and overall physical activity than Latina women, while Latina women engage in more household activity.

Sixth, it is important to learn about within-group differences (such as acculturation and immigration) as it relates to obesity-related behaviors and healthcare access. These can include generational differences, disabilities, religion, socioeconomic status, sexual orientation, and more. Acculturation is known to affect obesity, with those living in the US longer having a higher prevalence of obesity. Immigration status can also affect health, with undocumented and documented immigrants experiencing higher levels of anxiety and avoiding medical care. Skin color, a variable that has been consistently ignored in many studies, can be an important factor, with darker skinned Latinxs experiencing worse mental and physical health outcomes.

The seventh recommendation is to learn about the “Latinx health paradox”. This paradox, that Latinx Americans have lower mortality rates despite having lower average income and education, runs counter to existing knowledge about minority health. Many factors including ethnicity, immigration, and gender should be considered to further understand this paradox.

Language and culture in research

The eighth and ninth recommendations both involve language. Researchers must understand the impact of language on research, clinical care, education, and outreach. Individuals may prefer a different language depending on context, such as a formal work situation versus an informal social situation. Others may have anxiety regarding speaking a language or literacy in that language. Also, researchers must learn how to use interpreters and conduct culturally competent written translations of materials.

Dr. Sanchez-Johnsen closed by emphasizing the importance of cultural understanding. The tenth recommendation is for researchers to implement assessment and treatment considerations for Latinxs. Addressing adults with formal titles, allowing proximity in seating arrangements and personal communication, and following a hierarchical approach to greetings can go a long way in establishing rapport. The final recommendation is to engage in cultural humility, paying attention to your own thoughts, feelings, and interpersonal verbal and non-verbal behaviors. These recommendations can improve future efforts to understand the risk of obesity and cancer in the Latinx community.

Neighborhoods, Obesity and Cancer Among Latinxs in the US

Dr. Carola T. Sánchez Díaz is a postdoctoral fellow studying cancer epidemiology and health outcomes at Rutgers Cancer Institute of New Jersey.

The Latinx population now and in the future

To begin the presentation, Dr. Sánchez Díaz laid the groundwork for understanding the demographics of the Latinx population. First, it is the largest and second-fastest growing ethnic minority population in the US, with numbers expected to

Dr. Carola T. Sánchez Díaz

double in the next four decades. This growth is almost entirely driven by new births, not immigration. In 2016, about one third of Latinxs in the US were foreign born, but that number is expected to be less than one fourth by 2060, a year in which the Latinx population is also expected to be 28% of the overall US population.

Health in neighborhoods

Many factors contribute to obesity in the Latinx community, from individual factors, to interpersonal relationships, to the community at large, and finally to public policy. Neighborhoods in particular can be important social contributors to rates of obesity. Neighborhoods are made up of two components. The built environment includes public transportation, walkability, the food environment, public gathering spaces, and medical facilities. The social environment is made up of cultural norms, quality of education, crime, civic participation, and political influence. Both of these components contribute to obesity and the cancer continuum, and underline the fact that obesity is not simply an individual choice.

Many Latinxs live in ethnic enclaves, or areas of ethnic density based on language, birthplace, etc. These enclaves can have positive effects, such as access to resources, social support, collective efficacy, and certain cultural norms. However, they can also have negative aspects. They can be food deserts, have high poverty rates, lack green spaces, and be areas of high stress due to violence. All of these negative aspects can lead to higher BMI.

How neighborhoods can affect obesity and cancer

Studies considering obesity in the Latinx community often ignore the influence of neighborhoods on obesity, and the fact that these neighborhoods change over time. Dr. Sánchez Díaz and colleagues, however, recently performed a study assessing the effects of these complex neighborhood relationships on obesity and cancer. The study utilized latent profile analysis (LPA) to characterize neighborhood composition based on tract indicators of ethnic enclaves, disadvantage, and affluence.

Using the Metro Chicago Breast Cancer Registry, 13,815 Latinas over 40 years old with at least one mammogram were included. 25% of the participants were found to be obese, and 18% were morbidly obese. When compared to normal-weight women, these obese or morbidly obese participants were more likely to live in high disadvantage, in neighborhoods of low affluence, and in ethnic enclaves.

Some limitations of the study included the use of BMI as the measure of obesity which is an imperfect measure for obesity. The study was also not able to account for individual socioeconomic status or birthplace. Certain aspects of the built environment such as walkability and access to healthcare were also not considered, which could have a profound impact on obesity. Individuals also self-selected their own neighborhoods, which could affect accuracy.

The future of neighborhood-informed research

Despite limitations, the results of the study have important implications. The conceptualization of neighborhood factors is imperative, given the interacting influence of these factors on health. This study could also be a starting point for the disentangling of complex causal pathways that explain the impact of neighborhoods on Latinx health. Finally, to the extent that LPA can group women geospatially, this approach can indicate where intervention is needed.

In the future, Dr. Sánchez Díaz would like to explore the correlation between how obesity develops over time and the changing nature of neighborhoods over time. Acculturation and place of nativity should also be explored. Further, understanding the effects of social and built environmental factors on obesity and cancer could help inform programs and public policy. This could greatly increase the efficacy of programs promoting healthy behavior since these programs would be based on specific contextual factors in a given area.

2. THE STATE OF LATINO CANCER POLICY AND ADVOCACY

Effective Latino Cancer Policy Requires Effective Legislative Advocacy

Dr. Jaime Estrada is the Founder and President of Texas Doctors for Social Responsibility, as well as the Founder and Board Chair of the Adolescent and Young Adult Cancer Foundation.

Falling through the cracks: a case study

Dr. Jaime Estrada began by sharing a case study of a 35-year-old man from central Texas. This man was uninsured and working in construction when he began having headaches for several weeks. He was diagnosed with a curable brain tumor called oligodendroglioma. After moving to Austin where he was unable to find work and began having seizures, he moved to San Antonio to live with a relative. Although he applied for Medicaid, Social Security, and CareLink, was denied for each program and was eventually lost to follow-up. This heartbreaking case is an example of the deplorable state of healthcare for uninsured cancer patients in Texas. Nationwide, up to 650,000 cancer patients are uninsured and live in non-expansion states such as Texas. Many of them are Latinos.[1]

Dr. Jaime Estrada

Health insurance disparities among Latinx cancer patients

Latinos make up the largest and youngest community of color in the US with a population of 60.6 million. Despite substantial reductions in the percentage of uninsured workers following the passage of the Affordable Care Act, Hispanic men and women continue to be the least likely to have health insurance of any major racial or ethnic group in Texas. Among those 18 to 64 years of age, 26% of Hispanic individuals were uninsured, compared to 9% of non-Hispanic White individuals in 2017-2018. Uninsured rates are highest in the Mexican population (30%) and those who are foreign born (37%). Hispanics are also less likely to have a usual source of care compared to non-Hispanic Whites, especially men. Expanding Medicaid in states with large Hispanic populations, and extending coverage to undocumented immigrants, the majority of whom identify as Hispanic, would be a major step in addressing these inequities.[2]

Cancer is the leading cause of mortality among Latinos, accounting for 20% of deaths. In fact, 1 in 3 Hispanic men and women will be diagnosed with cancer in their lifetime, with 1 in 5 men and 1 in 7 women dying from the disease. Many factors contribute to this prevalence, including socioeconomic status, structural racism, cultural values and beliefs, acculturation, and access to care.[2]

Cancer is not the only condition affecting Latinos, however. The Covid-19 pandemic also disproportionately affected the Hispanic community and communities of color in the areas of virus case burden, mortality, employment, health insurance, and access to healthcare. Further, life expectancy in Hispanic individuals declined by three years in 2020, compared to a one year decline among non-Hispanic White individuals.[2]

The importance of Medicaid

Medicaid plays a vital role in providing healthcare coverage to lower income cancer patients and survivors, covering more than 2 million Americans with a history of cancer. Following the enactment of the Affordable Care Act, expansion states provided all low-income adults access to healthcare through Medicaid. However, countless individuals in non-expansion states such as Texas still lack access to a healthcare coverage option.[3]

Patients covered by Medicaid are more likely to receive preventive care and cancer treatment services. Cancer in these individuals is identified at an earlier stage with better outcomes. Medicaid also promotes tobacco cessation and provides financial protection for individuals and families. Medicaid expansion even has a positive impact on states’ economies.[3,4]

A pervasive problem and a potential solution

The lack of Medicaid expansion in Texas, along with the stringent eligibility requirements, have driven the uninsured rate in the state to 18.4% in 2019, the highest rate in the US, compared to the national average of 8.5%. Although 5 million residents are currently covered by Medicaid, an additional 1.7 million Texas residents would be covered if the state accepted expansion. In 2022, Texas left 15.3 billion federal dollars on the table by not expanding Medicaid. As a matter of fact, from 2014 to 2024, Texas residents will have paid $36.2 billion in federal taxes that will pay for Medicaid expansion in other states.[5]

Dr. Estrada concluded his presentation by outlining some tenets of effective legislative advocacy. First is participation in active state advocacy coalitions and organizations, which in Texas include Cover Texas Now, SickofitTX, and Texas Doctors for Social Responsibility. It is also vital to educate the public, medical professionals, and elected officials on the economic and health benefits of the expansion. Empowering constituents of key legislators to ask their representatives to sponsor and support expansion bills can be an effective strategy, as well as voting and supporting registration. If these principles of effective legislative advocacy are enacted, the hope of better healthcare for Latinos may be realized.

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The State of Policy Advocacy in Latino Cancer

Dr. Rogelio Sáenz is a Professor in the College of Demography at the University of Texas San Antonio, and has written extensively on Latinx race and ethnic relations, inequality, immigration, public policy, social justice, human rights, and the impact of COVID on the Latinx community. The presentation was co-authored by Julie Gonzalez, Ph.D. student in the Department of Demography at University of Texas at San Antonio.

The growing Latino population with an increasing cancer burden

Dr. Sáenz began by speculating possible reasons why the Latinx population is often overlooked in cancer research, despite cancer being the community's major killer. Potential causes of this neglect may be the youthfulness of the Latino population, the Latino paradox of longer life expectancy despite lower economic resources, or the lower cancer incidence. However, Latinos have higher rates of liver cancer, stomach cancer, and cervical cancer, all of which are infection-related, more likely to be preventable, and associated with low levels of access to adequate healthcare.


Dr. Rogelio Sáenz

The Latino population is growing, having quadrupled from 1980 to 2020 and accounting for more than half of US population growth from 2010 to 2020. The population is also aging, with the 85+ Latino population growing by 72.5% from 2010 to 2019, more rapidly than any other age group. Despite this growing population, however, Latinos have the highest percentage of persons 19 to 64 years of age without health insurance, at 25.9%. When considering those without US citizenship, that number increases to 49.0%.

The Latino population is also disproportionately bearing the burden of increased cancer rates. From 1999 to 2016, cancer cases have increased by 106.0% in the Latino community, compared to a 17.5% and 50.0% increase in White and Black communities respectively. This trend is expected to continue, with Latino cancer cases accounting for 8.1% of overall US cases in 2016, but predicted to account for 17.6% by 2060.

The state of Latino cancer advocacy

Despite the growing Latino population and the growing cancer burden on this population, Latino voices advocating policy change are missing. In Texas, for example, although Latino and White populations are approximately the same in number, only 50.7% of Latinos are eligible to vote, compared to 79.2% of the White demographic.

To combat this trend, Dr. Sáenz referred to the work of Dr. Kate Murray and colleagues as they studied Latino and political advocacy for cancer control in a US-Mexico border community. This work emphasizes the importance of widespread media dissemination and grassroots efforts related to immigration reform and environmental justice. In Dr. Murray's work, 42 participants were recruited from the border community to participate in political health advocacy. Several themes emerged. First, participants noted the lack of awareness of how politics are linked to fighting cancer. A second theme were the practical barriers to advocacy, including time, family responsibilities, immigration status, and more. Cultural and contextual barriers to advocacy, such as distrust in the government and a lack of Latino politicians, were also noted; as well as an overall need for tailored approaches regarding Latino engagement in advocacy.

Current players in the advocacy field

In light of this need, several organizations have stepped to the forefront of Latino cancer policy advocacy. Some examples are Salud America, which is dedicated to providing information on cancer in the Latino community and hosting an annual conference on the same topic; the UC Davis Health Comprehensive Center, which has started the Latinos United for Cancer Health Advancement (LUCHA); the Memorial Sloan Kettering Cancer Center, which focuses on Latinos; and the Nuestras Voces Network, which emphasizes education as well as organizational efforts. Other organizations, such as Public Health-Seattle & King County/Access & Outreach and the Hispanic Advisory Council of Cancer Treatment, are also involved in policy advocacy.

Dr. Sáenz concluded by providing the context of racism to the history of Latinos and cancer. For many years, the message was “know your place, keep quiet”. Now, however, democratic and social justice conceptual models show that education, advocacy, and policy changes at the grassroots level can be effective. Some such efforts are already underway, and others can be grown through coordination and collaborative energies. The heart of change, however, starts with each individual asking themselves “What can I do?” to contribute to building political advocacy.

3. LATINO CANCER RESEARCH METHODOLOGY

Framing Latino Cancer Research and the Census Bureau Data That Enable It

Mr. Robert L. Santos is the Director of the US Census Bureau, the first Latino to serve in that position.

Mr. Robert L. Santos

Lessons from a vibrant career

Director Santos began by sharing wisdom gleaned from 40 years of research, including two ways in which it is important to think differently about research problems. First, researchers tend to emulate the methods and thought processes that they have been taught, but these conventional approaches may become self-propagating, and unnecessarily constraining. Second, because research tends to be specialized, solutions should be specialized as well, and not holistic.

A whole life informing a holistic approach

In order to demonstrate the importance of a holistic approach, Director Santos related a story from early in his career in which he served on a health services research grant review committee. On this committee, he was not only the only statistician, but the only person of color as well. One proposal under review featured a randomized controlled trial designed to test an inexpensive alternative treatment for a chronic condition, aimed solely at uninsured patients. Director Santos was the only person on the committee troubled by the design of the study, his discomfort springing from his experience growing up as a Latino in a low-income barrio.

Director Santos's unique perspective made him uncomfortable with a two-tiered health care system, where the insured receive a conventional, high-quality treatment, but the uninsured receive a cheaper, and potentially less effective, treatment. On his recommendation, the study was revised so that the alternative therapy was offered to all patients regardless of health insurance status. After all, if the therapy is effective, it should be available to everyone. If Director Santos had restricted himself to a statistical analysis only, he would have approved the study, but he instead allowed his life experience, culture, and critical thinking to influence his research practice, leading to a more holistic and thoughtful result.

The broad story of cancer

Having such a holistic approach is important because cancer itself does not occur in a vacuum but is multifactorial. The environment can contribute to cancer, from living downwind from a chemical plant to pesticide exposure, to ultraviolet rays from the sun. Socioeconomic factors can also play a role, with many patients having limited access to healthcare, limited time off for doctors' visits, and limited access to broadband internet for telehealth visits, not to mention the struggle of paying healthcare costs. Compounding the problem, some patients may have untreated mental health conditions, or may be dealing with the stigma of being an ex-offender. Considering all these obstacles, healthcare providers can be a part of the solution, with research demonstrating improved outcomes if the provider speaks even a little Spanish.

Importantly, these many factors, often called social determinants of health, cannot be mere variables in detached research, but should rather "scream a story of human condition," said Director Santos. Cancer does not occur in a vacuum, and neither should the research.

The data informs the saga

The context of this human condition requires data. To this end, there is a wealth of publicly available information provided by the Census Bureau that can help characterize residents of Latino communities. Combined with environmental data, these tools can help identify neighborhoods that may be subject to chemical exposure. The 2020 Census Demographic Data Map Viewer, for example, can identify various demographic characteristics down to the census tract level. The American Community Survey is another important tool providing data on a variety of community factors at the tract level, including poverty rates, employment, internet access, and much more. Community Resilience Estimates provide data reflecting the capacity of individuals and households to absorb the external stresses of disasters, such as natural disasters, fires, hurricanes, and even pandemics such as COVID. These estimates are based on 10 risk factors, including income-to-poverty ratios, age, access to a vehicle, and internet access.

Director Santos closed by reiterating a major goal of the Census Bureau: to empower data users with understandable, accurate, and timely information and the knowledge to put it to work. The Census Bureau's publicly available data can assist in identifying underserved communities and equitably distributing resources. The tools listed above, along with the Census Bureau's data dissemination specialists, can play a large role in taking the next step toward data equity.

Why Structure Matters

Dr. Robert A. Winn is the Director of Virginia Commonwealth University Massey Cancer Center, as well as the Senior Associate Dean for Cancer Innovation and Professor of Pulmonary Disease and Critical Care Medicine at VCU School of Medicine.

Context informing progress

Dr. Robert A. Winn

Dr. Winn's presentation focused on the structure that surrounds a successful career, advising the audience on aspects of a situation that can support success, and also blind spots that can halt growth. He began the session by describing the context surrounding many great scientific achievements. Crick, Watson, and Franklin, for example, could never have discovered the structure of DNA without the institutions they were a part of, the setting they lived in, and the foundation laid by other scientists. The same can be said of more recent Nobel winners, such as David Baltimore, Phillip Sharp, and James Allison.

The history of science, however, is also filled with blind spots. One example is the life of Henrietta Lacks, a cancer patient who passed away in 1951. After her death, her cells, called HeLa cells, were used by Jonas Salk in the development of the Polio vaccine, and were the first cells ever cloned. Although the scientists who used her cells became generationally wealthy, Lacks' own family received none of the benefit, and were not even informed of the use of their mother's cells until 1973. This story and others corroborate the long-held fear of hospitals among people of color, as it has now been proven that, in the past, cadavers were often used for scientific purposes without permission from the family of the deceased. Understanding the history of blind spots in science and acknowledging the importance of opportunity and setting can set the stage for a well-balanced career.

The importance of structure

When considering a new career opportunity, many turn to three important factors: space, time, and money. Lab space, how much time can be devoted to research, and compensation packages are all important factors when starting a new endeavor. However, the structure that surrounds those surface considerations can be just as vital. What are the institution's resources and infrastructure? What shared resources are available? What is the value system of the institution? What is the institution's record of success? Are there others available to collaborate? What is the climate, and is there administrative support? These questions and others can help build an understanding of the overall structure of an institution.

Mentor or sponsor?

Another key aspect to a supportive structure is having a mentor and a sponsor, two roles that are often confused but that are independently crucial. A mentor is someone who provides guidance and career advice, someone from a similar field who can serve as a sounding board and role model. A successful mentor/mentee relationship is enjoyable, built on openness and support with clear expectations and roles. A mentor talks to the mentee, helping to craft a career vision and providing insight from experience.

A sponsor, on the other hand, is someone who advocates for a person's career, making sure that person is seen, heard, and recognized by important people. Sponsors are often in leadership positions and believe in the sponsee enough to vouch for them. A sponsor talks about the sponsee to those in positions of power, giving the sponsee access to their personal network and championing the sponsee's visibility.

Yes or no?

One question that is often asked when attempting to build a successful career is whether to say "yes" or "no" to opportunities that may arise. There is a risk and a benefit to each answer, and in all cases, options must be weighed and a balance found. The risk of saying "yes" is that time is taken from a person's own goals, reducing overall effectiveness. The benefits, however, are new opportunities and collaborations.

Saying "no" also has risks and benefits. The risks are limited opportunities, a reduced network, and maintaining the *status quo.* The benefit, however, is that a person's goals remain the focus and top priority.

The Team

Dr. Winn closed by stressing the importance of building a team. The team starts with stable front-office leadership, as well as a supportive administration. A healthy team should also have a good coach in the form of a mentor and sponsor, as well as solid teammates to provide peer-to-peer mentorship. Supportive postdocs and graduate students are also necessary, and even an effective facility management crew should not be overlooked. Finally, a nurturing community outside of a person's immediate unit can be immensely helpful. A strong team with these qualities can help develop a love for science not only at the individual level, but on a larger scale, and lead to cooperation that is greater than the sum of its parts.

Advancing breast and liver cancer research in Mexico

Dr. Martin Lajous works with the National Institute of Public Health in Mexico and is an adjunct faculty member at Harvard Chan School of Public Health.

Mexico as an important player in cancer research

In his presentation, Dr. Lajous set out to convince the audience that high-impact cancer research can be performed in Mexico and that international collaborations can be effective in advancing cancer research. Incidence of breast cancer in Mexico is 43 per 100,000, which is lower than the 93 per 100,000 among the Latinx population in the US. However, breast cancer mortality is 10 per 100,000, making breast cancer the top cause of cancer death in women in Mexico. Survival is also lagging, with an estimated 72% 5-year survival nationally with two third of cases presenting in advanced stages of the disease.

Dr. Martin Lajous

Establishing the Mexican Teachers' Cohort

Dr. Lajous, along with Drs. Isabelle Romieu and Ruy López-Ridaura and supported by Dr. Walter Willett, set out to perform a prospective study of over 115,000 teachers in 12 states in Mexico, called the Mexican Teachers' Cohort (MTC). Teachers were chosen because of their familiarity with self-reported questionnaires and available health data, which is mandated by publicly funded healthcare and pension fund management organizations. A clinical sub-cohort of certain teachers from seven states was also established wherein more clinical data was obtained, and a biobank of blood, plasma, and serum aliquots was initiated.

Cohort follow-up was conducted via paper, online, and telephone questionnaires. The first follow-up, conducted from 2011 to 2013 had an 82.7% response rate, while the second, conducted from 2014 to 2020, had a 63.4% response rate. After cross-referencing the results of self-reporting with electronic health records and registries, 1,212 of the participants were confirmed to have breast cancer.

Initial findings and future directions

Some risk factors, such as breast cancer family history, seemed to follow established patterns in the cohort. However, other risk factors, such as nulliparity, did not follow known patterns from other populations, which may indicate different risk factors in this population.

Much more work is needed to make full use of the MTC. First, an analysis of the relationship between lifestyle and breast cancer should be conducted, and a risk prediction model should be established for breast cancer in Mexican women. The relationship between diabetes and cancer could also be studied, as there were over 12,000 women with diabetes in the cohort. Finally, it is important to optimize the existing research infrastructure by georeferencing participants, enriching biospecimen collection, and strengthening data sharing and systems.

The liver cancer conundrum

Another of Dr. Lajous' studies, funded by the NIH, looked at types of cancer in Mexico. This study found that liver cancer was the number one cause of cancer deaths in certain Mexican states. Interestingly, these states had an equal number of liver cancer deaths among men and women, a ratio that is typically 3:1 male to female. Upon further investigation, the study found a relatively low number of viral factors and a relatively low rate of alcoholism. Instead, it was hypothesized that aflatoxin might be playing a role.

Aflatoxin is found in contaminated maize and is common among certain rural subpopulations. In order to further understand this possible association, a small pilot study of 100 participants was conducted in Chiapas, Mexico, a rural area with high incidence of liver cancer. This study found that 85.5% (95% CI, 72.1-93.1) of the overall population had exposure to aflatoxin.

The future of liver cancer research and the future of collaboration in Mexico

Based on these findings, Dr. Lajous is now looking retrospectively at aflatoxin and liver cancer cases in five Mexican states, as well as determining the feasibility of prospectively recruiting men and women with liver cancer. More work is needed to characterize the cancer risk distribution in Mexico and to explore determinants of aflatoxin levels. Another approach to the aflatoxin problem could be in collaboration with a National Cancer Institute initiative in Guatemala, the country with the highest aflatoxin exposure in the region. Compiling the results from Guatemala with findings in Mexico and other North American countries could reveal new associations between aflatoxin exposure and liver cancer.

Such collaborations are in fact a large part of what Dr. Lajous is striving to accomplish, working toward a more global view of public health goals and increasing data visibility and data sharing flexibility. These collaborations can also support junior investigators, providing them with career development opportunities. Dr. Lajous ended by stressing the importance of maintaining active cross-border conversations, engaging all parties for the greater good.

FIPOL: An International Effort to Support Latino Psycho-Oncology Research and Capacity Building

Dr. Rosario Costas-Muñiz

Dr. Rosario Costas-Muñiz is Assistant Attending Psychologist in the Department of Psychiatry & Behavioral Sciences at Memorial Sloan-Kettering Cancer Center.

A glaring hole in psycho-oncology knowledge

Dr. Costas-Muñiz began by discussing psycho-oncology. In 2011 an international movement began to declare stress management the sixth vital sign of cancer. This focus on acknowledging and managing psychosocial distress was spearheaded by the International Psycho-Oncology Society (IPOS). Within IPOS, the International Federation of Psycho-Oncology Societies is responsible for the global, panoramic view of psycho-oncology. Unfortunately, in this institution, Latin America is woefully underrepresented, with only Brazil and Peru having a presence, leaving a dearth of knowledge about psycho-oncology in this region.

Six years ago, in order to address this lack of knowledge concerning psycho-oncology in Latin America, Dr. Costas-Muñiz conducted a survey of 59 mental health providers of cancer patients. These providers reported the themes they addressed with patients, including coping strategies, patient autonomy, end-of-life concerns, family related issues, and others. The therapeutic approaches were also reported, with cognitive behavioral therapy (CBT) being the most common. Despite this new knowledge, however, it was clear that much more work was needed to build an understanding of psycho-oncology in Latin America.

The founding of FIPOL

To this end, Dr. Costas-Muñiz founded FIPOL, which stands for Formación en Investigación Psicosocial Oncologica para Latinoamérica, a rough English translation being “Capacity Building in Psychosocial Oncology for Latin America.” This international collaboration, founded in 2017, aimed to connect Spanish-speaking clinicians and researchers interested in psychosocial oncology from Latin America, the US, and Spain. FIPOL seeks to develop collaborative research projects and spread knowledge of the latest research in psychosocial oncology through four avenues: research initiatives, communication and dissemination, resource development, and seminars and events.

FIPOL built its audience through existing networks, provider studies, and professional conferences. It engages this audience using a broad approach: listserve, the website (www.fipol.info), LinkedIn, Twitter, Facebook, Instagram, and YouTube. Email is also used to share FIPOL course invitations, information about other organizations' events, recent article highlights, cancer prevention campaigns, invitations to participate in ongoing studies, and more.

The research of FIPOL

One of the research initiatives currently being spearheaded by FIPOL involves recommendations on the use of telehealth in psycho-oncology for Latin America. In a 2021 survey, 201 mental health providers were asked about the opportunities, challenges, and considerations of the use of telehealth. Issues such as the use of digital interventions, the challenges of working from home, institutional and governmental support, and considerations involving exposure to COVID were touched on in the survey. When asked under what circumstances telehealth would be appropriate for patients, providers most commonly listed living far from the clinic, living in rural or remote areas, a desire to avoid travel, and mobility limitations. When asked when telehealth would not be recommended, providers most commonly listed poor technological skills and older age.

FIPOL has many other areas of research interest as well. One current study is considering compassion fatigue within the oncology health team in Latin America. Another is focusing on the practice of psychosocial oncology during the COVID-19 pandemic. Still another involves validation of instruments used in the context of cancer. This study also includes a database of instruments indicating the studies in which the instruments have been used, the population studied, and the country involved.

The future of FIPOL

Dr. Costas-Muñiz ended by outlining the future focus of FIPOL research. One grant proposal concerns integrating mental health into health care systems in low- and middle-income countries. Another priority is the development of an app, eDESCANSO, to treat the cluster of depression, fatigue, and sleep disturbance.

The work that FIPOL undertakes comes with both challenges and opportunities. The challenges are multitudinous, including limited funding for global health initiatives, limited research infrastructure for psychosocial research, competing research priorities in participating institutions, lack of familiarity with psycho-oncology research, recruitment during the pandemic, and more. Opportunities, however, also abound. These include the commitment of the steering committee members and trainees, interregional collaboration, the wide availability of trainees, easy-to-use technologies like ZOOM and WhatsApp, social media tools, and shared language and values among Spanish-speaking clinicians.

Achievements of the Latin American Cancer Research Network (LACRN) and Lessons Learned: Notes to Improve Cancer Science in Latin America

Dr. Andrea Llera is the Executive Manager of Latin American Cancer Research Network (LACRN), as well as group leader of translational genomics at the Fundación Instituto Leloir in Buenos Aires, Argentina.

Dr. Andrea Llera

The founding of LACRN

Dr. Llera began by introducing the Latin American Cancer Research Network (LACRN), an initiative funded by the National Cancer Institute (NCI) and the governments of five Latin American countries: Argentina, Brazil, Chile, Mexico, and Uruguay. This project was started in 2010 with a goal “to build a sustainable model with a systematic approach to do cancer research in Latin America,” and was built with longevity in mind. Six main focus areas were outlined from LACRN’s inception, including training key personnel, infrastructure (such as biobanks, pathology automation, and genomics equipment), data quality, sustainability, standardization of procedures, and networking.

The first study conducted by LACRN as a proof-of-concept was a Molecular Profile of Breast Cancer Study (MPBCS), with the primary endpoint of characterizing the distribution of molecular profiles of stage II and III invasive breast cancer. In the study, all levels of public health care were represented, as well as institutes and universities in all five participating countries, and over 300 collaborators were involved. The challenges of such a widespread and collaborative study were many, and although the planning for the study began in 2009, the first data presentation was in 2021.

The Molecular Profile of Breast Cancer Study

The study enrolled 1,449 patients, of which 1,300 were found eligible. Around 1,000 patients were studied by gene expression arrays and genotyped. In this way, the distribution of the molecular ancestry in each country’s cohort was studied, revealing an overall mixture of

European and Indigenous American ancestries in Argentina, Chile, and Mexico, and an expected African presence in Brazil and Uruguay.

Regarding gene-expression subtyping, analysis of breast cancer in the MPBCS cohort showed a very similar pattern of disease to other hospital-based Latin American cohorts. The distribution of PAM50 subtypes showed a bias towards highly proliferative, more aggressive tumors. This was partly expected because of the recruitment bias towards advanced stages. When survival was analyzed by country for each PAM50 subtype, Luminal A tumors led to the best survival, while Basal-like tumors were the ones associated with worst survival. Within the Basal-like subtype, Mexican patients showed twice the probability of survival than Argentina. Survival in HER2E patients was conditioned by trastuzumab availability.

The challenges of non-interventional studies

Non-interventional studies, such as MPBCS, are rare in Latin American countries for several reasons. First, these studies depend on the extensive work of one or a few investigators who are the engines of the entire study. Second, local needs tend to be different from the needs of the international scientific community. Research teams are often siloed, each group figuring out how to do the study by themselves, making collaborations difficult to establish. Furthermore, the primary investigator is sometimes a non-medical researcher with experience in grant applications but less experience in the clinical ecosystem; this is because healthcare professionals are typically overwhelmed with routine work and have no protected research time available. Variations in data handling can also lead to fragmentation, and there may be insufficient access to training in state-of-the-art technologies.

The financial struggles involved in this type of project are daunting. To begin, the investigators usually have to “bypass” their financial institutions to receive necessary funding for the study. And because the primary investigator is usually a non-medical researcher with little clinical experience, there are often unforeseen hidden costs. Further, many local funding sources do not include money for building databases.

The successes of LACRN

Despite these struggles, however, much was achieved through the MPBCS study beyond even the analyzed outcomes. Medical training was delivered and incorporated into daily practice in each of the participating countries. Biobanks were founded and maintained. Dynamic databases were established. Although some of the infrastructure of the study was lost – such as data entry force and health center navigators – the knowledge of how to build these resources has been established, and funding is all that is needed. Despite the overwhelming difficulties involved in conducting such a study, LACRN and the MPBCS laid an invaluable foundation for the future of breast cancer research in Latin America.

4. THE IMPACT OF COVID-19 ON CANCER CARE

COVID-19 Past, Present and Future

Dr. Carlos Del Rio is Distinguished Professor of Medicine, Global Health, and Epidemiology. He is also Executive Associate Dean of Emory University School of Medicine, and President-Elect of the Infectious Disease Society of America (IDSA).

The continued presence of COVID

Dr. Del Rio began by pointing out that the COVID pandemic is not over, despite gains made over the past year. At the time of his presentation, there were still two million global cases diagnosed daily, and close to 10,000 global deaths daily. Further, while there have been around six million total confirmed COVID deaths globally, the reality may be closer to 15 to 20 million due to uncounted deaths in low- and middle-income countries.

Dr. Carlos Del Rio

In the US alone, at the time of Dr. Del Rio's presentation, 2,000 people per day were dying of COVID, a number which did not account for excess deaths. In these unreported COVID deaths, the US is second only to Russia. Many of those excess deaths are patients who died from diseases, like cancer, who did not get needed care during COVID. Officially, the US has passed 900,000 reported deaths, resulting in the highest death rate of all wealthy countries.

COVID among communities of color

These deaths disproportionately affect communities of color. In the Latino community, for example, cases have been 1.3 times higher than in the White population, with 3.2 times more hospitalizations and 2.3 times higher death rates. These numbers highlight the health disparities apparent in COVID, which in turn are merely indicators of greater health disparities at large.

Some of these disparities can be traced to low vaccination rates in minority communities, especially during the Omicron wave. This is largely due to a communication failure by public health officials. Vaccines were designed to prevent severe disease and death, not infection, but mixed messaging led to confusion among the public, despite the success of vaccines. A clear message detailing the overwhelming success of vaccines in preventing death and hospitalizations must be made public, especially with respect to minority populations.

Other factors have also had a greater effect on communities of color. Latinos, for example, have experienced the greatest drop in life expectancy due to COVID, with nearly three years of life expectancy lost. Minority communities of all types are also more affected by children losing one or both caregivers. In the US as a whole, 165,000 children have lost at least one caregiver.

The role of vaccines and the Omicron variant

As of Dr. Del Rio's presentation, 64.5% of Americans were vaccinated. The rate of vaccinations increased somewhat around the time of the Omicron spike, but rates have largely plateaued. Booster rates follow a similar trend, with only 43% of those eligible having received the booster.

The Omicron variant presents very differently than the Delta variant. Omicron is 2.7 to 3.7 times more transmissible than Delta, but is more likely to cause asymptomatic infections. It is also airborne and causes different symptoms, with a smaller likelihood of lower respiratory tract infection or loss of smell but a larger likelihood of sore throat. Omicron also has many more variants and poses increased risk of reinfection.

While previous COVID infection does not seem to protect people against Omicron, most vaccines are effective, especially with a booster. Having three doses of an mRNA vaccine, for example, shows 82% vaccine effectiveness in regard to ER visits (95% CI, 79-84), and 90% vaccine effectiveness in regard to hospitalizations (95% CI, 80-94).

The future of the pandemic

Dr. Del Rio concluded by acknowledging that although the COVID pandemic will continue, the end is near. This optimism is due to the efficacy of the vaccines, the development of therapeutics, and the widespread use of diagnostic tests. That being said, it is important to continue to advocate for vaccinations and boosters, especially in those over 65. The pandemic has also revealed weaknesses in our healthcare system and infrastructure, especially when it comes to clear and understandable messaging, and vaccine hesitancy among communities of color is a big problem. A priority in public health must be to regain trust in vaccines, not only for the current pandemic, but for all future public health crises.

The Impact of COVID-19 among Latinos and NIH Initiatives to Advance Health Equity

Dr. Monica Webb Hooper is Deputy Director of the National Institute on Minority Health and Health Disparities.

Health disparities in underserved populations


Dr. Monica Webb Hooper

Dr. Webb Hooper set out to discuss two studies designed to promote health equity in COVID-19 care, co-led by the National Institute on Minority Health & Health Disparities (NIMHD). The mission of NIMHD is to work with the NIH and the U.S. Department of Health and Human Services to advance the science of health disparities and to move closer to meaningful progress. The NIH has designated several groups as populations with health disparities, including Black Americans/African Americans, Hispanics/Latinos, American Indians/Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minority groups.

Health disparities in these populations are multifaceted and include higher rates of infant mortality, stroke, cancer, heart disease, diabetes, hypertension, and now COVID-19. During the pandemic, excess deaths were much higher in the Hispanic/Latino population compared to White patients. Life expectancy was severely affected as well, with Latina women showing a life expectancy loss of 2 years, and Latino men showing a loss of 3.7 years. Even among cancer patients during the pandemic, when compared to White patients, Hispanics/Latinos had a greater reduction in overall visits, were less likely to use telehealth, had greater treatment delays, and had higher rates of COVID-19 infection.

Another disparity in COVID-19 outcomes is the uptake of vaccines, which is influenced by vaccine hesitancy, a complex and nuanced issue affected by the three “C’s”: complacency, convenience, and confidence. Vaccination rates among Hispanics/Latinos have improved; however, booster rates remain alarmingly low in this population.

Evaluating vaccine intervention strategies

Dr. Webb Hooper described a funding opportunity that addresses this very issue. This Notice of Special Interest (NOSI) is entitled Research to Address Vaccine Hesitancy, Uptake, and Implementation among Populations that Experience Health Disparities, and aims to evaluate intervention strategies to facilitate vaccine uptake in general, not only COVID-19 vaccines. The initiative focuses on populations at increased risk for morbidity and mortality due to long standing social disparities and seeks to evaluate behavioral interventions, vaccine-related communications, and interventions addressing misinformation, using multi-level and other approaches.

Rapid Acceleration of Diagnostics - Underserved Populations (RADx-UP)

The second initiative presented by Dr. Webb Hooper is the Rapid Acceleration of Diagnostics - Underserved Populations (RADx-UP) initiative. RADx-UP seeks to enhance COVID-19 testing among underserved and vulnerable populations across the U.S. by supporting a consortium of over 100 community-engaged research projects to understand factors related to testing acceptance and uptake, as well as implementation of testing interventions. The three key components of RADx-UP are testing, return-to-school, and social, ethical, and behavioral implications (SEBI) research.

There are RADx-UP participants in all 50 states, several U.S. territories, and the District of Columbia, with 57 projects focusing on Hispanic/Latino populations. This consortium involves over 100 projects, with over 1.2 million participants and over 1.3 million tests conducted. At least 48 journal articles have been published on this work with more under review.

COVID-19 testing among Hispanics/Latinos

One RADx-UP study conducted in Baltimore found that Latinxs had a 31.5% SARS-CoV-2 positivity rate, compared with 7.6% among White patients. These Latinx patients tended to be younger and have a larger household size compared with White patients who tested positive for SARS-CoV-2; over half of the Latinx patients were asymptomatic, and they spoke Spanish as their preferred language. Another study from south Texas counties with mostly Mexican-American residents found that single-parent households and households with limited English proficiency had higher relative incidence risk for COVID-19.

One of the SEBI studies supported by RADx-UP from New Jersey used surveys and interviews to confirm that public health officials should seek trusted leaders within the community to aid in addressing unanswered questions to reduce vaccine hesitancy. Still another study was an online survey looking at the use of self-testing kits. Motivation to distribute kits was found to be associated with above-average income and completion of college, while motivation to self-test after receiving a kit was found to be associated with above-average income and Hispanic ethnicity.

The future of addressing disparities in COVID-19 among underserved communities

Dr. Webb Hooper closed by noting that funding opportunities for Phase III of RADx-UP are now published, with a focus on the use of rapid diagnostic testing, partnership-driven research, and variations on messaging. She also emphasized the lessons learned about engaging underserved communities in the COVID-19 pandemic, including culturally appropriate approaches for increasing trust, the use of community advisory boards to provide key recommendations and support, the importance of community engagement, flexibility and the ability to adapt, and partnerships with community health clinics.

The Impact of COVID-19 Among Pediatric Oncology Patients

Dr. Terrie Flatt, from Children's Mercy Hospital, presented a study on how COVID-19 impacted pediatric oncology patients. This understanding is crucial to recognizing associated complications, defining patients that are at highest risk for severe illness and delays in chemotherapy, and improving medical interventions and outcomes.

Dr. Terrie Flatt

Patient characteristics

Real-time chart reviews of 54 patients diagnosed with COVID-19 were performed between March 15, 2020 and April 15, 2021 at Children's Mercy Hospital in Kansas City, MO. This patient cohort was pre-Omicron variant, and was diagnosed via polymerase chain reaction (PCR) test or rapid-antigen test. The median age was 11.1 years (range 1-21), with 55.6% being female (n=30). Caucasian patients made up 53% (n=29) of the cohort, while Hispanic patients made up 31.5% (n=17). This was a disproportionate number of Hispanic patients, who represented approximately 15-17% of the entire oncology patient population at the hospital. The underlying cancer diagnosis was predominantly leukemia or lymphoma at 59.2% (n=32), and most patients were receiving active chemotherapy (62.9%, n=34).

Clinical presentation and outcomes of the cohort

Among the cohort, 63% (n=34) were symptomatic, with the most common presenting symptoms being fever (39%), fatigue (30%), and cough (15%). Hispanics represented a disproportionate number of symptomatic patients, however, with 83% being symptomatic, compared with 55% of non-Hispanics (*P*=0.068). Hispanic patients were also more likely to develop the following complications compared with non-Hispanics: transaminitis (73.3% versus 37.5%, *P*=0.0084), pancreatitis (22% versus 0%, *P*=0.044), and myelosuppression (73%, with 11/15 among Hispanics receiving active therapy).

Among those treated, chemotherapy was held in 46% of patients, although this number disproportionately represented Hispanics compared to Non-Hispanics (80% versus 25%, *P*=0.0011). Hospitalization occurred in 18.5% (n=10) of patients, with a median length of stay at 10.9 days (range 1-32). This was again a disproportionate representation, with 29% (n=5) of Hispanics being hospitalized compared with 17% (n=5) of non-Hispanics (*P*=0.256). Overall, two patients died of COVID-19 related complications, both of whom had undergone Chimeric Antigen Receptor (CAR) T-cell therapy for pre-B cell acute lymphocytic leukemia (ALL).

COVID-19, pediatric oncology, and Hispanic populations

Dr. Flatt closed by reporting the major conclusions of the study. First, pediatric cancer patients generally experienced mild illness with COVID-19. However, Hispanic patients were disproportionately affected by COVID-19 compared with other racial and ethnic groups, experienced more symptomatic illness, and more frequently had their chemotherapy doses held. The study also showed that patients with an underlying diagnosis of leukemia/lymphoma appeared to be at higher risk for severe COVID-19 related morbidities, and patients who had undergone CAR T-cell therapy that contract COIVD-19 were also at high risk for COVID-19 related morbidities and mortality. Finally, the study showed that understanding the clinical findings and outcomes among minority populations is critical to providing optimal clinical care and achieving best outcomes for all patients.

5. TACKLING SPECIFIC CANCER DISPARITIES

Updates in Genomics of Breast Cancer among Latina Women

Dr. Elad Ziv is a Professor of Medicine at the University of California San Francisco (UCSF), with a research focus on human genetics of cancer susceptibility and hematological traits.

Genomics explained

Dr. Elad Ziv

5To set the stage for his presentation, Dr. Ziv explained genomics in a lay-friendly way, describing it as a long series of letters. A change of one letter in this series, from an A to a G for example, can lead to anything from a change in height to a disease susceptibility. Not all pages of the “book” of genomics are understood, and there are portions of the genome that are still a mystery, so there is an aspect of careful deciphering involved each time a new individual is sequenced.

In the context of cancer, there are two types of genetic variation. The first is inherited genetic variation. This variation involves mutations in genes which can be passed down within families, which affect all cells, and which can affect disease susceptibility. The second is somatic genetic variation. This variation involves mutations in a small subset of cells, cannot be passed on from parent to child, and can sometimes lead to abnormal growth or cancer.

Insights from the Romero-Cordoba study

Until recently there has been very little research concerning somatic genetic variation in Latinas. One study by Romero-Cordoba and colleagues from the Mexican National Institute of Genomic Medicine found that 28% of Hispanic-Mexican women with breast cancer had a mutation in a gene called *PIK3CA*. This gene is commonly mutated in other populations as well, and it encodes a protein that is commonly targeted by anti-cancer therapies. The second most commonly mutated gene in Hispanic-Mexican women, *TP53*, is also common in breast cancer in other populations. However, the third most commonly mutated gene, *AKT1*, does not typically play a role in other populations. The fact that this gene encodes a protein that can be targeted by anti-cancer therapies makes it worthy of further study. Although Dr. Ziv's own work has not yet corroborated this elevated *AKT1* mutation prevalence in the Latina population, research is ongoing in this area.

A new look at breast cancer in Latinas

In Dr. Ziv's lab, 147 tumors from 141 Latina women were sequenced. The mean age of the cohort was 48.7 years, and most cancers were stage I and II, with only 14% being stage III or IV. Most tumors (82%) were estrogen receptor (ER) positive, and 71% were progesterone receptor (PR) positive. About 17% were human epidermal growth factor receptor (HER2) positive, a higher proportion than in the general population. Dr. Ziv compared his cohort with The Cancer Genome Atlas (TCGA) program, a large, publicly available genomic database that unfortunately has a very low number of Latina women.

Comparing somatic mutational signatures

In comparing the two cohorts, Dr. Ziv considered somatic mutational signatures, which look not only at individual mutations, but at common mutational patterns. Signatures 2 and 13, for example, are associated with an APOBEC mutational pattern, which is seen in breast cancer and other cancers. Signature 3 is associated with a homologous recombination repair defect that prevents cells from repairing double stranded DNA. All three of these signatures were found at similar rates in the Latina cohort and TCGA.

A new signature was found, however, that had not previously been reported in association with breast cancer. This new finding, signature 16, was amplified in two breast cancer subtypes, luminal A and luminal B, and was found to be more common in Latinas compared with non-Hispanic White patients. Signature 16 represented 27% of the Latina cohort in Dr. Ziv's work, and 20% of Latinas in the Romero-Cordoba study. However, signature 16 was only found in 10% of non-Hispanic White patients from TCGA.

Comparing genetic composition through copy number analysis

Another difference between the Latina cohort and TCGA was found through copy number analysis. Many tumors not only have mutations, but also amplify certain parts of the genome, which can be assessed through copy number analysis. In Dr. Ziv's Latina cohort, a gene called KIA0100 was found to have high amplification and high gene expression in 11 women. This was compared to zero women in the entire TCGA dataset.

In summary, Dr. Ziv emphasized the key findings from his work. First, signature 16, which is more commonly associated with luminal cancers, is more prevalent in Latinas. Second, although Dr. Ziv's findings have yet to corroborate the finding, the Romero-Cordoba study shows a higher rate of *AKT1* mutations in Latinas, representing an important area for future study. Finally, there is higher amplification and expression of the KIA0100 gene in Latina women.

Updates and Trends in Breast Cancer Treatment: Advancing the Science of Cancer in Latinos

Dr. Filipa Lynce is Assistant Professor of Medicine at the Dana-Farber Cancer Institute at Harvard Medical School.

Breast cancer in Hispanic women

Dr. Filipa Lynce

Breast cancer is the most commonly diagnosed cancer, as well as the leading cause of cancer death among Hispanic women. Although incidence of breast cancer in Hispanic women remains about 29% lower than in non-Hispanic White women, the rate increased by about 0.4% annually from 2006 to 2015, while it has remained stable in non-Hispanic White women. Mortality rates have been decreasing; however, the rate of decrease is 1.1% per year in Hispanic women versus 1.8% per year in non-Hispanic White women. Breast cancer is also less likely to be diagnosed at the localized stage in Hispanic women, with only 57% compared with 65% in non-Hispanic White women.

In the general population, 68% of breast cancer patients present with the hormone receptor-positive (HR+)/human epidermal growth factor receptor 2-negative (HER2-) subtype, 10% have HR-/HER2-, 10% have HR+/HER2+, 4% have HR-/HER2+, and 7% are unknown. Hispanic women, however, are more likely to be diagnosed with HR-/HER2+ and HR-/HER2- tumors. The latter, also called triple negative breast cancer (TNBC), affects Hispanic women at a rate of 16-17% compared with 11-15% for non-Hispanic White women. Both HR-/HER2+ and TNBC are associated with worse outcomes.

Novel therapies for breast cancer

Dr. Lynce presented five novel therapies recently approved for breast cancer. The first was immunotherapy, and pembrolizumab is currently the only immunotherapy drug approved for the treatment of breast cancer. Importantly, pembrolizumab is approved for the treatment of high-risk, early-stage TNBC, showing improvement in event-free survival (EFS) in early stages and overall survival (OS) in advanced settings when compared with chemotherapy alone. It is associated with some immune-related adverse events (irAEs), including skin conditions, gastrointestinal (GI) pathologies, and endocrinopathies.

Poly-ADP ribose polymerase (PARP) inhibitors represent another novel therapy for breast cancer treatment. Two therapies in this drug class, olaparib and talazoparib, have been approved for the treatment of HER2- breast cancers. Olaparib has shown improvement in disease-free survival (DFS) in the adjuvant setting in patients with high-risk, early-stage, HER2- breast cancer. The main toxicities are anemia, neutropenia, nausea, vomiting, and fatigue.

Another novel therapy involves antibody-drug conjugates, also called “smart bombs” due to their ability to deliver large doses of chemotherapies directly to tumors through linkage to specific antibodies. Two drugs that received recent approval are sacituzumab govitecan and trastuzumab deruxtecan. Sacituzumab govetican has been approved for the treatment of metastatic TNBC, and showed improvement in progression-free survival (PFS) and OS compared to chemotherapy. Trastuzumab deruxtecan has been approved for the treatment of stage IV HER2+ breast cancer.

Tyrosine kinase inhibitors are yet another novel approach to breast cancer treatment. Tucatinib, an oral chemotherapy agent, has been approved in combination with trastuzumab and capecitabine for the treatment of metastatic HER2+ breast cancer. It is also the first drug to show significant activity against active CNS disease.

Cyclin-dependent kinase 4 and 6 (CDK4/6) inhibitors were the final novel approach presented by Dr. Lynce. Three of these inhibitors have been approved for the treatment of HR+/HER2- breast cancer. Palbociclib and ribociclib have been approved in combination with endocrine therapy in the metastatic setting, showing improved PFS compared to endocrine therapy alone. Abemaciclib has been approved for the adjuvant treatment of node-positive early breast cancer at high risk of recurrence and metastatic HR+/HER2- breast cancer.

Unique challenges for novel therapies in the Hispanic community

Despite the promise of these novel therapies, questions and challenges specific to the Latino population remain. In immunotherapy, for example, there is insufficient data to determine whether differences exist between racial and ethnic groups on dosing, efficacy, and adverse events. When it comes to PARP inhibitors, there may be a lower number of Latinas eligible due to a lower uptake of genetic testing in the Latino population. In the pivotal sacituzumab study, which is one of the antibody-drug conjugates, the median duration of treatment was lower in Latinos compared with White patients. Finally, since the Latino population has been shown to have lower adherence to oral medications due to concerns with side effects as well as copays, therapies involving tyrosine kinase inhibitors and CDK4/6 inhibitors might be affected.

Dr. Lynce closed by stressing the disparity of Latinos represented in clinical trials. Despite representing 18% of the population, Latinos only represent 4-8% of clinical trial participants. In a recent study of almost 6000 precision oncology trials, all minority groups were underrepresented, with Latinos showing the greatest disparity.

The Landscape of Breast Cancer Genetics in Puerto Rico

Dr. Julie Dutil leads the Cancer Genetics & Genomics Research Program at the Ponce Research Institute at Ponce Health Sciences University in Ponce, Puerto Rico.

The importance of understanding genetic uniqueness

Dr. Dutil began by stressing the importance of genetic uniqueness in the realm of health and disease risk. However, genome-wide association studies (GWAS) show great disparity in cancer study representation, with Latin American patients accounting for only about 1% of participants. The Cancer Genome Atlas (TCGA) also shows underrepresentation, with only 3% of participants identifying as Hispanic or Latino. Even in laboratory research of cellular models of cancer, cellular lines originating from White or Asian patients are easily available, while African or Hispanic samples are more difficult to obtain.

Dr. Julie Dutil

Hispanic populations are admixed, meaning they originated from three different sources: Indigenous American, European, and African populations. Hispanic populations are therefore heterogeneous, and genetic components vary by area. The Mexican population, for example, has a larger Indigenous American component than the Puerto Rican population, which has a larger African component. Even within the Puerto Rican population genetic components vary, with residents in areas that were formerly sugar cane plantations having a stronger African genetic component.

The Puerto Rico Breast Cancer Genetics and Genomics Study

In order to assess how these genetic variations affect breast cancer risk, Dr. Dutil started the Puerto Rico Breast Cancer Genetics and Genomics Study (PUR-BCGG) in Ponce, Puerto Rico. In this study, both breast cancer patients and non-cancer controls were recruited from oncology practices, surgery practices, family medicine clinics, and community events. The study began as a hereditary cancer screening and has grown into a large biobank of almost 2000 participants with a wealth of information on each patient, including blood samples, pathology reports, family history, demographics, tumor formalin-fixed paraffin-embedded (FFPE) blocks, and ongoing 5-year follow-up data on recurrence and survival.

Founder and bottleneck effects in Puerto Rico

A principle component analysis of the Puerto Rican cohort showed varied heredity, with some participants showing strong European ancestry and others strong African ancestry. The cohort also showed founder and bottleneck effects, with individuals sharing longer chromosome segments than what is found in other populations. This results in a higher frequency of rare syndromes such as Hermansky Pudlack Syndrome types 1 and 3 (HPS-1 and HPS-3), due to a European founder effect, and Steel Syndrome (*COL27A1*), due to a bottleneck event in the Indigenous American population. For most populations, prevalence of all types of HPS is 1/500,00 to 1/1,000,000; however, in Northwest Puerto Rico, HPS-1 has a prevalence of 1/1800. Steel Syndrome, a collagen mutation associated with short stature, scoliosis, and dislocation problems, is almost absent from the rest of the world, but is relatively common in Puerto Rico.

A founder effect is also observed among cancer patients in Puerto Rico, where *BRCA2* mutations occur at a higher rate than in the rest of the world. Roughly 70% of breast cancer patients with a *BRCA2* mutation were found to carry the E1308X mutation, which originates from Europe. These individuals had a large, shared haplotype, indicative of founder effect. In many US-based Hispanic studies the pathogenic variants that are identified are similar to those found in Mexican studies, indicating a possible bias in the literature toward Hispanic or Latino research with Mexican origin compared to other countries.

Outcomes associated with African Ancestry

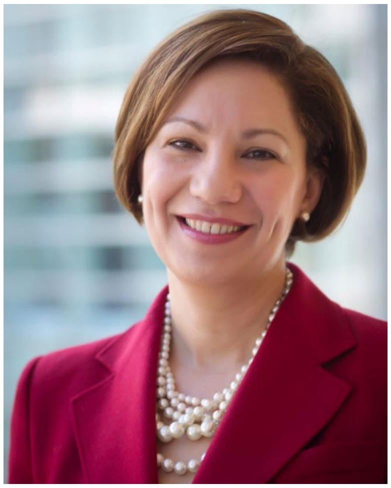
Using PUR-BCGG, Dr. Dutil also looked at whether the polygenic risk scores (PRS) used for predicting breast cancer risk could be applied in Puerto Rico, excluding *BRCA* mutation carriers or high-risk carriers. Populations that were very low in African ancestry but high in European ancestry were compared to populations that were fourth quartile African ancestry. Interestingly, PRS scores were found to be diminished as African ancestry increased.

African ancestry, however, was found to carry increased risk of triple negative breast cancer. To understand this trend, Dr. Dutil assessed the Puerto Rican cohort to identify sites in the genome that control that increased risk. Using mixture mapping, which involved looking at enrichment of certain ancestries in cases versus control, a site was found in triple breast negative cancer patients on chromosome 14 which was enriched for African ancestry. Fine mapping of that region showed two genes of interest, which are the focus of ongoing study.

To conclude, Dr. Dutil summarized the results of her work. First, a higher ratio of *BRCA2* to *BRCA1* mutations was observed in Puerto Rico, which has implications in the clinical management of cancer risk in carrier families. European founder *BRCA2* E1308X was the predominant pathogenic variant in this population. The architecture of breast cancer genetic risk may differ between Hispanic/Latino populations of different origins, with unique variants and altered frequencies in each population. Finally, a better understanding of the genetic basis to cancer susceptibility must be pursued as a key component for eliminating cancer health disparity.

Lung Cancer in Latinos: Disparities Across the Continuum of Care

Dr. M. Patricia Rivera is a Professor of Medicine and Chief of the Division of Pulmonary and Critical Care Medicine at the University of Rochester in Rochester, New York.



Dr. M. Patricia Rivera

Lung cancer in the United States

To set the stage for her presentation, Dr. Rivera began by explaining the magnitude of the burden of lung cancer in the United States. Lung cancer is the leading cause of cancer deaths in the US in both men and women.[1] It is also the leading cause of cancer deaths in Latino men in the US and is second to breast cancer in Latino women.[1] Black men and women, Native Hawaiians, Latino women, and White women have a higher risk of lung cancer at a younger age and lower smoking exposure.[2,3] In cancer care, socioeconomic status is associated with more significant disparities than racial or ethnic factors, and lung cancer is the disease most affected by socioeconomic factors.[4]

Latino men and women have lower smoking rates than White men and women, 12% versus 16% and 6% versus 16%, respectively.[5] That being said, smoking rates among Latino women vary widely by geographical location, with 6% of Central Americans smoking compared to 17% of Puerto Ricans.[5] While Latino high school students smoke at about the same rate as White students, Latino middle school students have higher smoking rates, at 9% compared to 6% for White students.[5] This may be due to tobacco companies targeting minorities and individuals of low-socioeconomic status. Low-income neighborhoods with a higher percentage of Blacks and

Latinos have higher numbers of tobacco retailers. There are also more tobacco retailers near schools in low-income neighborhoods.[6,7]

The Hispanic paradox

Latino men and women have much lower incidences of lung cancer and mortality than Black or White men and women.[8] However, Latinos are more likely to be diagnosed with advanced-stage lung cancer[9], more likely to have low socioeconomic status and treatment delays, and less likely to be insured and have access to lung cancer screening. This juxtaposition of lower mortality paired with high-risk factors describes the Hispanic paradox in lung cancer.[10]

Possible factors contributing to the lung cancer survival advantage among Latinos are many. The lower prevalence of smoking could play a role, as well as the higher incidence of adenocarcinoma, which has a better prognosis. Higher rates of *EGFR* mutations and lower rates of *KRAS* mutations are possible factors, along with dietary habits, community support, genetics, and selective migration.[10] The whole picture is unclear because much of the knowledge describing lung cancer in Latinos is missing.

The importance of lung cancer screening

Lung cancer screening is one of the most critical interventions for decreasing lung cancer mortality, second only to smoking prevention and cessation. Patients who undergo early screening are much more likely to be diagnosed with stage I disease, which is curable. However, the National Lung Screening Trial (NLST), the largest randomized trial in the history of lung cancer screening, comprised more than 90% of White participants.[11]

In 2021 the United States Prevention Services Taskforce (USPSTF) lowered its recommended age for lung cancer screening to adults aged 50 to 80 with a 20-pack-year smoking history.[12] This represents 14.5 million people eligible for lung cancer screening, an 87% increase over the 2013 recommendations and a 112% increase in eligible Hispanics.[13] Despite these gains, eligibility-to-incidence ratios are still higher in White populations than in Hispanics.[14] This is partially due to a low number of screening centers in areas with high Hispanic populations.[15]

Cessation of smoking in the Hispanic community

When considering smoking cessation, Hispanics are more motivated to quit than their White and Black counterparts.[16] However, they have limited access to cessation medication and support services. Only 42.2% of Hispanics have access to physician advice, compared to 60.2% for White individuals and 55.7% for Black individuals.[16] A lower percentage of Hispanics have access to counseling than White and Black individuals (5.1% vs. 6.9% and 7.6%, respectively). Further, only 16.6% of Hispanics receive pharmacotherapy compared to 32.6% for White individuals and 25% for Black individuals.[16]

Hispanic involvement in clinical trials

Although immunotherapy has revolutionized the treatment of advanced stages of lung cancer, very few Hispanics have been enrolled in clinical trials, representing only 3% of clinical trial participants.[17,18] When comparing participants in clinical trials from 1996-2002 with participants from 2003-2016, Hispanic and Black participation has decreased, with 3.1% Hispanic participation before 2002 compared with 2.6% participation after 2003.[17,18]

To close, Dr. Rivera discussed strategies to help overcome healthcare disparities in lung cancer. Increasing access to healthcare, recruiting minority physicians, building trust through communication, providing education, using nurse/patient navigators, and involving communities are all critical approaches. Tailoring strategies to each culture and providing cultural competency training is also imperative. With these interventions, the burden of disparity in lung cancer can be lessened, and more equitable healing can begin.

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Targeting Tumor Microenvironments in Lung Cancer

Dr. Josephine Taverna is Assistant Professor in the Division of Hematology Oncology in the Department of Medicine with a joint appointment in the Department of Molecular Medicine at the University of Texas Health Science Center.

The poor prognosis of lung cancer

In clinical practice Dr. Taverna treats lung cancer patients, approximately 50% of whom are Hispanic. Unfortunately, many of her patients present with advanced-stage lung cancer, which has a poor prognosis. Chemotherapy alone is associated with a 5-year overall survival of 5%, while recent advances in immunotherapy have increased that number to 24%. Clearly, novel therapies are needed to improve survival.

Dr. Josephine Taverna

The AXL signaling pathway and the STAT3 bypass

One pathway that plays an important role in tumor biology is the AXL signaling pathway, which is upregulated in many tumors, including lung cancer tumors. This pathway triggers other oncological pathways, creating resistance not only to chemotherapy and immunotherapy but also to targeted drugs such as EGFR and ALK inhibitors. To make matters worse, it also pushes the tumor to metastasize.

In order to further understand how the AXL pathway works, Dr. Taverna and colleagues analyzed 50 tumors for high AXL versus low AXL expression. Tumors that metastasized were found to have high AXL expression, while stage I and II tumors were found to have low but increasing AXL expression. Accordingly, when AXL was inhibited, tumor growth was slowed.

AXL inhibition alone, however, proved to be insufficient in completely halting tumor growth and proliferation. When blocking the AXL pathway, many oncological pathways were inhibited as expected; however, a bypass mechanism was discovered called STAT3. The STAT3 pathway became amplified when the AXL pathway was blocked and continued to drive tumor growth and alter the tumor microenvironment despite AXL inhibition. The implication of this bypass is that an AXL inhibitor alone would be insufficient for tumor treatment.

Macrophages in the tumor microenvironment

To understand AXL and STAT3 on a deeper level, Dr. Taverna undertook tumor ecosystem single cell profiling for the first 15 tumors, which meant exploring the entire tumor microenvironment: tumor cells, immune cells, macrophages, stromal cells, endothelial cells, and more. In the more aggressive tumors, it became clear that the AXL and STAT3 pathways were upregulated not only in the tumor cells, but in other cells as well, including macrophages. In fact, tumor cells and macrophages were found to have a mutual dependency which was strengthening the cancer.

When tumors begin, they typically have macrophages that act against them, activating T-cells or phagocytizing the tumor cells. After the AXL and STAT3 pathways are amplified, however, macrophages are recruited and polarized from M1 to M2 macrophages. The M2 macrophages then work with the tumor to suppress the immune system and initiate angiogenesis for the tumor’s benefit.

Testing AXL-STAT3 inhibitors

To test drug efficacy against these tumors, organoids were grown to replicate tumors, which were then treated *ex vivo*. Organoids that showed high AXL/STAT3 signaling (measured with cytometry time of flight (CyTOF)) were treated with AXL/STAT3 inhibitors. Response by the organoid to this inhibition indicates the patient may respond to this type of treatment regimen and should be enrolled in a clinical trial. This is the future of personalized lung cancer treatment.

One patient, for example, a 57-year-old female who smoked heavily, had low expression of AXL and STAT3. Accordingly, when her organoid tumor was treated with an AXL and STAT3 inhibitor, little improvement was noted. However, when treating an organoid from a patient with an aggressive tumor, which exhibited high AXL and STAT3 expression, the organoid tumor responded very well to inhibitor therapies.

The astounding effects of AXL-STAT3 inhibition

The A549 lung cancer xenograft mouse model was then used to test this theory. Treating these mice with a JAK inhibitor had no effect, treating with an AXL inhibitor had some effect, but combining the two produced the strongest outcome of tumor growth inhibition. In fact, the combined JAK/STAT3 inhibition actually dismantled the tumor microenvironment and there was an M2 to M1 shift in the macrophages. In fact, when tumors were treated with both AXL and STAT3 pathway inhibitors, the entire tumor microenvironment was affected. Macrophages not only decreased, but actually shifted from M2 back to M1. Recruitment of other cells was also interrupted, including fibroblasts, endothelial cells, natural killer cells, B lymphocytes, and T lymphocytes.

In concluding her presentation, Dr. Taverna promoted the personalized approach as the future of cancer therapy. In contrast with chemotherapy, which attempts to kill tumor cells with little regard for the patient’s experience, this approach allows clinicians to select targeted therapies that most successfully destroy the tumor cells for each individual patient, leading to improved patient quality of life. One such therapy, AXL/STAT3 inhibition, shows great promise against aggressive tumors, not only in inhibiting tumor growth, but in affecting the entire tumor microenvironment.

Lung Cancer Drivers in Hispanic/Latinos

Dr. W. Douglas Cress is a Senior Member at the Moffitt Cancer Center.

Dr. W. Douglas Cress

Lung cancer by the numbers

Lung cancer is the leading cancer killer of Latino men, and is second only to breast cancer in Latina women.[1] Although Latinos have a lung cancer incidence rate of only 40 per 100,000, compared with 68 per 100,000 for the White population, Latino lung cancer patients die earlier than White patients, with 5.2 years of potential life lost compared with just 4.3 years for White patients.[2] Dr. Douglas Cress seeks to address these troubling trends through his research on adenocarcinoma, one of the four major histological types of lung cancer (adenocarcinoma, squamous cell, small cell, and large cell). Adenocarcinoma is the most common histological type and represents 45% of all lung cancers.

Adenocarcinoma comes from type II pneumocytes, small cells in the lung that produce surfactants and participate in immune function. Two of the key driver mutations in adenocarcinoma are the *EGFR* and *KRAS* genes, which encode growth signaling molecules. The other three key driver mutations are in tumor suppressor genes: *TP53*, which is the guardian of the genome; *KEAP1*, which is involved in antioxidant protection; and *STK11*, which is involved in energy metabolism. When looking at The Cancer Genome Atlas (TCGA), a national cohort of mostly White participants, these five mutations account for a great deal of the disease. Among the patients in this cohort, 46% had a *TP53* mutation, 33% had a *KRAS* mutation, 17% had a *KEAP1* mutation, 17% had a *STK11* mutation, and 14% had an *EGFR* mutation.[3]

A lung cancer cohort representing Latinos

Only 3% of TCGA participants, however, were Latino[4], a population which is expected to represent a quarter of the US population by 2060. To address this disparity, Dr. Cress has been involved in the Puerto Rico Biobank, a core of the Ponce Health Sciences University and Moffitt Cancer Center U54 partnership to address cancer health equity. By partnering with the Oncology Research Information Exchange Network (ORIEN), the Puerto Rico Biobank has been able to contribute to the formation of a cohort similar to TCGA, but with a much greater Latino representation.

Lung cancer presentations unique to Latinos

When comparing this Hispanic cohort to TCGA, *KRAS* and *STK11* mutations were found to be much lower in Hispanic patients, while *TP53* mutations were found in similar numbers. *EGFR* mutations, however, were found in about 37% of Hispanics, compared with only about 15% of non-Hispanic White patients (P<0.001). Hispanic women had higher rates of EGFR mutations than Hispanic males (P<0.01), non-Hispanic males (P<0.01), and non-Hispanic females (P<0.001). *EGFR* mutations were also more common in non-smokers, a trend that was seen in both cohorts.[5]

Next, with the help of Dr. Julie Dutil, an expert in ancestry informative markers, the ancestry of the cohort participants was determined and divided into three groups: European, Indigenous American, and African. *EGFR* mutations were much more prevalent in the Indigenous American group than the European or African groups, an observation which has been noted among other researchers as well. Because of the small number of patients, the difference did not reach statistical significance. In a study of over 1000 participants from Latin America, Jian Carrot-Zhang and colleagues also found elevated *EGFR* mutations and decreased *KRAS* and

STK11 mutations in Hispanic patients.[6] To take ancestry into account, they calculated a local ancestry risk score showing that *EGFR* mutations were significantly positively correlated with Indigenous American ancestry (coeff.=0.55; 95%CI: 0.35-0.75; $P=9 \times 10^{-8}$).

A new finding in the Latino cohort

Dr. Cress closed by sharing about a project designed to examine the patients in the Latino cohort who did not have either *EGFR* or *KRAS* mutations. To this end, Dr. Cress performed Archer sequencing, targeted to identify fusion transcripts, on 55 tumors with no *EGFR* or *KRAS* mutations. Of the 55 tumors, 10 had unexpected novel fusions, 5 of which showed a fusion between *ADCK4*, a gene which encodes a protein involved in antioxidant metabolism, and *NUMBL*, a gene which encodes a protein involved in stemness. These two genes are very close together with only six kilobases between the two.

Research exploring the mechanism and prevalence of this fusion is already underway, but Dr. Cress and colleagues hypothesize that intergenic splicing of *ADCK4* with *NUMBL* drives the expression of *ADCK4-NUMBL* chimeric transcripts. They also hypothesize that these transcripts express oncoproteins, and that these chimeras are expressed more frequently in Latino patients than in non-Hispanic White patients.

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Feasibility and Acceptability of Culturally Adapted Survivorship Care Virtual Group Medical Visits (GMVs) for Spanish-Speaking Latinas with Breast Cancer in a Diverse Public Hospital Setting

As the most common type of cancer among Latinas, breast cancer produces a complex web of unmet needs in this community, both in terms of treatment and survivorship care. The more than 2.8 million breast cancer survivors in the United States face a risk of recurrence and secondary cancers, long-term adverse events from cancer treatments, difficulties in mental and sexual health, and challenges in access to preventive care, among other hardships.

Barriers to Effective Survivorship Care

Dr. Ana I. Velazquez of the University of California San Francisco and colleagues conducted a study evaluating group medical visits as a survivorship care strategy for Spanish-speaking Latinas who have survived breast cancer, and she presented her results on Wednesday, February 23, 2022, in the Rapid Fire Session. She began by detailing the complexities of breast cancer survivorship care and the need for access to cost-effective, comprehensive care that is both sustainable and high quality. To address the challenge of inefficient care delivery models, Dr. Velazquez and her group examined the feasibility and acceptability of culturally adapted GMVs, which have been used in other chronic diseases, as an avenue of delivering care for Latinas with breast cancer who speak Spanish.


Dr. Ana I. Velazquez

The GMVs consisted of eight to ten patients meeting with providers on a weekly or regular basis for a total of four two-hour sessions. In each session, the patients received one-on-one time with the provider along with an hour-long lecture providing education surrounding the care of their chronic condition. These are billable healthcare appointments that allow more patients to be seen in a shorter amount of time.

Adapting the Survivorship GMV Model for Spanish-Speaking Latinas

A survivorship GMV model that had been implemented in an English-speaking population was culturally adapted to Latinas using a three-tier model. First, semi-structured interviews with patients and stakeholder meetings were conducted to set the stage. Second, modifications to the GMV model were made to create the initial adaptation, and primary and exploratory outcomes were selected. Third, the adapted survivorship GMV model was pilot tested and debrief sessions were carried out along with post-intervention surveys and semi-structured interviews. The primary outcomes were feasibility and acceptability of survivorship GMVs for Latinx patients with breast cancer, and the exploratory outcomes were knowledge, self-efficacy, and fear of cancer recurrence.

Acceptability and Feasibility of the Adapted Survivorship GMVs

Out of 17 patients enrolled, 15 (88%) attended all sessions, and the other 2 attended three of the four sessions. All were Spanish speaking with little to no English proficiency. When comparing the patient responses before and after the four GMV sessions, there was a substantial increase in the patients' confidence regarding the following three statements: "I know what to expect now that my initial treatment is finished," "I know how to take care of myself after cancer," and "I will be able to give my primary care doctor details of my cancer treatment." Although Dr. Velazquez and colleagues have not completed their analysis on all the qualitative data, the data they have so far indicate that their model is worth exploring as a method of increasing access to survivorship care for more patients.

The cost-effectiveness of GMVs as a healthcare delivery model, the relationship between GMVs and clinical and patient-reported outcomes, and the continuity and quality of survivorship care offered through GMVs need to be further evaluated in larger studies.

Social Determinants of Health Impact Gastric Cancer Risk in South Texas Minorities

Dr. Dorothy Long Parma, a physician from UT Health San Antonio, started her session with a discussion of how gastric cancer (GC) disproportionately affects the Latino community compared to non-Hispanic whites (NHWs). Disparities exist in both incidence and mortality, with the Latino risk of GC being at least twice that of NHWs. Furthermore, GC is the 6th and 8th leading cause of cancer death in Texas for Latino men and women, respectively. Among South Texas Latinos, multiple social determinants of health (SDoH) increase the vulnerability of this population to developing cancer.


Dr. Dorothy Long Parma

Using Electronic Medical Records and the US Census to Build a Data Set

To examine the effect of ethnicity and SDoH on GC risk, Dr. Parma and colleagues used deidentified electronic medical records (EMRs) from adults 18 years of age or older diagnosed with GC and GC precursors on the Correa cascade at UT Health San

Antonio and its safety net provider affiliate University Health System. The search for EMRs was done using ICD9/10 diagnostic codes and keywords. SDoH data was obtained from the American Community Survey and the US Census. With a sample size of 23,320, GC represented 2.6% (n=600) of the cases; more than half of the GC cases were male, and more than half were Hispanic; roughly 25% were on Medicare with about the same number privately insured. The result of the statistical analysis that followed shed light on certain factors associated with greater or lower risk of GC.

Higher Risk For Latinos and Lowest-Income Neighborhoods

According to Dr. Parma's analysis, both Latino ethnicity and living in the lowest-income neighborhoods were associated with a higher risk of GC diagnosis (odds ratio [OR]: 1.24; 95% CI: 1.02-1.51; *P*=0.031 and OR: 1.3; 95% CI: 1.01-1.69; *P*=0.045, respectively). Interestingly, CareLink insurance, government insurance, being uninsured, and being underinsured all had lower odds of being diagnosed with GC compared with private insurance (OR: 0.31-0.56; all *P*<0.05), while military insurance was associated with an increased GC risk (OR: 2.67; 95% CI: 1.19-5.40; *P*=0.01). These numbers suggest a disparity in access to care between the Latino community and NHWs.

Insurance Barriers in the Latino Community

Using interaction models, the study revealed that Latinos without high school education had higher GC risk compared with Latinos with high school education (OR: 1.24; 95% CI: 1.10-1.52; *P*=0.04), and Latinos without insurance had higher GC risk compared with Latinos with insurance (OR: 1.16; 95% CI: 0.97-1.39; *P*=0.1). The "Other" category of race/ethnicity, including Asians, Native Americans, and those of multi-racial ethnicity, also showed an interaction with certain SDoH. Specifically, poverty and lack of insurance contributed to increased risk in this ethnic population (both *P*<0.05).

Dr. Parma concluded that minority groups with specific SDoH factors have increased GC risk compared with NHWs, and that solutions to overcome insurance barriers inhibiting early access to GC care should be actively pursued.

Cardiometabolic Comorbidities in Hispanic/Latino Cancer Survivors: Prevalence and Impact on Health-Related Quality of Life and Supportive Care Needs


Dr. Ashley Maras

Also in the Rapid Fire Session was **Dr. Ashley Maras** of the Feinberg School of Medicine, whose talk addressed the issue of cardiometabolic comorbidities in Hispanic/Latino cancer survivors and the associated health outcomes. Illness related to these comorbidities is the leading cause of death for cancer survivors treated for early-stage cancer, including prostate, breast, and colorectal cancers. Furthermore, these comorbidities are more prevalent in the Hispanic/Latino communities in the US compared with non-Hispanic whites (NHW). Overall, poor cardiometabolic health after cancer treatment is an issue in the Hispanic/Latino community that may have an effect on health-related quality of life (HRQoL), needs for supportive care, and health behavior changes.

Up to now, there has been a paucity of information concerning the prevalence of cardiometabolic comorbidities in Hispanic/Latino cancer survivors and the relationship between these comorbidities and health-related outcomes. More studies on these complex topics are likely to bring about better supportive care and improved HRQoL along with knowledge of specific survivorship needs and increased cardioprotective health behaviors.

Baseline Assessments of Hispanic/Latino Cancer Survivors with Cardiometabolic Comorbidities

Dr. Maras presented the results of a study in which participants, identified via medical chart review, were recruited from major tertiary centers in Chicago and San Antonio. Eligible patients had a diagnosis of breast, colorectal, or prostate cancer, had completed primary cancer treatment within the past 15 months, were self-identified as Hispanic/Latino, and were verbally fluent in Spanish or English. The baseline assessment measures included the Supportive Care Needs Survey (SCNS), the Functional Assessment of Cancer Therapy (FACT-G), the Charlson Comorbidity Index, the American Cancer Society (ACS) Lifestyle Behavior Scale, and electronic health records (EHR)-extracted medical/cancer information.

Sociodemographic Characteristics, Cardiometabolic Comorbidities, and Health Behavior Changes

The average age of the participants in the study was 56 years; 65.6% had an education level of high school or less; 68.4% had a household income of $50,000 or less; 59.4% were foreign-born; and 54.2% were monolingual Spanish-speaking. In terms of prevalence rates for cardiometabolic comorbidities, about one quarter of the patients had diabetes (compared to 10% in the general US population), about one fifth had peripheral vascular disease (compared to 4-10% in the general US population through age 79), and two to three percent had myocardial infarction, congestive heart failure, or stroke. The health behaviors that increased most commonly after a diagnosis of cancer were regular health check-ups, attempts to lose weight, and exercise.

Cancer Survivors With Cardiometabolic Comorbidities Versus Without

When compared to survivors without cardiometabolic comorbidities, those with cardiometabolic comorbidities reported lower overall HRQoL, functional wellbeing, emotional wellbeing, social wellbeing, and confidence in patient-provider communication (all $P<0.05$). In terms of supportive care needs, the survivors with cardiometabolic comorbidities reported greater unmet sexual needs ($P=0.002$). No differences were detected in increases in positive health behaviors between patients with and those without cardiometabolic comorbidities.

Dr. Maras speculated that the complexities of managing cardiometabolic comorbidities and cancer care contribute to the patients' lack of confidence in communicating with providers, leading to unmet supportive care needs. She concluded by calling for more research and greater efforts toward the strategic development of intervention techniques to increase cardioprotective behaviors and improve outcomes for Hispanic/Latino cancer survivors with cardiometabolic comorbidities.

Cultural Differences in Family Caregiver Support in End-of-Life Cancer Care

Dr. Paul Maciejewski is Associate Professor of Biostatistics in Radiology at Weill Cornell Medicine as well as Co-Director of the Cornell Center for Research on End-of-Life Care.

Advanced care planning

Because of the breadth of information involving the role of caregivers and end-of-life care, Dr. Maciejewski chose to focus his presentation on family influences on advanced care planning (ACP) among patients with advanced cancer. ACP is a process that enables patients to make plans regarding future medical care that may include discussions about end-of-life (EoL) care and completion of advance directives. Benefits of ACP include less frequent receipt of intensive, unbeneficial, burdensome care coupled with more value-concordant care; earlier hospice referrals; less suffering and loss of dignity; and better quality of death. Unfortunately, there is disparity in ACP, with Latino patients less likely to engage in ACP than non-Latino patients.

Understanding ACP in Latinos

In order to further understand this disparity, Dr. Maciejewski and colleagues began the Coping with Cancer III study, comparing ACP and end-of-life care in Latinos and non-Latinos. This study, sponsored by NIH Minority Health and Health Disparities, set out to determine if religious, familial, and cultural beliefs mediate or moderate disparities in ACP and EoL care. It was a multi-site, prospective cohort study of advanced cancer patients, their family/informal caregivers, and their oncology providers with recruitment sites in New York City, Chicago, Dallas, El Paso, and Miami.

Dr. Paul Maciejewski

The study included patients with advanced lung, gastrointestinal, and gynecological cancers and their informal/family caregivers. Among these patient/caregiver dyads, 57 were Latino, and 90 were non-Latino White, totalling 147 dyads. The study outcomes focused on aspects of ACP such as patient EoL discussions with oncologists and completion of advance directives (e.g., do-not-resuscitate (DNR) orders, living wills, and healthcare proxies). Variables of interest included caregiver ethnicity, relationship to patient, and cultural attitudes and beliefs, as well as patient consultation with family members about important medical decisions.

Disparities in Latino patients and caregivers

Both Latino patients and caregivers were more likely to be younger, live in lower income households, and be less well educated when compared to non-Latinos, although patients were equally likely to be married. Latino patients were also less likely to complete DNR orders, have living wills (LWs), or have designated healthcare proxies (HCP). Latino caregivers were less likely to be spouses or partners of patients and more likely to be adult children of patients. These adult child caregivers were more likely to live with the patient in the Latino cohort, at 65%, while only 10% of non-Latino adult child caregivers lived with the patient.

Patient consultation with family members

When considering patient consultations with family members about medical decisions, Latino and non-Latino patients were equally likely to discuss important medical decisions with spouses, adult children, parents, and siblings. Among Latinos, however, patients who had consulted with a parent were five times more likely to have a DNR than not. Further, if a Latino patient consulted with a parent or sibling, they were more likely to designate a HCP. These findings, together with the fact that parents and siblings are less likely to be primary caregivers, indicate that discussion with loved ones who are not the primary caregiver increases the likelihood of a DNR order and the designation of an HCP.

Four critical cultural beliefs

Latino caregivers were found to be more likely to value four cultural attitudes: fatalismo, familismo, machismo, and respeto. Fatalismo is the belief that events are beyond one's control, familismo involves dedication and loyalty to family, machismo is a sense of masculine pride, and respeto indicates a deferential respect of the medical care system. All of these beliefs, in particular fatalismo and machismo, may prevent ACP in patients and caregivers. The Coping with Cancer Care III study showed that caregivers of patients without a DNR order or HCP displayed greater fatalismo, machismo, and respeto. All four beliefs were also stronger in caregivers of patients without LWs.

In summarizing his conclusions, Dr. Maciejewski emphasized the evidence of ethnic disparities in ACP. He also noted that Latino caregivers were less likely to be spouses and more likely to be adult children. While Latino and non-Latino patients were equally likely to discuss important medical decisions with family members, among Latino patients, consulting with parents was associated with more DNRs and more HCPs. Finally, certain cultural beliefs (fatalismo, machismo, respeto) were stronger in Latino caregivers and associated with fewer advance directives (DNRs, LWs, HCPs).

Gastrointestinal Cancers in Latinos: Recent Trends and Emerging Risk Factors

Dr. V. Wendy Setiawan is the Jane and Kris Popovich Chair in Cancer Research and a professor of population and public health sciences at Keck School of Medicine of the University of Southern California (USC).

A closer look at liver and pancreatic cancer

For her presentation, Dr. Setiawan chose to focus on two cancers which are important in the Latinx population: liver and pancreatic cancer. Among Latinx patients, the most prevalent GI cancers are colorectal, liver, and pancreatic cancer in men; and colorectal and pancreatic cancer in women. Liver and pancreatic cancer are among the top six cancer killers in Latinx men and among the top seven cancer killers in Latinx women. Although mortality rates for colorectal cancer and stomach cancer have decreased in the general population over the past three decades, liver and pancreatic cancer mortality rates have increased in both men and women.

Liver cancer in the Latinx community


Dr. V. Wendy Setiawan

In Dr. Setiawan's own large, prospective, multi-ethnic cohort study, Latinos had the highest incidence rates of liver cancer compared to other ethnic groups. Furthermore, the study examined whether generation status among Mexican Latinos influenced risk of liver cancer. The population was divided into four groups: immigrants born in Mexico with Mexico-born parents, US-born first-generation residents with Mexico-born parents, US-born second-generation residents with one parent born in Mexico, and US-born second-generation residents with both parents born in the US. Compared to Mexico-born participants, all US-born participants had a higher risk of liver cancer. The risk was highest among the second-generation residents with both parents born in the US. Birthplace, however, was a more predictive risk factor for liver cancer than generation status.

Metabolic syndrome and NASH

Other risk factors for liver cancer include Hepatitis B and C, excessive alcohol intake, and metabolic syndrome. Non-alcoholic steatohepatitis (NASH), the liver manifestation of metabolic syndrome, is the most severe form of non-alcoholic fatty liver disease (NAFLD), and incidence of NASH-related liver cancers in the US increased eightfold between 2002 and 2016. By contrast, alcohol-related liver cancer rates were quite stable. Although chronic hepatitis C remains the leading etiology for liver cancer in White patients, NASH recently surpassed chronic hepatitis C as the leading etiology for liver cancer in Latinx patients. Accordingly, population-attributable risks suggest that eliminating diabetes would have the highest impact in terms of liver cancer prevention in the Latinx community.

Factors contributing to the progression of fatty liver or NASH to liver cancer are also important to identify. A recent study using data from 270,000 participants from the Department of Veterans Affairs (VA) identified factors associated with disease progression to liver cancer: age, obesity, Hispanic ethnicity, cirrhosis, hypertension, dyslipidemia, obesity, and diabetes. Diabetes, hypertension, dyslipidemia, and obesity showed a stepwise increase in liver cancer risks with each additional metabolic trait, with diabetes conferring the highest risk of progression to liver cancer among patients with fatty liver.

Pancreatic cancer in the Latinx community

Although cancer death rates in the US have been declining from 1994 to 2018, pancreatic cancer death rates have steadily increased, and the disease is predicted to become the second leading cause of cancer death after lung cancer. Since 1994, early onset pancreatic cancer incidence has increased much more in Hispanic and non-Hispanic White women compared with men, while late onset pancreatic cancer has increased at approximately the same rate in both genders.

Known risk factors for pancreatic cancers include cigarette smoking, chronic pancreatitis, family history of pancreatic cancer, obesity, and diabetes. In fact, more than 50% of pancreatic cancer cases are diagnosed within three years of a diabetes diagnosis. This is an important finding because diabetes is prevalent in both African American and Latinx populations, although pancreatic cancer risk is higher among African American communities.

Dr. Setiawan summarized her presentation by reiterating that Latinx patients are at increased risk of liver cancer. Evidence also suggests that early onset pancreatic cancer is increasing in Latinx women. With NASH becoming the most common underlying etiology of liver cancer in Latinx patients and diabetes greatly increasing pancreatic cancer risk, global awareness about metabolic risk factors is needed. Furthermore, more research must be conducted to identify high risk populations for both diseases, and screening protocols must be updated to increase the chances of early detection.

6. CANCER SCREENING DISPARITIES

Cancer Screening in Puerto Rico Challenges and Opportunities to Address Health Disparities

Dr. Guillermo Tortolero-Luna is Director of the Division of Cancer Control and Population Sciences Program at the University of Puerto Rico Comprehensive Cancer Center.

Cancer statistics in Puerto Rico

Dr. Tortolero-Luna began by describing the cancer landscape in Puerto Rico. In 2012, malignant cancers became the cause of death with the highest age-adjusted mortality rate in the territory. The highest cancer sites among Puerto Rican men are prostate, colon/rectum, and lung/bronchus; while cancer in women most often affects the breast, followed by colon/rectum. The same cancer sites also have the highest mortality in men and women, with the top three sites in men causing 42.6% of all cancer deaths, and the top two sites in women causing 32.2% of cancer deaths.

Dr. Guillermo Tortolero-Luna

Although incidence rates of prostate and colon/rectum cancer in Puerto Rican men have remained constant since 2000, lung/bronchus cancer is decreasing. In women, although incidence rates for colon/rectum cancer have remained constant since 2000, breast cancer rates are increasing. Mortality trends in men have, as expected, decreased over the past two decades, with the exception being the unchanged mortality rate of colon/rectum cancer. In women, mortality rates for colon/rectum cancer have improved, but breast cancer mortality rates have remained constant.

Cancer screening in Puerto Rico

Cancer screening rates in Puerto Rico in 2020 were slightly lower than in the US. In Puerto Rico, 73.3% of people aged 50 to 75 had been recently screened for colorectal cancer, compared with 74.3% of the general US population. Furthermore, 70.4% of Puerto Rican women over the age of 40 had received a mammogram in the last two years, compared with 71.5% of US women.

Many barriers are responsible for this disparity in breast cancer screening: religious beliefs, embarrassment, pain with procedure, worry about work, being a caregiver for another, couples issues, fear of diagnosis, physical or mental impairment, economic issues, transportation, and concern about COVID-19. Barriers for colorectal screening are similar, with the added burdens of fear of the test, lack of knowledge about the disease, concern about insurance coverage, and lack of physician recommendation.

The PRBCCEDP

The Puerto Rico Breast and Cervical Cancer Prevention and Early Detection Program (PRBCCEDP) has been working to combat these trends since 2017. By increasing population-based approaches and working within health system clinics and communities, the PRBCCEDP has focused on decreasing disparities in screening through evidence-based interventions (EBIs). The program has sought to address barriers to screening by using a multifaceted approach that includes workplace approaches, external partnerships, health system interventions, community-clinical linkages, and cancer data and surveillance.

Future plans of the PRBCCEDP include using surveillance systems and population-based surveys to assess cancer burden, examining health disparities, focusing program efforts, and addressing social determinants of health (SDOH). The PRBCCEDP will also support partnerships for cancer control and prevention as well as deliver cancer screening to primary care clinics that serve women impacted by health inequities.

Disparities and solutions

Demographics and socioeconomic factors in Puerto Rico are very different than in the US. Residents over the age of 65 make up 21.3% of the Puerto Rican population, for example, compared with 16.6% of the US population. Only 78.8% of Puerto Rican residents have a high school education or higher, compared with 88.6% of US residents. Even more startling, the Puerto Rican median household income is $20,474, compared to $65,712 in the US. These disparities are partially due to recent economic crises, natural disasters, low birth rates, and the emigration of young Puerto Rican men and women to the US, resulting in an 11.8% decrease in population since 2010.

Partially because of these socioeconomic disparities, addressing cancer health disparities in Puerto Rico is a multifaceted problem. One important step towards a solution is the use of burden data to identify and describe populations experiencing the greatest disparities and the subsequent allocation of resources to prioritize these populations. Once populations have been identified, it is important to find partners with experience working within that population and expertise in addressing under-resourced communities. Engaging communities to help identify root causes and solutions, and identifying community resources is also key. Finally, efforts must be made to evaluate outreach efforts, monitor progress, and measure impact on reducing disparities.

Dr. Tortolero-Luna closed by discussing how partnerships in cancer control in Puerto Rico, organized by the Coalición para el Control de Cáncer en Puerto Rico, are focused on these very solutions. Along with the PRBCCEDP, many other organizations participate in this effort, including Registro Central de Cáncer de Puerto Rico, immunization programs, tobacco control programs, academic and medical institutions, and many more. Through collaboration and partnership, cancer control in Puerto Rico can make substantial and measurable steps toward a more equitable future.

Practice Transformation to Improve Cancer Screening Outcomes at an Academic Medical Center

Dr. Rebecca Jones is Faculty Associate at the Institute for Health Promotion Research at UT Health San Antonio (UTHSA).

VBC and DSRIP

Dr. Jones began by describing Value-Based Care (VBC) Programs, which reward health care providers with incentive payments for the quality of care they provide to their patients. This model has four key aims: improving the patient experience of care, improving the health of individuals and populations, reducing the cost of healthcare, and improving the work life of health professionals.

Dr. Rebecca Jones

Dr. Jones presented another type of program as well, the Delivery System Reform Incentive Payment (DSRIP) program, which focuses on four key areas: infrastructure development, system redesign, clinical outcome improvements, and population-focused improvements. In 2011, Texas received federal approval for the 1115 Healthcare Transformation Waiver, which supported the DSRIP program pool, incentivizing the transformation of service delivery practices to improve quality, health status, patient experience, coordination, and cost-effectiveness. In 2017, the Texas DSRIP Program included cancer screening performance as a quality metric.

Practice transformation in Texas

Based on knowledge of these two programs, Dr. Jones and her colleagues at UTHSA began a practice transformation initiative aimed at improving cancer screening rates among Medicaid, low-income, and uninsured patient populations. Major findings from a root cause analysis conducted in 2017 were as follows: cancer screening, ordering, and scheduling were variable across primary care clinics; barriers to ordering screenings included not having information on patient's previous screenings; and health IT, the quality department, and primary care were central departments in improving performance.

Three key departments

The health IT department was responsible for data maintenance, data optimization, data reporting, and aligning electronic health record workflows. To improve performance cancer screening rates, this department developed registry dashboards to assist in identifying patients in need of a cancer screening; developed flags in patients' medical records to display needed screenings; optimized forms to standardize the capture of screening history; optimized order forms; and created result notification reminders.

In Dr. Jones's initiative, quality departments were responsible for overseeing and supporting UTHSA-managed care contracts, such as the DSRIP Program. This meant that the quality department interacted in real time with primary care clinics to remind clinics of patients with upcoming appointments and screening needs. The quality department also communicated with patients to retrieve cancer screening records and/or schedule screenings, and made data-driven decisions based on recommendations from a team of data analysts.

The final department recommendation involved a VBC taskforce and the primary care department. The task force convened twice a month to discuss performance and intersecting roles between health IT, primary care, and the quality department. Major focuses were educating clinicians and clinic staff on cancer screening guidelines; communicating preferred clinic workflows to health IT and the quality department; and approving protocols and scripts to be used by the quality department when reaching out to patients. Medical directors, clinic managers, quality department leaders, and patient experience members served on the task force, giving a diversity of perspective. Based on recommendations by the task force, primary care clinics were responsible for reviewing registry dashboards daily, capturing screening history, ordering cancer screenings, and communicating cancer screening results.

Initial successes and goals for the future

Dr. Jones closed her presentation by outlining the successes of the program, as well as directions for future growth. The practice transformation program initiated by UTHSA, and spurred by the Texas DSRIP program, seemed to have a positive impact on cancer screening. From 2017 to 2018, colorectal cancer screening prevalence increased by 85% (PR: 1.85, 95%CI: 1.63-2.11); cervical cancer screening prevalence increased by 44% (PR: 1.44, 95%CI: 1.18-1.76); however, increase in breast cancer screening prevalence did not reach statistical significance (PR: 1.11, 95%CI: 0.98-1.27). The quality department, primarily focused on retrieving records and scheduling, achieved these increases in cancer screenings through health IT empowerment, record retrieval, and in-clinic intervention; but more work is needed to make these changes sustainable. Effective workflows and health IT enhancements are key in the push to scale screening efforts to other care contracts. Importantly, partnerships with VBC programs represent an incredible growth opportunity for researchers and organizations that have successful cancer screening initiatives.

Despite early successes, more work is needed. One avenue for further change, and a future focus of the program, is the involvement of community health workers (CHWs). CHWs can provide cancer screening education, screen for social determinants of health and address barriers, schedule screenings, and follow patients until screenings are complete. By using CHWs, as well as the established program of practice transformation, Dr. Jones and colleagues hope to make meaningful strides in cancer screening rates throughout the state of Texas.

7. CANCER CLINICAL TRIALS

Novel Therapeutic Approach to Reduce Health Disparity in B-cell Acute Lymphoblastic Leukemia in Hispanic/Latino Children

Dr. Sinisa Dovat is Professor of Pediatrics, Pharmacology, and Biochemistry and Molecular Biology at Pennsylvania State University College of Medicine. He is also Four Diamond Endowed Chair and Director of Translational Research and Experimental Therapeutics in Pediatric Hematology/Oncology at Penn State University.

B-Cell acute lymphoblastic leukemia and Hispanic children

B-Cell acute lymphoblastic leukemia (B-ALL) is the most common childhood malignancy. Although B-ALL is 80% to 90% curable, more children die of B-ALL than any other malignancy. Survival is less than 50% for relapsed ALL, and this has not changed in over 40 years. Young Hispanic children are 1.2-1.75 times more likely to develop ALL than their non-Hispanic White counterparts, and Hispanic adolescents are 2.09 times more likely. Hispanic children also have a 40% higher death rate than non-Hispanic White children after correcting for socioeconomic factors.


Dr. Sinisa Dovat

The importance if *IKZF1* deletion in B-ALL

In 2021, Dr. Dovat and colleagues published a study demonstrating that *IKZF1* (Ikaros) deletion is the key genetic alteration in B-ALL in Hispanic/Latino children. Among children with B-ALL from Los Angeles Children's Hospital, Hispanic/Latino children were two times more likely to have *IKZF1* deletion compared to all others, and three times more likely if over the age of ten. Unfortunately, *IKZF1* deletion is associated with an 8-to-10-fold increase in relapse rate.

When considering *IKZF1* deletion concomitant with *IGH-CRLF2* translocation, these patients were almost exclusively Hispanic/Latino. Approximately 60% of the Hispanic/Latino group had *IKZF1* deletion alone, while approximately 40% of the group had both *IKZF1* deletion and *IGH-CRLF2*. Dr. Dovat hypothesized that *IKZF1* deletion occurred first, followed by *IGH-CRLF2* translocation in some.

Improving Ikaros expression through CK2 inhibitors

Because *IKZF1* deletion is a key driver of high-risk B-ALL in Hispanic/Latino children, Dr. Dovat set out to target the Ikaros-regulated signaling pathways that control leukemia progression and drug resistance. Ikaros binds the promoter of the *mTOR* gene, leading to reduced *mTOR* transcription when Ikaros is expressed, and increased *mTOR* transcription when Ikaros is inhibited. CK2 kinase, which regulates Ikaros DNA binding by phosphorylation, is overexpressed in almost every malignancy, particularly leukemia. When Ikaros is phosphorylated, it does not bind DNA, leading to impaired tumor suppression. CK2 inhibition, however, restores Ikaros function in high-risk B-ALL, therefore decreasing *mTOR* transcription.

Using patient-derived xenografts from Hispanic/Latino children with high-risk B-ALL, Dr. Dovat assessed the use of CX-4945, a CK2 inhibitor, in conjunction with rapamycin, an mTOR inhibitor. In this approach, a patient's tumor cells were injected into immuno-incompetent mice, and therapeutic combinations were assessed. The mice with patient-derived xenografts that were treated with either CX-4945 or rapamycin survived longer than the control mice, while those treated with a combination of therapies survived longer still.

In a similar approach, the use of CX-4945 was assessed in conjunction with doxorubicin, a chemotherapy drug used for high-risk leukemia. Ikaros inhibits expression of the *BCL-XL* gene, which is known to increase resistance to doxorubicin, so CK2 inhibition by CX-4945 should increase Ikaros expression, therefore decreasing BCL-XL facilitated doxorubicin resistance. The two drugs were found to be synergistic, and the combination of CX-4945 and doxorubicin led to improved survival in the mice with xenograft from Hispanic/Latino children with high-risk B-ALL.

The future of *IKZF1* research

These promising results indicate many directions for further study. For example, it is important to understand why *IKZF1* deletion occurs more frequently in Hispanic/Latino children. Furthermore, the reasons why *IKZF1* deletion predisposes Hispanic/Latino children to *IGH-CRLF2* translocation must be understood. How basic science discoveries can be used to design new treatments must also be explored.

To answer these questions, Dr. Dovat suggested using functional molecular epidemiology to integrate genomics and functional epigenomics with outstanding computational biology/bioinformatics. Rationally designed, targeted combination treatment could also be used to implement basic science discoveries, targeting specific signaling pathways, and designing more efficient and less toxic therapies.

Dr. Dovat concluded his presentation by emphasizing the need for collaboration and funding. Cancer is the leading cause of death by disease for children under the age of 19 in the US, and NIH allocates just 4% of the National Cancer Institute's annual budget to childhood cancer research. More high-risk B-ALL samples are needed to create pre-clinical models of B-ALL, and collaboration with pediatric institutions serving Hispanic/Latino children in the US and South America is imperative.

Overcoming Disparities in Cancer Care: The Importance of Clinical Trials

Dr. Gladys I. Rodriguez is a medical oncologist with the START Center for Cancer Care with special interest in access to care for cancer patients. She also serves on the American Society of Clinical Oncology (ASCO) Board of Directors and previously served in the Health Disparity Committee and the Workforce Advisory Committee. In 2021 she co-founded a Conquer Cancer Young Investigator Award for Latina Research.

Dr. Gladys I. Rodriguez

The changing landscape of clinical trials

Dr. Rodriguez began her presentation by defining clinical trials as research studies in which people volunteer to help find answers to specific health questions. In the world of oncology, these trials address effectiveness of medications, survival, side effects, mechanisms, quality of life, and more. In general, Phase I trials assess dosage or side effects, Phases II and III look at specific activity and then compare that to an already approved treatment, and Phase IV trials focus on a larger population after a drug has been approved.

Over the past decades, drugs have been approved at a faster rate and at earlier phases of development than ever before; and a large portion of these are oncology drugs. While about 1601 clinical trials were conducted in 2015, 6,442 trials were conducted in 2021, 2,426 of which were early phase trials.[1] Of the almost 60 new drugs approved by the FDA in 2021, 20 were new oncology drugs.[2]

In Phase I clinical trials from 2013 to 2017, however, only 2.8% of participants were Hispanic/Latino, compared to 84.2% White participants. Furthermore, in trials for oncology drugs approved by the FDA from 2008 to 2018, of the 70,201 patients who reported their racial background, only 630 were Hispanic.[3] Among clinical trials sponsored by Pfizer in the areas of cardiology, hematology, endocrinology, and nephrology almost 80% had Hispanic/Latino participation at or above US census levels; however, only 6.5% of oncology trials achieved this benchmark.[4]

A four-part plan addressing trial participation inequity

The first strategy Dr. Rodriguez proposed to address this inequity was improved access to studies. A recent analysis showed that 49% of presenting cancer patients had no clinical study available to them, 18% were ineligible to participate, and 19% chose not to participate, leaving only 14% of these patients participating in clinical trials.[5] In order to reverse this trend, it is imperative to identify and open studies at institutions with diverse patient populations that mirror community demographics. Patient navigators and outreach programs can also help bridge the gap between studies and patients, providing information, connection, and communication. The most important aspect of improving access, however, is listening to patient voices, acknowledging their problems, and addressing concerns by changing the design of the study.

The second focus to improve disparity in participation is the trial design itself. In order for clinical research to be accessible, affordable, and equitable, trials must allow for more flexible inclusion criteria. For example, in a recent proposal to broaden trial eligibility criteria for patients with advanced non-small cell lung cancer, proposed updated FDA regulations would approve over 10,000 participants compared to around 5,500 under traditional eligibility requirements.[6] Trials can also be simplified, streamlined, and standardized to allow for virtual consent, remote assessments, reduced unnecessary visits, or visits at local providers.[7]

The third approach to improve trial participation is identifying and resolving biases. Provider assumptions prevent many patients from being informed about clinical trials for which they would otherwise be eligible. Programs to identify and resolve providers’ biases towards minorities are currently being established to address this problem. Diversity promotion among providers and researchers, and patient education programs about clinical research and importance are also underway. These efforts, however, must be undertaken at every level of the clinical trial system, from institutions, to communities, to professional societies.

The final strategy for improving equity in trial participation is removing economic and social barriers. This begins with advocating for coverage of clinical trial participation for all patients. Patients should be provided with adequate economic compensation for time, travel, and lost wages. Improved study designs can also be helpful, making participation easier through decreased frequency of visits, decreased length of visits, virtual visits, and more. Finally identifying and partnering with community resources can drastically improve participation.

The plan in action

In concluding her presentation, Dr. Rodriguez shared a real-world example of these strategies in action at the START Cancer Center in San Antonio. In their early Phase I oncology drug development program in 2021, of the 400 patients who participated in Phase I clinical trials 36% were of Hispanic or Latino ethnicity. This compared to 40% Latino patients in the cancer center in general. The deliberate implementation of the four-part plan demonstrates the success of these strategies to improve participation and inclusion in clinical research.

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Developing Cancer Drugs for All: A Regulatory Perspective

Dr. Lola Fashoyin-Aje is a medical oncologist and Deputy Division Director in the Division of Oncology 3 (DO3) in the Office of Oncologic Diseases (OOD) at the Food and Drug Administration (FDA). She is also Associate Director in the Science & Policy Program to Address Disparities at the Oncology Center for Excellence (OCE).

Dr. Lola Fashoyin-Aje

Diversity in clinical trials

Dr. Fashoyin-Aje's presentation focused on two main points: demographic representation in cancer trials and addressing barriers to clinical research participation. Inclusivity in clinical trials is important to increase access to potentially promising drugs which may represent a treatment option in situations where no other options are available. Clinical trial diversity can also generate data to inform the safety and effectiveness of drugs, which may differ across subgroups.

Although typically thought of in terms of race and ethnicity, Dr. Fashoyin-Aje's definition of diversity is broad and inclusive, covering race, ethnicity, age, sex, gender, geography, underserved populations, and more. Part of this broader understanding is recognizing the limitations of parameters used. Race, for example, does not necessarily denote biological differences that are exclusive to that particular race or ethnicity. Rather, the goal is to increase overall variability in study population in order to evaluate differential drug response.

A dearth of diversity in clinical trials

In a recent analysis of clinical trials for 40 new drugs approved for the treatment of solid tumor malignancies over a six year period of time, 20,000 patients were included. Of those patients, 49% were from Europe and 31% were from North America, while only 2% were from South America, less than 1% was from Africa, and there was no representation from Central America. Only 4% of participants identified as Hispanic when asked about ethnicity, with almost 40% of the ethnicity data not collected or reported.

Factors that contribute to this disparity are multifaceted and include societal factors such as bias, racism, ageism, socioeconomic disparities, global inequities, and more. Biases in the health care system are also evident through disparities in access, site or investigator selection practices, clinical trial-related costs, lack of awareness, and communication practices. Trial-specific factors, such as eligibility criteria and burdensome procedures, contribute to inequity as well.

Strategies for inclusion

Strategies to promote equity in clinical trial representation must be intentional, prospective, specific, consistent, and accountable. The FDA's Oncology Center for Excellence (OCE) seeks to embody these values through patient, community, and external engagement, as well as in the realms of policy development and research. One focus area is the establishment of clear expectations for clinical trials regarding representation of demographic groups that are historically inadequately represented.

To this end, OCE provides guidelines focusing on how to collect and present data on race and ethnicity. Broadly speaking, guidelines include developing a prospective diversity plan, broadening clinical trial eligibility criteria, simplifying trial procedures and operations, and prioritizing diversity in the context of global drug development.

Specific OCE guidelines

According to these guidelines, a diversity plan should begin with an understanding of the epidemiology of the disease, including clinical characteristics, populations with increased case burden, and populations with increased death burden. Enrollment goals should then reflect that epidemiology to represent a diversity of minority groups, reflecting differences in race, ethnicity, age, sex, and more. The plan for enrolling that diverse population should address issues of site location, financial access, disability access, patient and community engagement, and reduction of trial design burdens.

Broadening eligibility criteria can greatly increase diversity in a clinical trial and allow the trial to serve the patients instead of the patients serving the trial. Trial design is also important, allowing flexible study assessments and using technology to assess patients remotely. The use of local laboratory, imaging, and health care teams can increase participation as well.

In closing, Dr. Fashoyin-Aje summarized the strategies for diversity in clinical trials. The development and implementation of a prospective plan is key to ensuring diverse representation in clinical research. This allows increased access to clinical research, generates data that reflects a diverse US population, and improves the generalizability and applicability of study results. This strategy should also include specific goals across the full spectrum of clinical research, reflect a cross-discipline approach with full integration, and include metrics to facilitate accountability.

What We Don’t Know Might Hurt Us: The Impact of Racial and Ethnic Minority Underrepresentation in Cancer Clinical Trials

Dr. Jose Trevino is Chair of the Division of Surgical Oncology at the Virginia Commonwealth University (VCU) School of Medicine, as well as Surgeon-in-Chief of the Massey Cancer Center.

Dr. Jose Trevino

Pancreatic cancer and diversity in clinical trials

Despite common ancestry, there is great diversity within the Latinx community, a community that is expanding. Furthermore, by 2060 minority populations will make up 50% of the US population, indicating how quickly diversity is rising in the country as a whole. Dr. Trevino began his presentation by posing the question, “why is diversity in clinical trials important?”

To answer this question, he spoke of pancreatic cancer, which is predicted to be the number two cancer killer in the US by 2030. After a diagnosis with pancreatic cancer, only about 25% of patients will receive surgical resection, and only 5-8% will achieve five-year survival. These poor outcomes are due to the deadliness of the disease, the frequency of late diagnosis, and the difficulty of treating a constantly changing disease. Furthermore, pancreatic cancer affects certain populations more than others.

Variability of pancreatic cancer outcomes

Pancreatic cancer is a systemic disease, partially due to the release of cytokines and proteins which can lead to cancer cachexia, or muscle and energy loss. As movement and energy are lost, the ability to tolerate treatment is lost, which can lead to earlier death. It is known that Black pancreatic cancer patients tend to have poorer outcomes than White patients. Dr. Trevino and colleagues found that this disparity could be due to greater muscle loss from cachexia in Black patients.

Interestingly, Latinx pancreatic cancer patients tended to have better outcomes than either White or Black patients. Furthermore, within the Latinx population, Dominican and South Central American patients fared the best. This survival disparity according to origin disappeared, however, when considering only neuroendocrine pancreatic tumors. These types of tumors followed the more expected trend of socioeconomic factors as predictors of disease outcomes. These studies and others like them demonstrate the importance of studying different cancer types as independent entities and treating them accordingly.

When considering treatment, minimally invasive approaches have a benefit for survival. White patients in the US, however, are offered these minimally invasive options more often. Clearly, differences in pancreatic cancer outcomes based on ancestry or socioeconomic status, as well as differences in treatments based on racial and ethnic background, reveal the importance of diversity in clinical research.

Disparities in clinical trial representation

From 2008 to 2018, 80% of clinical trial participants in the US were White. Studies specific to breast, prostate, lung, colorectal, and pancreas cancers all showed similar disparities, despite many of these cancers exhibiting increased risk in minority populations. Inclusion and exclusion criteria for many of these trials, found on clinicaltrials.gov, provide insight into why so few minorities are represented. Uncontrolled diabetes, HIV, and previous cancers were all listed as exclusion criteria for many trials, despite medical advances making many cases easily controllable. The fact that these conditions affect certain ethnic groups more than others may be one reason minorities are underrepresented.

A surprisingly simple solution

After consulting with many oncologists, Dr. Trevino's group came up with updated inclusion criteria for these clinical trials. Hepatitis B and C, which are curable, were no longer reasons for exclusion. Previous cancers, diabetes, and HIV were considered acceptable as well. Under these updated guidelines, participant demographics were almost balanced.

In closing, Dr. Trevino emphasized the importance of research that differentiates populations within the Latinx community in order to understand disease risk more fully. Patients' biospecimens should be diversified to more specifically identify patient ancestry; the deeper the ancestry can be elucidated the better. This differentiation has led to interesting areas of research focus in Dr. Trevino's lab, including answering the question of why Dominican pancreatic cancer patients have such good outcomes. Diversity in Latinx ancestry knowledge coincides with a need for diversity in clinical trials. Expanding inclusion and exclusion criteria represents a practical step that can immediately increase inclusion of minorities in the research setting.

8. LATINO CANCER SURVIVORSHIP

Leading Pathways: The Hispanic/Latino Survivorship Study

Dr. Frank Penedo is Associate Director of Cancer Survivorship & Behavioral Translational Sciences at the Sylvester Comprehensive Cancer Center at the University of Miami.

The Leading Pathways study

Dr. Penedo began by presenting a summary of Leading Pathways, a Hispanic/Latino survivorship study, a collaboration between the Mays Cancer Center at UT Health San Antonio and the Sylvester Comprehensive Cancer Center at the University of Miami. The study has five key aims, the first of which is to establish a Hispanic/Latino survivorship cohort. The study also aims to examine multiple determinants of symptom burden, health-related quality of life (HRQoL), and disease activity. The final three aims include evaluation of psychosocial mediators, evaluation of biological mechanisms, and exploration of potential moderators.

Dr. Frank Penedo

The six-year UG3/UH3 study set out to enroll 3,000 participants, with 50% being Mexican American and 50% from other Latino backgrounds, including approximately 23% from Central and South America and 18% from Cuba. The study also aims to have 50% female participation and 30% of participants to come from rural areas. Furthermore, the design calls for 70% of participants to come from a cancer center and 30% from state registries. All of these goals reflect demographics in areas surrounding participating cancer centers in Florida and Texas.

Primary outcomes, determinants of outcomes, and mediators

The primary outcomes of the study are symptom burden (pain, fatigue, sleep, and depression), HRQoL (both general and cancer-specific), and disease activity (cancer remission or recurrence, secondary cancer, incident comorbidity, and palliative or hospice care). In order to fully understand these outcomes, however, determinants of outcomes will also be assessed. These determinants of outcomes are divided into two domains: the sociocultural domain, and the stress and adversity domain. The sociocultural domain includes socioeconomic factors such as income, occupation, education, and access to healthcare, as well as cultural factors like nativity, years in the US, and language preference. The stress and adversity domain covers chronic stress, traumatic stress, discrimination, and neighborhood stress.

Another goal of the study is to understand what mechanisms might mediate the association between the determinants of outcomes and the primary outcomes themselves. These mechanisms are divided into a lifestyle and behavior domain, including diet, physical activity, substance use, and treatment adherence; a psychosocial domain covering optimism, spirituality, social integration, and family cohesion; and a biological domain comprised of leukocyte gene expression, cardiometabolic markers, and genetic admixture.

Recruitment to meet benchmarks

At the time of presentation, the study was in the third quarter of the first year of UG3. The benchmark for UG3, which covers the first two years of the study, has two key components. The first component is recruitment of 18% of the cohort (~560) in approximately similar distribution to the final cohort with regards to sex, Hispanic/Latino origin, urban/rural, and cancer site. The second benchmark component is collection of baseline questionnaires and blood specimens from 85% of enrolled patients.

Advertisements for the study are disseminated through health system clinics, websites, social media, TV and radio spots, and community events. Other patients are identified through the two state registries, Florida Cancer Data System (FCDS) and Texas Cancer Registry (TCR) Procedures. Inclusion criteria stipulate that participants be age 18 or older, have completed primary cancer treatment, have no metastatic disease, and have one of the following eight primary cancer diagnoses as confirmed by electronic medical record (EMR) or cancer registry: breast, prostate, colon, kidney, liver, lung, stomach, or uterine.

The assessment schedule for each participant includes seven data collection points: baseline, 6-months, 12-months, and annual follow-ups thereafter. Biosample collection takes place at baseline and at the 12-, 36-, and 60-month follow-ups. The Sylvester Center in Florida and the Mays center in Texas are responsible for biosample collection, processing, and storage, while all gene expression is performed at the University of California, Los Angeles (UCLA).

Potential impacts of the Leading Pathways study

Dr. Penedo concluded by outlining the potential impacts of the Leading Pathways study. First, findings will provide novel, critically needed information to inform and guide secondary and tertiary prevention by characterizing actors that influence trajectories and outcomes. Second, the study will discern the differential impact of outcome determinants in diverse Hispanic/Latino populations. Finally, results will identify modifiable psychosocial, behavioral, and biological mechanisms that could be targeted via psychosocial interventions or clinical management to improve survivorship outcomes.

Equity in Cancer Care: Loriana's Story


Loriana Hernandez-Aldama

Loriana Hernandez-Aldama is an Emmy award winning journalist with over 20 years of experience at CNN, FOX, and NBC affiliates in Atlanta, Ga, and Dallas/Ft. Worth and Austin, TX. She is also founder and spokesperson for the ArmorUp for Life campaign.

Loriana is a survivor of acute myeloid leukemia in 2014 and breast cancer in 2020. In the first instance, she endured five rounds of chemotherapy and radiation, overcoming a 30% chance of survival. As a two-time cancer survivor, Loriana emphasizes the mental, physical, and financial brokenness that results from fighting cancer. Depression, anxiety, neuropathy, bone pain, vision issues, and more are issues that are not often discussed in conversations surrounding cancer survivorship.

In response to this gap in awareness, Loriana started the ArmorUp for Life campaign, an initiative that emphasizes not only prevention, but preparation and prehabilitation as well. She explains the importance of ensuring no toxic chemicals are in the home, creating a space for positive energy, and exercising the body, mind, and soul. Loriana also stresses living in the moment and learning to be present; appreciating those who love and support you; and exercising compassion and being empathetic. Finally, the three "P's" are at the heart of Loriana's message: you must **P**repare yourself for illness, so you can **P**resent well to your medical team, and position yourself to ultimately **P**revail.

Read more about Loriana Hernandez-Aldama in a Salud Hero story from the *Salud America!* program at UT Health San Antonio: https://salud-america.org/webinar-april-25-overcoming-implicit-bias-in-the-doctors-office-and-research-studies/

Hear more from Loriana Hernandez-Aldama on an episode of the Salud Talks Podcast from the *Salud America!* program at UT Health San Antonio: https://salud-america.org/webinar-april-25-overcoming-implicit-bias-in-the-doctors-office-and-research-studies/

Equity in Cancer Care: Daniel's Story

Daniel G. Garza is an actor, HIV and anal cancer advocate, spiritual life coach, and community leader.

Daniel G. Garza

As a survivor of anal cancer, Daniel spreads awareness about taboo topics surrounding the illness. For example, after his anal cancer diagnosis his sexual relationship with his partner was greatly affected. Chemotherapy and radiation were discussed at length with his physician, but practical changes in his sex life were not even mentioned, despite erectile dysfunction being a well known effect of radiation. Surgery removing half of his anus left Daniel with many uncertainties involving anal sex, and an ostemy bag on his abdomen left oral sex greatly changed as well.

These changes and difficulties led to feelings of shame, embarrassment, and unworthiness, says Daniel, which is why therapy is so important for cancer survivors. Both individual therapy, and couples therapy with a partner are imperative. Couples tend to create rituals and patterns, especially as they navigate the cancer treatment process, and recapturing the romantic moments in a relationship can be challenging. This challenge is exponentially worse for gay men with anal cancer, which is why therapy can be so healing. Finding worth outside of the patient's body, or their sexual relationship, can help couples regain intimacy after the grueling fight with cancer.

Hear more from Daniel Garza on an episode of the Salud Talks Podcast from the *Salud America!* program at UT Health San Antonio: https://salud-america.org/men-why-should-you-get-screened-for-cancer-join-this-webinar-6-9-22/

The Therapeutic Alliance and End-of-life Care Disparities for Latino Cancer Patients

Dr. Ana I. Tergas is Assistant Clinical Professor in the Department of Surgery, Division of Gynecologic Oncology, and the Department of Population Science, Division of Health Equity, at City of Hope Comprehensive Cancer Center.

Understanding the landscape of end-of-life care

Dr. Tergas began by defining the goals of palliative care (PC) and end-of-life (EoL) care as outlined by the National Comprehensive Cancer Network (NCCN). The goal of palliative care

(PC) is to anticipate, prevent, and reduce suffering and support the best possible quality of life (QoL) for patients, families, and caregivers. End-of-Life (EoL) care becomes the focus when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired.

EoL care inequity for Latino patients

PC and EoL care are generally underutilized, but disuse can vary by racial or ethnic group. Non-White patients tend to be less knowledgeable about EoL care options and use EoL care processes less often, such as advanced care planning (ACP). Because Latinx patients are less likely to engage in ACP, they are more likely to receive aggressive EoL care, including increased ICU admissions and chemotherapy use. This aggressive care is associated with poor QoL, minimal survival benefit, and high cost. The likelihood of dying in a hospital is also higher among Latinx patients, who receive less prognostic communication, which can lead to inaccurate expectations of survival.

Dr. Ana I. Tergas

Providing quality EoL care can be challenging in the Latinx community due to the diversity of the population, immigration status, language proficiency, and more. Culture often plays a large role, influencing how patients experience and respond to symptoms, make healthcare decisions, and even express distress related to the dying process. Decisions about EoL care can be greatly influenced by cultural constructs such as personalismo, a respect for personal relationships; familismo, an emphasis on family loyalty and cohesion; machismo, a view of male dominance and strength; and others.

Certain health care beliefs are held more strongly among Latino patients. For example, compared to White patients, terminally ill Latino patients are more likely to believe that they are curable, that cancer pain cannot be controlled, that God will perform a miracle to cure them, and that do-not-resuscitate (DNR) orders conflict with their religious beliefs.

The therapeutic alliance EoL care

One aspect of patient care that may improve these EoL care disparities is the therapeutic alliance (TA), a construct that encompasses the interrelated and essential dimensions of the patient-physician relationship: trust, respect, understanding, and concern. The TA was first described in psychotherapy literature but has also been successful in cancer patients for improving QoL at EoL, decreasing ICU care at EoL, increasing emotional acceptance of terminal illness, and decreasing invasive interventions at EoL.

TA is measured by the Human Connection Scale, which evaluates five key aspects: the extent to which the patient feels that the oncologist listens to and understands the patient's concerns about the illness; whether the relationship involves mutual caring and respect; whether the patient understands the information being shared by the oncologist; whether the patient trusts the oncologist; and whether the oncologist and patient work well together.

The therapeutic alliance and Latino patients

A recent study by Dr. Tergas showed that US-born Latino patients, US-born non-Latino patients, and non-Latino immigrants had 8 to 12 times higher odds of having a better TA than Latino immigrants, adjusted for patient education, insurance, and geographic region. The adjusted odds ratio of TA levels among US born Latino patients compared to Latino immigrants, for example, was 11.8 (95% CI: 2.1 - 66.5). The main drivers of this inequity were that Latino immigrants did not feel that their oncologist cared about them, took the time to listen, or offered hope.

Dr. Tergas ended by outlining future areas of study, including quantitative analysis of patient-level factors. Focus groups with patients and in-depth interviews with oncologists were another area of interest in order to gain a more nuanced understanding of the TA and its relationship to EoL care for Latinx advanced cancer patients. The final priority mentioned by Dr. Tergas was behavioral interventions aimed at improving the TA between oncologists and Latino advanced cancer patients.

9. THE INDUSTRY ROLE IN CANCER RESEARCH INNOVATION

Transformative Strategies for Integration of Health Equity Principles in Science and Access in the US

Dr. Edith A. Perez is the Serene M. and Frances C. Durling Professor of Medicine at the Mayo Clinic College of Medicine and the Chief Medical Officer at Bolt Biotherapeutics. Her presentation outlined strategies for health equity as exemplified by the National Academies of Sciences, Engineering, and Medicine (NASEM) Committee for Inclusion in Research, and the Health Equity Committee at Stand Up To Cancer (SU2C).

The NASEM initiative, which was requested by congress, focuses on improving the representation of women and underrepresented minorities in clinical trials and research. This work aims to identify policies and programs aimed at increasing inclusion, analyze the economic benefits of inclusion, highlight new programs designed to have the most positive impact on underrepresentation, and identify factors that best predict which programs and interventions are replicable and scalable.


Dr. Edith A. Perez

SU2C's Health Equity Committee began in 2018 and is committed to lowering the barriers of access to new treatments for all cancer patients. The committee seeks to change the health disparities landscape by supporting the inclusion of underrepresented populations into clinical trials, supporting clinical trials and research studies that include these populations, and influencing other funders to take similar, tangible steps to improve health equity. In pursuit of these goals, the committee developed criteria for proposals within the context of SU2C, including three critical components: an indication of whether the research will address the populations expected to benefit from widespread use of newly developed treatments; patient recruitment and retention plans for including historically underrepresented racial and ethnic populations; and a letter of support from the lead institution's Chief Diversity Officer, or an equivalent position.

Dr. Perez closed by emphasizing the feasibility of making a significant and meaningful impact. It is an achievable and noble goal to ensure all communities have equal access to new, more effective screening, diagnosis, and treatments. In this way, cancer risk can be decreased, and all persons diagnosed with cancer may become long-term survivors.

Advancing Precision Medicine Through Comprehensive Molecular Profiling

Dr. Yashira Negrón Abril is Medical Science Liaison at Caris Life Sciences. She began by discussing the transition in health care over recent years from the "one-size-fits-all" approach of traditional medicine, to precision medicine enabled by comprehensive molecular profiling. This profiling allows physicians to identify patients at high risk, select the most appropriate treatment options, and match patients to clinical trials.

Caris Life Sciences is a molecular and diagnostic company that assesses DNA, RNA, and proteins for almost all cancer types to reveal a molecular blueprint that helps physicians and cancer patients make more precise and personalized treatment decisions. Over the past 10 years, Caris has gathered longitudinal clinical outcome data for over 275,000 patients, and more than 356,000 patients were tested in 2021 alone.

Dr. Yashira Negrón Abril

In order to build on this wealth of data, the Caris Precision Oncology Alliance (POA) was created, enabling physicians and researchers to optimize clinical care for cancer patients through scientific collaboration. POA members include over 59 leading cancer centers and universities from across the US, Europe, and Asia.

Dr. Negrón Abril closed by discussing the POA's Healthcare Disparities Council, which was recently established to guide and drive high impact research studies focused on minority populations. To expand precision medicine's reach, Dr. Negrón Abril stressed, equal access to comprehensive molecular profiling must be ensured, as well as the diversity of patient cohorts in both biomedical research and clinical trials. All stakeholders must continue working together to address the challenges of disparity in cancer treatment, ultimately achieving health equity across all populations.

How BMS is Addressing the Need for Greater Diversity in Clinical Trials

Lorena Kuri is Head of Diversity Strategy for Research and Development at Bristol-Myers Squibb (BMS). She began by discussing the need for diversity in clinical trials. In the US, four out of ten people are non-White, but only one out of ten clinical trial participants are non-White. Bristol-Myers Squibb is addressing this inequity through the Diversity in Clinical Trials Program.

Through the Diversity in Clinical Trials Program, BMS is committed to doing its part to help ensure patients have a fair and just opportunity to achieve optimal health outcomes. To achieve this goal, the program seeks to improve recruitment of a diverse participant population, with the goal that clinical trials become more reflective of real-world demographics. This program is process-driven, with permanent change as the ultimate goal, and it is empowered by diverse and inclusive talent. The program aims at having 25% of the US sites participating in new BMS clinical trials located in racially & ethnically diverse areas.


Lorena Kuri

Dr. Kuri closed by outlining the Diversity in Clinical Trials Program’s focuses for the future: ensuring that processes are aligned with external commitments when selecting US sites and investigators; reducing practical obstacles to clinical trial participation; strictly adhering to FDA guidelines; tracking performance and ensuring commitments are maintained; incorporating community groups, partnerships, and external thought partners; and committing to internal and external diversity training. These goals will propel BMS on its path toward a more inclusive and equitable clinical trials program.

Increasing Access to Cancer Screening: Working with Latinx Communities in Texas

Dr. Michael del Aguila is Senior Director & Head of Population Health Sciences at GRAIL, a healthcare company focused on saving lives and improving health by pioneering new technologies for early cancer detection. Dr. del Aguila began by emphasizing the importance of early detection for survival, explaining that cancer patients show an 89% 5-year survival rate when diagnosed early, compared to 21% when diagnosed after metastasis. Furthermore, although the United States Preventive Services Task Force (USPSTF) has recommended screening for five cancers, 68% of cancer deaths are due to cancers without screening recommendations. Early detection therefore represents an important area in which GRAIL may make impactful change.


Dr. Michael del Aguila

Because tumors shed nucleic acids carrying cancer-specific information into the blood and other bodily fluids, GRAIL developed a proprietary methylation-based technology for cancer detection. Selected for development based on the results of the first sub-study of the Circulating Cell-free Genome Atlas study (CCGA), GRAIL has since refined and commercially launched this technology as an investigational, multi-cancer, early detection Test called Galleri. The test was launched in June of 2021, and has a 44% positive predictive value, 0.5% false positive rate, and an 89% rate of cancer signal origin predicted correctly, with more than 50 cancer types detected.

Dr. del Aguila ended his talk by discussing the Reflection study from the Population Health Sciences program at GRAIL. This study is designed to distribute Galleri to 35,000 patients, with effort to achieve broad geographic, racial/ethnic, and socio-economic diversity. The Galleri test and the Reflection study represent a shift in approach for cancer screening: instead of screening for an individual cancer, individuals are being screened for multiple cancers. This shift could have a far-reaching impact on the cancer survival landscape.

Increasing Diversity in Clinical Research


Dr. Veronica Sandoval

Dr. Veronica Sandoval is a Principal in the Patient Inclusion and Health Equity team in the Chief Diversity Office at Genentech. Genentech’s mission is to deliver scientific innovations that drive outcomes for people, patients, businesses, and communities; and the company is taking bold action to champion diversity, equity, and inclusion. One of Genentech’s main pillars is advancing inclusive research and health equity, meaning that by 2025, all molecule teams will include population-specific assessments and inclusive action plans.

The Latino community makes up approximately 17% of the US population, but only 1-8% of clinical trial participants. Furthermore, 90% of the genomic material available to scientists is of European ancestry. To address this inequity, Genentech launched the Advancing Inclusive Research Site Alliance, a pilot partnership with four key sites: City of Hope in Los Angeles, the O’Neil Comprehensive Cancer Center in Birmingham, West Cancer Center in Memphis, and Mays Cancer Center in San Antonio. Each of these centers has built trusting relationships with underrepresented communities and can help bridge the gap of clinical trial inequity.

Dr. Sandoval closed by discussing Genentech’s Health Equity Innovation Fund, which is focused on investing in programs that prioritize inclusive research, patient equity and care, and workforce diversity. In 2020, 40 programs received innovation grants from Genentech, six of which were in Texas. The partnerships represented by the Health Equity Innovation Fund, as well as the Advancing Inclusive Research Site Alliance, represent collaboration between industry, payers, healthcare providers, patients, legislators, and more. It is these partnerships that will decrease barriers, and deliver equitable health care to the Latino community.

10. LATINO CANCER RESEARCH RESOURCES

Using Science to Address Latino Health Disparities Research

Eliseo J. Pérez-Stable, M.D., is Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH).

Health disparities and social determinants of health


Dr. Eliseo J. Pérez-Stable

Dr. Pérez-Stable began his presentation by discussing the ways in which science can reduce inequities in healthcare. First, standardized surveys, tools, and measurements are needed so that data can be combined, facilitating discovery through large data sets. Science should also be an engine for promoting diversity of the scientific and clinical workforce, cultivating community engagement, and building trust for sustainable relationships. Community engagement should be considered an essential platform for doing research especially in reducing health disparities. Finally, there is a large body of evidence on efficacy of interventions and yet our systems often fail in implementing these interventions in the most disadvantaged communities.

NIMHD defines populations with health disparities as one of the following populations: racial/ethnic minority populations defined by the Census; populations with less privileged socio-economic status of any race or ethnicity; underserved rural residents; and sexual and gender minorities. All these populations have a social disadvantage partly due to discrimination or racism and being underserved in health care. NIMHD defines a health disparity as a worse health outcome compared to the reference population. In response to these health disparities, and in an attempt to standardize data, NIMHD started the Social Determinants of Health (SDOH) common data elements as part of the PhenX Toolkit. SDOH are contributing factors to inequity such as cultural identity, spirituality, language proficiency, literacy, housing, broadband, transportation, schools, and more.

One of the more important SDOH, socioeconomic status, shows a startling association with mortality. US residents in a household of four with an income less than $25,000 show a mortality ratio of 3:1 when compared to those with a household income of greater than $115,000. Education level of the head of household is another striking SDOH, with male Latino children showing a 24.4% prevalence of obesity if their head of household achieved less than a high school education, compared with a 12.9% prevalence of obesity if their head of household has a college degree.

NIMHD initiatives

NIMHD's purpose is to counter these disparities through multiple initiatives. NIMHD funding has steadily increased over the past decade, with larger funding expected in fiscal year 2022 to address the disparities made evident by the pandemic and the awakening to the issues surrounding racism. Although the success rate of R01 grant applications in 2021 was 12.9%, that number is expected to improve with more funding. Also, Career Development (K) awards have been expanded and are generally funded based on score and available budget. Many NIMHD funding opportunities were recently announced, including health of immigrant populations, patient-clinician communication, social epigenomics, sleep disparities, liver cancer, lung cancer etiology, and more.

One of NIMHD's initiatives is the Health Disparities Research Institute, a week-long intensive training experience launched in 2016 targeted to early-stage investigators and postdoctoral fellows. The training includes lectures by selected leading scientists, a mock grant review session using real applications, a writing course sponsored by the American Association of Medical Colleges (AAMC), meetings with NIH scientific program staff, and consultations on the development of research interests into a K or R01 application. Of the 332 participants in the past six years, about 60% came from underrepresented race/ethnic groups and 20% were physicians.

COVID and CEAL

In 2020, there were 477,000 excess deaths in the US, 74% of which were from COVID. Case rates and hospitalizations due to COVID were two to three times higher in Latino, African American, and American Indian/Alaskan Native populations compared to White populations. To counteract these disparities, the NIH established the Community Engagement Alliance (CEAL) Against COVID-19 Disparities. CEAL's overarching goals include understanding factors that contribute to the disproportionate burden of COVID-19 in underserved communities; supporting effective community-engaged strategies to address misinformation and mistrust; and promoting education, awareness, trust, access, and inclusion in COVID-19 research, prevention, and treatment. CEAL's mantra is "move at the speed of trust," an ideal pursued by supporting initiatives such as telehealth hotlines in Texas; supporting agricultural workers in California's Central Valley; fighting misinformation with fotonovelas; collaborating with the White House to speak on Spanish-language media; working with stakeholders to produce educational Spanish-language conversations; the Salud America Podcast; and other online resources.

Dr. Pérez-Stable closed by discussing structural racism and the importance of patient-clinician communication for improved patient satisfaction and health outcomes. Part of this strategy involves training more African American and Latino clinicians since these physicians care for more than 50% of minorities and more than 70% of those with limited English proficiency. Expanding access to health insurance, coordinating care, emphasizing patient-centered care, and community-engaged research should also be utilized to counter health disparities. By implementing these strategies and continuing to hold the health care system accountable, change can become reality.

Update from the National Cancer Institute

Dr. Katrina Goddard is Director of the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI).

Challenges facing the Latinx community

Dr. Goddard began by reflecting on the 2020 presentation of her predecessor as Director of the DCCPS, Dr. Bob Croyle. In that presentation, Dr. Croyle outlined challenges facing the Latinx community, including the rapid population growth among the US Hispanic population; aggregated data masking important differences within the heterogeneous Hispanic population; higher rates of infection-related cancers among Latinx patients; cancer incidence varying substantially by nativity; misclassification of ethnicity in medical records; the frequency of incomplete information on place of birth; and multiple risk factors compared to the White population, such as lower educational attainment, increased poverty, language barriers, increased obesity, and high uninsured rates. Misinformation is another challenge affecting the Latinx community, with social media misinformation even more prevalent in Spanish posts than in English.

Dr. Katrina Goddard

The SEER program

In order to address these challenges, NCI has focused on creating change in four areas, the first being improved data collection and analysis to support subgroup-specific cancer rates and trends. To this end, the Survey, Epidemiology, and End Results (SEER) program has been expanded to now cover about 50% of cancer cases in the US. Since the changes in 2021, 69.2% of cancer cases among Hispanic patients are now included in the SEER registry, compared to less than 45% from 2015 to 2020. However, because the registry does not collect information directly from patients, but extracts information from existing medical records and through linkages with other data sources, incomplete or inaccurate information continues to be a problem.

In order to fill these data gaps, DCCPS has turned to geographic data sources, incorporating these into the SEER program. State Cancer Profiles and census tract information can be used to assess areas of high cancer incidence, and pair that data with overall demographic information for that area. For example, in an assessment of liver and bile duct cancer in Texas, Hispanic patients were found to have higher incidence of these cancers across five different socioeconomic categories, with very little difference between rural and urban areas. Non-Hispanic White patients, however, showed much lower rates in rural areas compared with urban areas.

Culturally appropriate interventions and clinical trial representation

NCI's second area of focus has been supporting the development and adaptation of culturally appropriate interventions for increasing the uptake of preventive services and adoption of healthy lifestyles. To this end, NCI has funded many clinical trials focusing on Hispanic populations across the cancer care continuum, and the DCCPS has funded many research grants. Although NCI's funding opportunities are too numerous to list, Dr. Goddard highlighted the opportunities focused on workforce diversity, training to promote diversity, and international collaboration.

The third area of focus by NCI is increasing Hispanic/Latino enrollment in clinical trials and cohort studies with high-quality, annotated biospecimens. To further this work, the DCCPS created the Cancer Epidemiology Descriptive Cohort Database (CEDCD), a searchable database containing descriptive information about cohort studies that follow groups of people over time for cancer incidence, mortality, and other health outcomes. The goal of the database is to facilitate collaboration and highlight the opportunities for research within existing cohort studies. Two recent studies included in the database are the Leading Pathways study by Drs. Frank Penedo and Amelie Ramirez, and the Survivorship and Access to care for Latinos to Understand and address Disparities (SALUD) study by Dr. Michael Scheurer.

DCCPS-supported research infrastructure

The final focus of the NCI is leveraging all DCCPS-supported research infrastructure. There has recently been tremendous growth in health disparities work at DCCPS, with 76% of grantees now focusing on either understudied populations, health disparities, or both. The

Cancer Epidemiology in Hispanic Populations Virtual Workshop is another part of this infrastructure, identifying scientific gaps and opportunities for cancer research in Hispanic populations. Another resource is the “Did You Know?” YouTube video series, educating patients on common questions regarding various cancers. Finally, DCCPS has developed the Health Disparities Calculator (HD*Calc), a tool that allows scientists to apply statistical analyses to the SEER database.

The future of DCCPS

Rural cancer control is a key future DCCPS initiative, with the department recently funding nine R1 applications. Another focus is the relationship between persistent poverty and cancer, with persistent poverty being defined as more than 20% of people living in a census tract having been beneath the federal poverty level since at least 1980. The Continuing Umbrella of Research Experiences (CURE), another area of future focus, offers unique training and career development opportunities to enhance and increase diversity in the cancer and cancer health disparities research workforce. Finally, the Cancer Moonshot has been reignited by President Biden. This initiative seeks to accelerate scientific discovery in cancer, foster greater collaboration, and improve the sharing of data, with the goal of cutting today’s age-adjusted death rate from cancer by at least 50 percent over the next 25 years. With the help of these ambitious and collaborative initiatives, the DCCPS and NCI seek to drastically improve cancer outcomes, especially in communities experiencing health disparities.

Cancer Epidemiology in Hispanic Populations: Overview, Future Directions, and Resources

Dr. Tram Kim Lam is a Program Director in the Environmental Epidemiology Branch of the Epidemiology and Genomics Research Program (EGRP) in the National Cancer Institute’s (NCI) Division of Cancer Control and Population Sciences (DCCPS).

Dr. Tram Kim Lam

The Cancer Epidemiology in Hispanic Populations Virtual Workshop

Dr. Tram Kim Lam began by providing a summary of the Cancer Epidemiology in Hispanic Populations Virtual Workshop, a three-day workshop held in September of 2021. The workshop sought to identify scientific gaps and opportunities for cancer epidemiology research in Hispanic populations, to encourage the use of existing resources and identify gaps in resources to enable cancer epidemiological research in Hispanic populations, and to facilitate and coordinate cross-discipline collaboration to inform research in Hispanic populations.

Funded cancer epidemiology research in Hispanic/Latino populations

Dr. Lam also highlighted cancer epidemiology research studies from 2016 to 2021 that focused on Hispanic/Latino populations. The Leading Pathways study by Drs. Frank Penedo and Amelie Ramirez was an important Hispanic/Latino cancer survivorship cohort study. The Survivorship and Access to care for Latinos to Understand and address Disparities (SALUD) study by Dr. Michael Scheurer assessed pediatric cancer survivors. The Discovering cancer Risks from Environmental contaminants And Maternal/child health (DREAM) study by Drs. Tracey Woodruff and Peggy Reynolds focused on the environmental exposure of Hispanic and Asian women. Finally, the Southern Liver Health Cohort represents the first large-scale effort to longitudinally determine the link between environmental contaminants, liver disease, and cancer in a residentially and ethnically diverse population. With these research initiatives and others funded by the NCI, our knowledge of the field of cancer epidemiology in Hispanic populations is broadening and information gaps are being filled.

Optimizing Patient-Clinician Communication for Hispanic/Latino Persons with Cancer through Open Notes and the 21st Century Cures Act

Dr. Carli Zegers is Assistant Professor in the School of Nursing at the University of Kansas, and an Emergency Department Nurse Practitioner at University Health Truman Medical Center.

Dr. Carli Zegers

The 21st Century Cures Act

Dr. Zegers began by giving background on the 21st Century Cures Act. Part of this act, the Interoperability and Information Blocking Rule, was passed on April 5, 2021, and requires clinicians to provide patients with on-demand access to clinical notes using a tool such as OpenNotes. Since patient-clinician communication in the cancer setting is complex, with added social and cultural factors affecting Hispanic/Latino patients and their families, this act provides a tool to combat health disparity.
Access to cancer care and specialists, communication about insurance and cost burden, health literacy, and linguistic and cultural discordance can all be improved through access to clinical notes. This is especially important since it is known that insufficient communication in

the Hispanic/Latino community results in unmet needs in the areas of support, satisfaction, increased symptom burden, decreased patient activation, and knowledge deficits.

An OpenNotes Study

Dr. Zegers is conducting a convergent, parallel, mixed-methods study using interviews and surveys to conduct a cross-analysis of Hispanic/Latino and non-Hispanic/Latino patients. Interviews focused on understanding how patients are or are not using information that their health care team shared in the MyChart section of OpenNotes and assessing the impact of shared clinical notes and test results on their cancer care experience. Additionally, a clinical note was read with the interviewer, and the interviewee made suggestions for improvement. Surveys included demographic information; a questionnaire to gain a general sense of patients' knowledge, confidence, comfort, and concerns with OpenNotes; and the Functional, Communicative, and Critical Health Literacy Tool. Recruitment was performed using a University of Kansas Cancer Center program called Curated Cancer Clinical Outcomes Database (C3OD). This database contains 116,524 active cancer patients, 3389 of which are Hispanic/Latino.

Themes of the study

General themes that have emerged from the study include a feeling of data ownership. Patients often made comments such as ”It's my data,” “I don't have to wait,” and “I can share with others.” Another theme was control of care. Patients felt a sense of control, saying “I feel more in control,” “I have something to refer back to to help me recall,” and “I feel more comfortable/knowledgeable/in control of my cancer care.” Some negative impacts of increased access also emerged, however. Patients expressed concerns that “messages from the care team can appear non-compassionate,” that the lag time between receiving results and being able to talk about them with a physician causes anxiety, and that the instant access to results increases anxiety and worry.

Some positive themes emerged that were specific to Hispanic/Latino patients. In the area of role management, for example, patients made comments such as “I use the notes to advocate, not take ‘no’ for an answer,” and “I can manage my care and my dad's care.” Improved communication was also important, with patients noting, “[MyChart] lets me immediately communicate with [the oncologist] and message back and forth.” One survey question asked “What would make you comfortable?” Responses included a template for medical abbreviations or terms, explanations during office visits, and the ability to opt out of receiving information. Patients' highest medical concerns involved medical terms, privacy, bad news, and understanding.

Benefits of improved communication

Conclusions of the study were many. First, whether the patient was at the beginning of their patient journey or farther along made a difference on the impact of OpenNotes. Furthermore, Hispanic/Latino participants had unique uses for OpenNotes, especially as caregivers. Although OpenNotes was generally supported and viewed as beneficial, privacy was a concern. It is important to note that providers must be considerate of anxiety and have options to prevent harm. For example, releasing a radiology report on a Friday evening, with no option for the patient to consult with anyone until the following Monday, can cause extreme anxiety. Overall, the study found that partnerships between providers and patients are important and are supported by this resource, and OpenNotes allows individuals to advocate better, be prepared, ask questions, and locate valuable resources.

Dr. Zegers concluded by noting areas where further research is needed. For example, more information on the impact of OpenNotes on the Hispanic/Latino community is needed, as early data suggests unique patterns of use in this community. More research on dissemination and implementation strategies is also vital, specifically to engage individuals in the Hispanic/Latino community. Despite this need for more study, however, initial results on the 21st Century Cures Act prove promising in addressing communication gaps between providers and patients.

CONCLUSIONS AND RECOMMENDATIONS

Conclusion

To eliminate cancer disparities in Latinx populations, *Advancing the Science of Cancer in Latinos* brought together researchers, scientists, physicians, healthcare professionals, patient advocates, and students from across the US and Latin America. These presenters shared research advancements, identified gaps, developed actionable goals, updated clinical best practices, described effective community interventions, and detailed professional training programs aimed at addressing inequity. In the process, most of the speakers made recommendations, either specific to their field of study or more broadly. The following are some key recommendations abstracted from their conference presentations.

Recommendations

Addressing Systemic Inequities Behind Cancer Disparities

Change comes most naturally at the community level. Communities themselves are the best source of insight into their own needs, and community leaders or individuals who have proven trustworthy to the community are the most powerful agents of change. Health behavior changes, increased access to care, and the closing of many inequity gaps can be achieved by simply listening to and relying on generational wisdom. Importantly, providing fair compensation and adequate support for community health workers is paramount to engaging communities in a socially just way. [Nunez-Smith, Molina, Bandera, Sanchez-Johnsen, Rivera, Jones]

Addressing systemic racism starts with self-assessment. Healthcare professionals must practice self-interrogation, acknowledging the structural racism in healthcare systems and ensuring that instead, diversity and anti-racism are the norm. Since unconscious biases are worse in times of high stress, the COVID-19 pandemic only exacerbated the problem, emphasizing the importance of self-awareness. [Nunez-Smith, Duma]

The physician workforce must reflect the population. Patients often show bias, preferring doctors that look and sound like themselves. These microaggressions against racial minorities, as well as the LGBTQ+ community, lead to feelings of isolation and exclusion. In fact, there has been no increase in Latinx and Hispanic medical students over the last 10 years. [Duma, Rivera]

Cancer risk reduction must include strategies for addressing obesity. Among Hispanic adults in the United States, 44.8% are obese, second only to non-Hispanic Black adults at 49.6%. Of the obese population, however, Hispanic adults have the highest percentage of females with a waist circumference over 88 cm. This can be partially attributed to the nature of Latinx neighborhoods, which can be food deserts, have high poverty rates, lack green spaces, and be areas of high stress due to violence. All of these negative aspects can lead to higher BMI. An estimated 5% of all cancers in men and 11% in women are attributed to excess body weight, with endometrial, gallbladder, and liver cancers being the most affected. [Bandera, Rodriguez-Rodriguez, Diaz, Sanchez-Johnsen, Setiawan]

Disaggregating the Latinx cancer population into subgroups can give more accurate data. The US Latino population is a heterogeneous mix of subgroups that may differ in country of origin, acculturation, nativity, socioeconomic status, generation, disability, religion, sexual orientation, imigration status, and US region in which they reside; these factors can influence cancer risk and outcome. Most US cancer studies report data on Latinos as an aggregate group, obscuring the differences that exist among subgroups. [Sanchez-Johnsen, Trevino]

Language and culture must be considered when designing research. Researchers must understand the impact of language on research, clinical care, education, and outreach. Latinx patients have distinct worldviews, cultural values, and gender roles that affect the way these patients perceive and participate in clinical research efforts. Values such as familism (family values), personalism (personal relationships), and machismo (culturally-prescribed ways for a man to behave) can greatly impact health decisions both in the patient and the caregiver. [Sanchez-Johnsen, Rivera]

Communication is key. Speaking Spanish (or using an interpreter/patient advocate), understanding culture, and providing more frequent points of physician access (e.g., through access to clinical notes) can improve patient understanding, confidence, and compliance. [Velasquez, Sanchez-Johnsen, Zegers]

The State of Latino Cancer Policy and Advocacy

Legislation addressing social inequity is needed. Upstream social inequities are responsible for disparities in cancer risk, incidence, and outcome, indicating the need to engage in policy outside of the healthcare system. Key strategies include advocating for and implementing legislative strategies that counteract racism; participating in active state advocacy coalitions and organizations; educating the public, medical professionals, and elected officials on the economic and health benefits of policy changes; empowering constituents of key legislators to contact their representatives; and voting and supporting voter registration. [Nunez-Smith, Estrada, Saenz]

Medicaid expansion is vital. Medicaid plays a vital role in providing healthcare coverage to lower-income cancer patients and survivors, covering more than two million Americans with a history of cancer. Following the enactment of the Affordable Care Act, expansion states provided all low-income adults access to healthcare through Medicaid. However, countless individuals in non-expansion states such as Texas still lack access to a healthcare coverage option. [Estrada, Long Parma]

Latinx voices must be heard. Many factors lead to the silencing of Latinx voices: lack of awareness of how politics are linked to fighting cancer; practical barriers to advocacy such as time, family responsibilities, and immigration status; cultural and contextual barriers to advocacy such as distrust in the government and a lack of Latino politicians; and an overall need for tailored approaches regarding Latino engagement in advocacy. Education, community engagement, better access to support services, and policy changes can be effective in reversing these trends at the grassroots level. [Saenz]

Latino Cancer Research Methodology

Holistic approaches to cancer research are needed. A holistic approach is important because cancer itself does not occur in a vacuum, but is multifactorial. Social determinants of health cannot be mere variables in detached research, but should rather “scream a story of human condition.” Understanding the history of inequity in cancer research is also important, as this brings about an awareness of historical blind spots in the treatment of minorities in clinical and research science. [Santos, Winn]

More data on Latinx populations is needed, and current data should be more utilized. Differences in Latinx cancer patient presentations, including genomic findings, are proving instrumental in better understanding uniquely Latinx considerations. Existing data sources, such as the Census Bureau for example, already have publicly available data that can be used to inform Latinx research initiatives. [Santos, Ziv, Long Parma]

International collaborations can be effective in advancing cancer research. Maintaining active cross-border conversations can lead to a more global view of public health goals and increase data visibility and data sharing flexibility. Interregional collaboration, the wide availability of trainees, easy-to-use technologies like ZOOM and WhatsApp, social media tools, and shared language and values among Spanish-speaking clinicians make international collaborations across Latin America more accessible than ever. Existing collaborations, such as the Latin American Cancer Research Network (LACRN), have helped to establish biobanks, dynamic databases, and infrastructure for future studies. [Lajous, Costas-Muñiz, Llera]

The Impact of COVID-19 and Cancer Care

Clear messaging is vital to effectively engaging the public. The COVID-19 pandemic revealed weaknesses in the healthcare system and infrastructure, especially when it comes to clear and understandable messaging. As a result, vaccine hesitancy among communities of color is a major problem. A priority in public health must be to regain trust in vaccines, not only for the current pandemic, but for all future public health crises. [Del Rio]

Health initiatives must establish trust at the community level. During the pandemic, excess deaths were much higher in the Latino population compared to White patients. Life expectancy was severely affected as well, with Latina women showing a life expectancy loss of 2 years, and Latino men showing a loss of 3.7 years. Health initiatives that proved successful during this time involved culturally appropriate approaches for increasing trust, the use of community advisory boards, the importance of community engagement, flexibility and the ability to adapt, and partnerships with community health clinics. [Webb Hooper]

Understanding uniquely Latinx presentations is critical to providing optimal clinical care. Latinx patients during the COVID-19 pandemic presented uniquely, especially within niche groups such as pediatric cancer patients. In such populations, having a clear understanding of clinical findings and outcomes proved critical in providing optimal clinical care and in achieving best outcomes. [Flatt]

Avenues of Change Throughout the Cancer Continuum

More diversity is needed in genomic databases. Publicly available genomic databases such as The Cancer Genome Atlas (TCGA) program lack diversity, with only 3% of TCGA being Latinx. Recruitment of Latinx participants in the building of these databases can provide a more complete understanding of Latinx genomics, while helping researchers understand differences within Latinx subgroups. [Ziv, Dutil, Cress, Dovat]

Increased genetic testing for Latinx cancer patients can lead to more individualized care. In cases such as poly-ADP ribose polymerase (PARP) inhibitors for breast cancer treatment, fewer Latinas are eligible due to the paucity of genetic testing in the Latinx population. Furthermore, targeted therapies based on genetic testing can increase treatment efficiency, leading to improved patient quality of life. One such therapy, AXL/STAT3 inhibition, shows great promise against aggressive tumors, not only in inhibiting tumor growth, but in affecting the entire tumor microenvironment. [Lynce, Dovat, Taverna]

Virtual group medical visits (GMVs) can be an effective tool for healthcare in Spanish-speaking Latinx breast cancer patients. Initial results show that the GMV concept, a low-cost healthcare delivery option, increases patient confidence and access to survivorship care for participants. [Velazquez]

Better quality of life can be achieved through support for specific comorbidities such as cardiometabolic comorbidities. When compared to survivors without cardiometabolic comorbidities, those with cardiometabolic comorbidities reported lower overall health-related quality of life, functional wellbeing, emotional wellbeing, social wellbeing, and confidence in patient-provider communication. Intervention techniques are needed to increase cardioprotective behaviors and improve outcomes for Latinx cancer survivors with cardiometabolic comorbidities. [Maras]

Cancer Screening Disparities

Disparities in Latinx cancer screenings must be addressed. Many barriers to cancer screening exist in the Latinx community, including religious beliefs, embarrassment, pain with procedure, worry about work, being a caregiver for another, couples issues, fear of diagnosis, physical or mental impairment, economic issues, transportation, and concern about COVID-19. Lung cancer screening, for example, is one of the most important interventions for decreasing lung cancer mortality. However, the National Lung Screening Trial (NLST), the largest randomized trial in the history of lung cancer screening, was composed of more than 90% White participants. Value-Based Care (VBC) Programs and Delivery System Reform Incentive Payment (DSRIP) programs can be used to improve Latinx screening access and participation. [Rivera, Tortolero-Luna, Setiawan, del Aguila]

Cancer Clinical Trials

Clinical trials must allow for more flexible inclusion criteria. In Phase I clinical trials from 2013 to 2017, only 2.8% of participants were Hispanic/Latino, compared to 84.2% White participants. In order for clinical research to be equitable, trials must allow for more flexible inclusion criteria. [Duma, Dovat, Rodriguez, Trevino, Penedo, Perez, Kuri]

Enrollment goals should reflect the epidemiology of the disease being studied. A diversity plan should begin with an understanding of the epidemiology of the disease, including clinical characteristics, populations with increased case burden, and populations with increased death burden. Enrollment goals should then reflect that epidemiology to represent a diversity of minority groups, reflecting differences in race, ethnicity, age, sex, and more. [Duma, Rodriguez, Fashoyin-Aje, Penedo, Perez, Kuri]

Health provider and researcher biases must be identified and resolved. Provider assumptions prevent many patients from being informed about clinical trials they would otherwise be eligible for. Programs to identify and resolve providers' biases towards minorities are currently being established to address this problem. Diversity promotion among providers and researchers and patient education programs about clinical research and importance are also underway. [Rodriguez]

Removing economic and social barriers to clinical trial participation is imperative. This begins with advocating for coverage of clinical trial participation for all patients, who must be provided with adequate economic compensation for time, travel, and lost wages. Study design modifications can also play a part, making participation easier through decreased frequency of visits, decreased length of visits, virtual visits, and more. Furthermore, identifying and partnering with community resources can drastically improve participation. [Duma, Rodriguez]

Latino Cancer Survivorship

End-of-life (EoL) care for Latinx patients can be improved through the therapeutic alliance. Providing quality EoL care can be challenging in the Latinx community due to the diversity of the population, immigration status, language proficiency, and culture. One strategy for addressing this challenge is the therapeutic alliance, a construct that encompasses the interrelated and essential dimensions of the patient-physician relationship: trust, respect, understanding, and concern. [Tergas]

It is important to encourage advanced care planning (ACP) to improve EoL care among Latinx patients. Latinx patients are less likely to complete do-not-resuscitate orders, have living wills, or have designated healthcare proxies, partially due to the four cultural values of fatalismo, familismo, machismo, and respeto. However, patient consultation with family is associated with higher involvement in ACP. [Maciejewski]

The Industry Role in Cancer Research Innovation

Government and industry initiatives must have high standards for funding proposals. The Health Equity Committee at Stand Up To Cancer (SU2C), for example, requires an indication of whether the research will address the populations expected to benefit from widespread use of newly developed treatments; patient recruitment and retention plans for including historically underrepresented racial and ethnic populations; and a letter of support from the lead institution’s Chief Diversity Officer, or an equivalent position. [Perez]

Equal access to comprehensive molecular profiling and cancer screening must be ensured for all patients. Medicine is transitioning from a “one-size-fits-all” approach to precision medicine enabled by comprehensive molecular profiling. Cancer screening is also evolving from screening for individual cancers to simultaneous screening for multiple cancers. In order to make these processes possible, equal access to comprehensive molecular profiling and screening must be ensured, as well as diversity of patient cohorts in both biomedical research and clinical trials. [Abril, del Aguila, Sandoval]

Industry must be the driver for more equitable clinical trials. Clinical trial design must do the following: ensure that processes are aligned with external commitments when selecting US sites and investigators; reduce practical obstacles to clinical trial participation; adhere to FDA guidelines; track performance and ensure commitments are maintained; incorporate community groups, partnerships, and external thought partners; and commit to internal and external diversity training. [Kuri, del Aguila, Sandoval]

Further Resources

The National Institute on Minority Health and Health Disparities (NIMHD) at the NIH. Through initiatives such as the Health Disparities Research Institute and the Community Engagement Alliance (CEAL) Against COVID-19 Disparities, the NIMHD is seeking to lead scientific research to improve minority health and reduce health disparities. [Perez-Stable]

The Division of Cancer Control and Population Sciences (DCCPS) at the NCI. The DCCPS seeks to (1) improve data collection and analysis to support subgroup-specific cancer rates and trends through the Survey, Epidemiology, and End Results (SEER) program; (2) support the development and adaptation of culturally appropriate interventions for increasing the uptake of preventive services and adoption of healthy lifestyles; (3) increase Hispanic/Latino enrollment in clinical trials and cohort studies with high-quality, annotated biospecimens; and (4) leverage all DCCPS-supported research infrastructure. [Goddard, Lam]

PICTURES FROM THE CONFERENCE


ADVANCING
THE SCIENCE OF CANCER
IN LATINOS


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