How The American Healthcare System Will Accommodate The Projected Increase In Racially Ethnically Diverse Cancer Patients In The 85 Years Or Older Population During The Next 50 Years

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The population of the United States is aging and diversifying. Concurrently, cancer prevalence increases with age, which will lead to more cancer patients who are both older (over 85 years old) and racially and ethnically diverse. However, both older cancer patients and minority cancer patients experience worse cancer outcomes than younger and white patients. The challenges older cancer patients face include underrepresentation in clinical trials, medical complexity, and incomplete medical evaluation. The challenges minority cancer patients face include underrepresentation in clinical trials as well as limitations in cancer screening. Underrepresentation in clinical trials is a challenge for both older, racially and ethnically diverse patients independently that prevents them from receiving optimal cancer outcomes and could be further exacerbated with the projected change in population. To address this challenge, a push is called for to generate the participation and the inclusion of patients who are older, racially and ethnically diverse in clinical trials. This comprehensive review provides a combination of information on both very old cancer patients and racially and ethnically diverse cancer patients, culminating in a closer look at the intersection of the challenges and potential solutions for both groups in order to fill in the gaps of prior works which solely focus on groups either old or ethnically and racially diverse but not accounting for both.

1 Introduction

The U.S. population is projected to age and diversify over the next 50 years. People 85 years of age and older, or the "oldest old," are the fastest growing age-group in the U.S.[1] Furthermore, the population of Non-Hispanic White population in all age groups is predicted to decline by 8% by 2060 relative from the early 2010s.[2] This change will be even more dramatic in the older age group, with a 23% decline in Non-Hispanic White population over age 85 by 2060[1]. By 2044, the US is expected to have a majority-minority, which means that the Non-Hispanic White population will be the largest ethnic group but no individual group will make up the majority of the overall population[2]. While each ethnic group will grow overtime except for the Non-Hispanic White population, the Two or More Races group will experience the most growth with a projected 226% increase between 2014 and 2060, followed by the Asian population with a 143% increase, the Hispanic population with a 115% increase, the Native Hawaiian and Other Pacific Islander population with a 63% increase, the Black population with a 42% increase, and the American Indian and Alaska Native population with a 40% increase[2].

These changes in the US population are expected to have an impact on both the age and ethnicity distribution seen in cancer patients, leading to more racially and ethnically diverse cancer patients over 85 years old. Because cancer incidence rate increases with age, projected aging of the US population will increase the proportion of oldest old patients with cancer[3]. Additionally, with the diversification of the older population, it is also expected that patients with cancer in the oldest old age group will be more racially and ethnically diverse. Patients who are a part of the oldest old population and are minorities will be the most negatively impacted by this projected increase in cancer incidence.[1,3,4] This brings to question how the American healthcare system will accommodate the projected increase in racially and ethnically diverse cancer patients in the 85 years or older population in the next 50 years. The aim of this work is to understand and analyze the challenges of both older and minority patients, determine an issue for the healthcare system to solve, and present suggestions to resolve the issue to answer the research question. While prior works focus on groups either older or racially and ethnically diverse, this comprehensive review combines information on both groups and looks at where the challenges and potential solutions for these two groups meet.

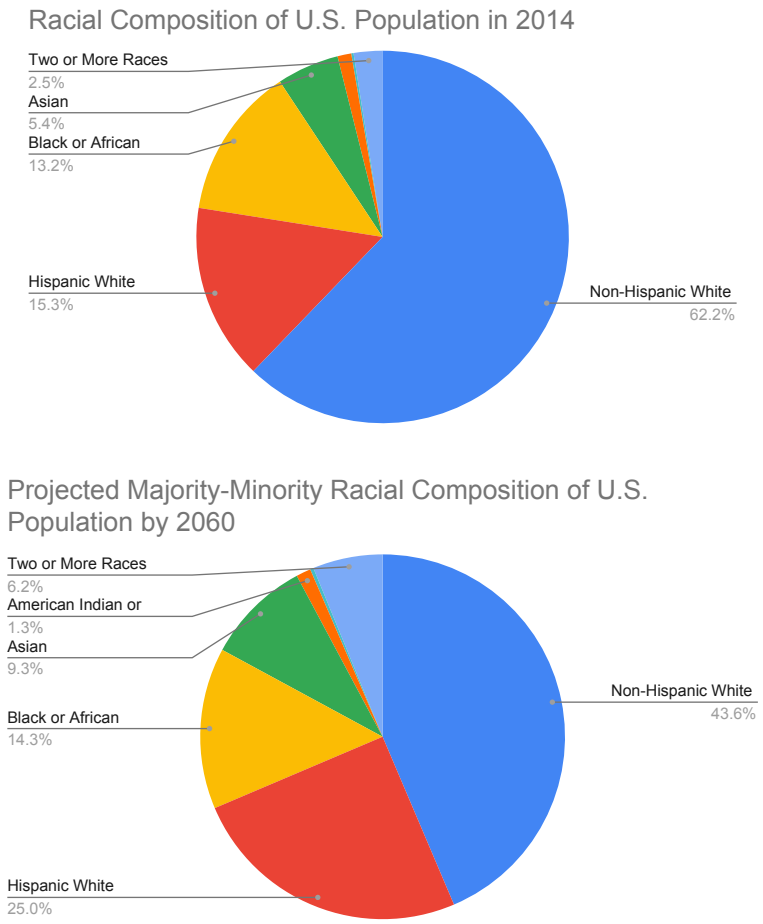

Fig. 1 The U.S. population is projected to become a majority-minority population by 2044 as demonstrated by the difference in racial composition between 2014 and 2060.

2 Multiple Factors Contribute to Worse Cancer Outcomes for Patients 85 And Older

Older patients face worse cancer outcomes than their younger counterparts with 8% of all cancer diagnoses, and 17% of all cancer-related deaths.[3] There are many factors that can increase the difficulty of caring for older cancer patients and can influence their outcomes, including medical complexity, limited research involving older patients, a limited evaluation of older patients despite the existence of some guidelines, and caregiver burdens. First, older cancer patients can be more complicated medically than their younger counterparts, due to frailty, polypharmacy, and a high rate of comorbidities. Frailty, or physiological decline due to age, increases the risk of death, decreases quality of life, and negatively impacts patients' health because it leaves patients vulnerable to occurrences such as falls and fractures. Polypharmacy, or taking multiple drugs at once, complicates patient treatment due to accommodating different medicines. Comorbidities are when a patient has multiple ailments. Patients with comorbidities experience a reduction of screening rates an increased rate of late diagnoses in advanced stages of cancer, reduced use of chemotherapy, a decreased the quality of life, and a worsened patient outcome.[3] These patients' challenging care is further complicated by a lack of medical research supporting care for older cancer patients. Older patients are also under-enrolled in clinical trials with the median age in 302 randomized clinical trials being 6.5 years younger than that of the general population.[5] The exclusion from clinical trial participation of this group is caused by using upper age limits and restrictive criteria based on geriatric syndromes[3]. In addition to general exclusion from trials, older patients are also typically not evaluated correctly when included in clinical trials. Geriatric patients are not evaluated at all in most clinical practices using

specific geriatric evaluations, assessments of an older person's functional status, comorbidities, cognition, and socioenvironmental circumstances. Geriatric evaluations are the best practice.[1] In a large-cohort study of older patients where geriatric assessments were recommended to each patient, only 35% of recommendations were acted upon.[3] In a smaller study, 409 patients were recommended a geriatric assessment, however only 35% of patients received their assessment.[3] Older cancer patients are not always evaluated using the best practice available and are therefore not being appropriately treated.

Finally, cancer patient treatment is complicated by many socio-economic factors as well as caregiver factors. Patients with good socioeconomic backgrounds face better circumstances than those not as wealthy, for many socioeconomic related factors such as poverty, education, homeownership, perceived neighborhood safety, resource availability, and health insurance status have been discovered to be related to health disparities.[6] Furthermore, a patient's health is impacted by the quality of life and emotional status of their caregiver, and 75% of all caregivers experience caregiver burden, in which they face physical and emotional challenges.[3]

3 Several Factors Contribute to Worse Health Outcomes for Minority Patients

Minority patients also have worse cancer outcomes than non-minority populations. For example, Hispanic patients have higher morbidity rates and disability rates than their Non-Hispanic White counterparts,[6] and black men have a 5% higher mortality rate despite a lower incidence rate for cancer.[1] Also, Asian Americans have the fastest increasing mortality rate due to cancer than any other ethnic group.[7] For Asian Americans, Native Hawaiians, and Pacific Islanders, cancer is the leading cause of mortality.[4] These morbidity and mortality statistics are daunting on their own, but further compounded by the expected cancer population changes in the next 50 years. While the cancer incidence rate is expected to increase 31% for the white population, it is expected to increase 99% or more for minority groups including Alaskan natives, African Americans, Hispanics, Asian Americans, Hawaiian natives, and Pacific Islanders.[4] This is due in part to the fact that cancer incidence rates and lifespans are proportional. Unless morbidity and mortality rates improve in racially and ethnically diverse patients, even more minority patients will face worse cancer outcomes in the future.

Worse cancer outcomes in racially and ethnically diverse patients appear to be due to difficulty accessing cancer screening care, the presence of different risk factors in these patient groups, and the available medical research supporting patient care. Low screening rates are prevalent in minority patient populations. For example, both Hispanic and African American patients have been shown to have lower screening rates for both colorectal and breast cancer,[8–15]while Asian-Americans have the lowest rates of tests for cancers such as the Pap smear (68%) and endoscopy (19%) out of all US ethnic groups.[4] In Hispanic patients, this lower rate has been attributed to lower socioeconomic status, language barriers, and cultural factors.[6,16] In Asian American patients, it is attributed to linguistic and cultural barriers.[4] In African American patients, this is attributed to insurance and economic challenges, lack of physician facilitated screening, and limitations on screening education.[15]

In addition to lower screening rates, variability in cancer risk factors and types can contribute to worse outcomes or higher cancer rates for some ethnically diverse patients. For example, Southeast Asian men have much higher smoking prevalence rates, which are 35% to 72%, than the California smoking prevalence rate of 21%.[7] Additionally, Hispanic patients are more likely to have cancers caused by prior infection, such as liver cancers due to Hepatitis B and Hepatitis C or gastric cancer due to H. Pylori.[16] These alternative risk factors create different screening needs that can be compounded by the already lower rates of cancer screening.

Finally, there is an overall lack of minority representation in clinical trials. African American representation in the majority of clinical trials was less than 5%, which is less than half of their 13.4% stake in the overall U.S. population.[17] Asian-Americans also experience systematic underrepresentation in US surveys and clinical trials due to inadequate data collection strategies and methods, with Asian Americans being eliminated from some surveys altogether.[4]

Furthermore, although there is already some targeted research regarding Hispanic cancer patients, there is a lack of research surrounding many other important needs of this population, most notably cancer control and survivorship, and culturally adapted evidence-based interventions.[16] Although Asian Americans, Native Americans, and Pacific Islanders represent over 5.0% of the U.S. population, they were found to be represented in only 0.2% of health-related grants of 7 government agencies and in only 0.4% of top 20 U.S. foundations' investments.[18,19] Finally, there were almost no funded projects found that support the participation of Native American and Pacific Islander populations in clinical research.[20]

4 Clinical Trial Representation and Receiving the Best Care Issues are Compounded for Older, Ethnically Diverse Patients

While older and ethnically diverse patients can have their own unique set of challenges, there are important areas where their problems overlap. These areas of overlap, which include clinical trial representation and receiving the best clinical care,

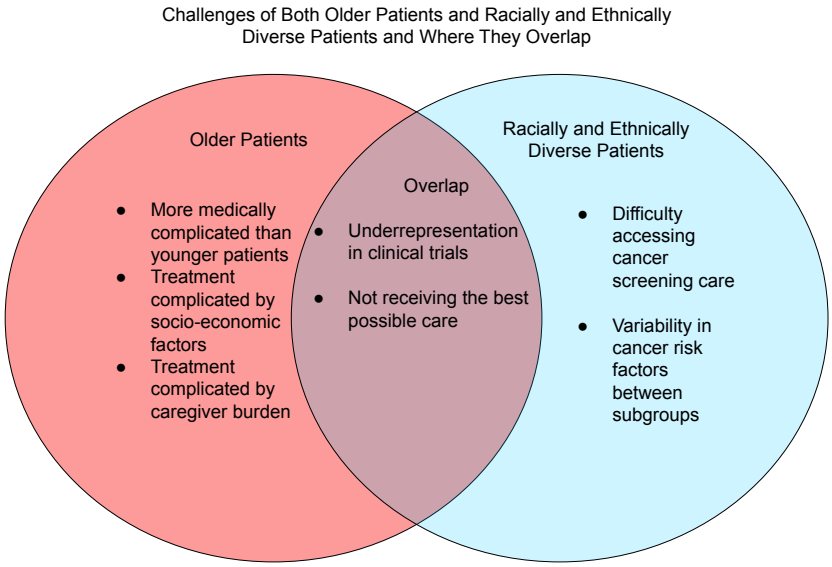

Fig. 2 The challenges of older patients and racially and ethnically diverse patients overlap in the areas of underrepresentation in clinical trials and in not receiving the best possible care.

may be significant challenges in the future due to how these challenges independently affect older and minority patients, and will be compounded as the patient population grows to include more of those both older and ethnically diverse.

As stated in the prior section, the majority of clinical trial participants do not reflect the age, racial composition or ethnic composition of the general US population Therefore, more research surrounding older, racially and ethnically diverse patients is needed. Without this research, there will be a lack of understanding regarding how to treat the age-related challenges of older patients as well as missing information on the most effective course of treatment for diverse patients. This widens the already massive gap in research that benefits patients who are both older and diverse, which is a rapidly growing group. Without research, there will not be available information on how to best treat these patients, and this knowledge gap creates an absence of guidelines to define their best clinical care.

Both older and diverse patients are having worse cancer outcomes, which will be compounded for those who are both older, racially and ethnically diverse. Due to the lack of research, as stated above, there are a lack of established guidelines on how to best treat this growing group of patients. These outcomes may also be due to the lack of knowledge and enforcement of existing guidelines. For example, physicians do not use geriatric evaluations, recommend screening for patients, or are unaware of cultural and risk factors that influence patient ailment and their interaction with the healthcare system as much as they should. All these factors should be changed in order to provide the best clinical care possible for this group of patients. Creating guidelines, getting specialized teams of providers, as well as different training for physicians can solve this issue. Based on the factors that are important for both older patients and patients of certain ethnicities, the lack of representation in clinical trials for both older and minority patients emerge as a more pressing problem that negatively affects these patients' outcomes through a lesser quality treatment.

5 Better diversity in Clinical Research is Necessary to Provide Better Care for the Aging and Diverse Cancer Population

The improvement in care for older, diverse cancer patients depends on the scientific information available and guidelines around how to best treat these patients. Because there are many facets that impact patient clinical trial participation, the solution to this problem will therefore be multifaceted. One way that has been proposed to increase the amount of research directed towards older, racially and ethnically diverse patients is increasing the accessibility of clinical trials. Placing study sites in community centers,[17] offering extended or adaptive trials,[20] increasing clinician recruitment of these patients,[20] as well as using new technologies such as trial matchmaking websites eases the burden of participating in trials for this group. While having more inclusive recruitment criteria may create follow up and data analysis challenges, more inclusive recruitment should be an incentivized practice to further generate research for older and diverse patients.[18] The

FDA should be given the authority to require inclusion of older adults and racially and ethnically diverse adults.[20] Journal policies should also incentivize research to provide factors such as age distribution, health risk profiles[20], as well as diversity of research participants. Furthermore, building trust between medical establishments and local communities should be a priority[17]. A diverse pool of investigators and staff in clinical trials that racially and ethnically represent nearby communities allows for them to serve as ambassadors, make connections, and removes implicit bias between from within the clinical trial[17]. Finally, there should be awareness of the issues caused by a lack of age and ethnic diversity in clinical trials through more programs such as the All of Us Initiative[17] to further enforce positive inclusion of this group in research. Another important factor in a lack of racial and ethnic diversity in clinical trials is less interest in trial participation from minority populations. The notorious Tuskegee Study, where African American men were denied Syphilis treatment in an effort by doctors to study how the disease progressed, has caused distrust and fear of the medical establishment in the African American population[17]. Other complications such as not having access to medical institutions which are centers for clinical trials or the inability to take time off from work make clinical trial participation a burden for minority populations[17].

6 Conclusion

In conclusion, the older, racially and ethnically diverse population is a rapidly growing US sub-population. This change in population is leading to an increase in the number of oldest of the old, racially and ethnically diverse adults with cancer. Both of these populations face unique challenges leading to worse cancer outcomes and for those who fall into both categories, the outcome of their cancer diagnosis and treatment is further compounded. This paper argues that a lack of representation in clinical trials proves to be the most pressing problem, as it results in lesser quality care and worse outcomes. Moving forward, the healthcare system should strive to better represent the increasing population of older, minority cancer patients in clinical trials through increasing accessibility, providing incentive, and spreading awareness to generate more research and therefore provide the best clinical care for this group.

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