

Being Seen and Being Heard; Capturing Alzheimer's in the Black Community

"Why can't I go with you? I want to go with you! Let's go home," are the familiar sentences that have painfully punctuated the close of many visits to the nursing home. I watch my mother fidget and awkwardly explain to my grandmother that "this" is her new home. No, she cannot go with us. No, we cannot we stay in the spare bed in her room. That bed belongs to her roommate.

Somehow, after months and maybe years of this ritualistic conversation, we have moved past the phase where my mother, in futile, struggles to explain to my grandmother why we must leave and she instead stay. Sometimes truth is not always the answer; in the realm of dementia lying is merciful. This has been a difficult lesson for my mother to learn, just to say "we'll be back soon" and leave it at that. She is surely not alone in this fight to adjust.

African Americans are disproportionately diagnosed with Alzheimer's disease. Alzheimer's disease "is the most common form of dementia, a general term for memory loss and other cognitive disabilities severe enough to interfere with daily life"

(https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp)

Yet despite the fact that African Americans are twice as likely to develop Alzheimer's, "African Americans are nearly invisible in clinical Alzheimer's trials: Despite representing more than 20% of the 5.5 million Americans who have the disease, African Americans account for only 3 to 5 percent of trial participants." (https://www.washingtonpost.com/lifestyle/magazine/why-are-african-americans-so-much-more-likely-than-whites-to-develop-alzheimers/2017/05/31/9bfbc3132-11e7-8674-437ddb6e813e_story.html?noredirect=on&utm_term=.e769890042fd)

It seems that in the medical world the way diseases and health concerns differently impact people of color are often forgotten. Award winning author Marita Golden has brought awareness of this disparity through some of her recent work.

The Wide Circumference of Love by Marita Golden deposits readers straight into the emotional tension of an African American family at the behest of Alzheimer's disease. Gregory Tate is one the most prominent D.C. architect's—co-owner of Caldwell & Tate. Married to a family court judge Diane, Gregory and Diane with their two children represent the epitome of #Blackexcellence. Yet, Gregory's early on-set Alzheimer's threatens to crumble everything their family has built. The novel primarily follows Diane's point of view but occasionally shifts to show the perspective and background of other main characters. Occasional chapters highlight Gregory and Diane's children Sean and Lauren, as well as Gregory himself.

In the novel Gregory seems to be a part of the rare percent of Alzheimer's cases where the disease was genetically passed down. Although is not confirmed, Diane's flashbacks to meeting Gregory's dementia afflicted father, Ramsay, are a crucial aspect of the novel. When Gregory and Diane had begun seriously dating, Gregory's father was wheel chair bound. The disintegration of his mind was so severe that he could no longer walk or care for himself. After one Sunday dinner with Gregory's family Diane reflects, "This is what families did Diane

thought. They cared for one another, loved even more fiercely the weakest among them” (79). It is that exact feeling that care givers struggle with when caring for their loved one becomes a demand they can no longer meet.

Within the African American community taking care of family members was just something you did, and placing them in the care of strangers was something you didn't do. Historically white American families with means have always outsourced the care of their children and elderly to workers, frequently African American. Look at the history of Black nursemaids and the mammy figure (<http://historymatters.gmu.edu/d/80/>). For marginalized communities that historically have not had the resources to outsource the labor of love and care, there is an additional layer of tension and complexity. When Diane first leaves Gregory in his new home at an assisted living facility she looks at the dining room area and thinks, “ here he would stay, among absolute strangers. People stranger than even she and Lauren and Sean were to him now.” Although it is often a necessary decision, leaving your loved ones in the care of strangers always feels like abandonment. For communities whose ancestors endured and survived familial separation from various institutions of oppression such as slavery, war, displacement, mass incarceration—the choice to part from loved ones is particularly arduous.

Golden manages to poignantly capture the distress of that first goodbye between care taker and their loved one. After napping with Gregory for a few hours, Diane decides its finally time to go, but Gregory won't let her. Diane pleads with Gregory to let go of her so that she can leave, but like a child he simply commands, No. A nurse must help Diane pry free from her husband's grasp and metaphorically her old life, in order to move into the new future that awaits her. For 3 weeks Diane is forbidden from visiting Gregory so that he can acclimate to his new life and surroundings. I feel certain my mother never would have agreed to such conditions.

For 20 years, I have grown up watching my mother try face the devastation that is Alzheimer's. Alzheimer's is the worst kind of thief—by stealing memories, it steals people's sense of identity. For loved ones it is incredibly difficult understanding that someone you once admired, maybe even feared is no longer themselves. They are not who you remember them to be and they are beyond logical reasoning. Often they appear as a petulant child, and the worst kind—one who can never atone or make amends for their trespasses, because they simply forget, only to do it again another day.

The cause of Alzheimer's disease along with its cure remain shrouded in mystery. Although the disease was discovered over 100 years ago in 1906, there has been relatively little development towards a cure. However, recent research suggests strong connections to physical activity, hypertension, diabetes, sleep patterns and depression for impacting the development of Alzheimer's. When one thinks of the health crises that have swept over African American communities, it seems like no wonder that Alzheimer's is an increased risk.

My grandmother worked over 30 years as a nurse attendant, predominantly scheduled for the graveyard shift—from 11pm to 7am. As a divorced Black mother in the 1950's and 1960's who

also cared for her own mother, she often could not get her full 8 hours of sleep during the day. By the time I was born in the 1990's, my grandmother had been retired for years but her "night owl" habits remained. At some point in her adult life she had been diagnosed with Type 2 Diabetes, which "doctors now know significantly increases a person's risk for Alzheimer's."ⁱⁱ In communities where marginalized people must often work unfavorable jobs that come with even more unfavorable health risks and side effects, Alzheimer's is just another worry to add to the growing list. From living in food deserts where fresh fruits and vegetables are scarce, to communities so devalued that crime and stress are equally high, it is no wonder that health problems cascade like dominoes for people of color.

Ultimately Golden's novel, as well the Washington Post article she wrote bring awareness to Alzheimer's in the African American community. *The Wide Circumference of Love* beautifully recounts the triumph that life and love can continue despite the havoc Alzheimer's wreaks on minds and hearts. Although Alzheimer awareness month is coming to a close its especially important to recognize how communities of color are erased from public health discussions. In TIME magazine's special issue on Alzheimer's, there was barely a mention of people of color and how they are further at risk. This makes the work of organizations like Us Against Alzheimer's (<https://www.usagainstalzhaimers.org/networks/african-americans>) that much more important. Support those who see us and distance ourselves from those who don't and won't.

ⁱ Golden, Marita *The Wide Circumference of Love* 23.

ⁱⁱ Sifferlin, Alexandra "The Varied Paths to Progress" TIME 47.