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OPINION/EDITORIAL

WE MUST WEIGH PAST INJUSTICES AGAINST FUTURE CONSEQUENCES



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Q-Tip, celebrated hip-hop artist, producer and founding member of A Tribe Called Quest took to Instagram recently to honor his mother, who is living with Alzheimer's. Known for lyrics that touch fans with their eloquence while simultaneously educating them on timely issues, the pioneering hip-hop star said that taking on the role of caregiver has been eye opening and inspirational.

When prominent people, like Q-Tip talk about Alzheimer's it helps to diminish the stigma connected to the disease and brings light to the often socially isolating experience of caregiving. Q-Tip's candor also provides an opportunity for a more specific conversation about the impact of Alzheimer's and other dementias on the black community. Generations of black Americans were robbed of cultural memory through separation and marginalization. Now, Alzheimer's disease threatens our memories in a radically different way. According to the 2019 Alzheimer's Association Facts and Figures report, African Americans make up 20 percent of the 5.7 million Americans living with Alzheimer's and African Americans are about two times more likely to develop Alzheimer's than whites. In spite of the disproportionate impact of Alzheimer's on the black community, African Americans are severely underrepresented in the clinical trials that researchers depend on to find new medicines and one day, hopefully, a cure for Alzheimer's.

Perhaps low clinical trial partici-

pation is in part due to a lack of understanding of the scale of the problem. Deaths from Alzheimer's have increased by 89% since 2000. Alzheimer's has not been the subject of a public health campaign like the community-supported efforts around Sudden Infant Death Syndrome (SIDS) and prostate cancer. A comprehensive public health campaign that builds awareness through education is a vital first step in the process. Understanding Alzheimer's as the public health crises that it is and the role that both healthy and diagnosed individuals play in research, can help to pave the way for a more successful recruitment process.

There is evidence that community-based outreach plans, where researchers and institutions prioritize buy in from the black community, are effective in increasing African American study participation. At the 2018, Alzheimer's Association International Conference researchers from Indiana University School of Medicine reported the results of a successful pilot project that utilized a community advisory board at the Indiana Alzheimer's Disease Center and worked with the local Alzheimer's Association chapter. The advisory board was predominately African American and included respected community members like an elder law attorney, pastors and representatives from the state and county boards of health.

The advisory board worked with researchers to develop recruitment messaging and activities with communities of color in mind. The Alzheimer's Association collaborated with the project at community outreach events to increase participation in Alzheimer's Association TrialMatch. TrialMatch is a free, clinical studies matching service that connects people with Alzheimer's, caregivers and healthy volunteers to research studies. As a result of the pilot project, 300 African American volunteers were added to the Alzheimer's Association TrialMatch database and the Indiana Alzheimer's Disease Center increased participation from communities of color from 8.8% to 19%. Of course, medical research and the black community cannot be

discussed without context. The so-called Tuskegee experiment, an unethical study of untreated syphilis in black men, perpetrated by the United States government, only ended in 1972. Today, experiences with medical institutions often leave African Americans feeling like they do not receive the best care and that race is a factor. According to a 2017 University of California analysis, racial discrimination was the most common reason that black patients said they received poor service or treatment from a doctor or hospital.

These realities cannot be dismissed. In making an informed choice to participate in Alzheimer's research we must weigh past injustices against future consequences. Including our bodies but also our voices in the world of Alzheimer's and dementia research gives us the power to influence outcomes. This crippling disease does not have to define our destiny. As a people, are we willing to take a calculated risk to protect not just the black community at large but in fact our own families and ultimately ourselves as individuals?

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