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Author

Bonnell, Janaé

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Disparities in Cancer Incidence and Mortality on Native American Reservations

Janae' Bonnell

Abstract

Native Americans who live on reservations lead vastly different lives than those of other American citizens. The many disparities between the issues faced by people in remote communities on reservation land and those seen in the rest of the population have major effects on people's health, with cancer being one such ailment. While cancer has a genetic component, it is also vastly influenced by a person's lifestyle and their living environment. The likelihood that someone smokes, lives in poverty, or is employed in a hazardous occupation is higher on reservations than in other parts of the country. Also, the responsibility for healthcare on most reservations falls to the Indian Health Service (IHS), which is chronically underfunded and lacks the means to provide truly comprehensive, quality care to patients. On reservations, people also face increased carcinogen exposures that stem from the continued existence of environmental racism and reservations' remote locations. In addition, the tenuous relationship between Native Americans and Western medicine discourages many from receiving potentially life-saving screenings and treatment. This report discusses the multitude of factors that impact disparities in cancer incidence and mortality rates on Native American reservations in the United States and examines how these factors differ from those seen in other populations.

Background

Cancer is a disease that develops when the DNA in a normal cell in the body acquires mutations that result in the cell dividing uncontrollably. In solid cancers, the multiplying cells form tumorous growths, while in liquid cancer, such as leukemia, these cells spread throughout a bodily system. As cancer cells grow, they begin to disrupt normal body functions in the

surrounding tissue, and eventually spread to other parts of the body through the process of metastasis.

The growth and spread of cancer are influenced by many different factors. For example, exposure to carcinogens, chemicals that induce cancer-causing mutations, can increase the incidence of cancer in a group of people. This is seen in Native American populations due to the disproportionate amount of carcinogenic substances in their environments. In addition, lifestyle factors, such as habitual smoking, can increase a person's cancer risk. Once diagnosed with cancer, a person's survival and health outcomes are dependent on their access to quality, timely medical care. Of all ethnic groups across the nation, Native Americans have one of the poorest rates of cancer survival, and this needs to change (White et al., 2014). By virtue of the location, environment, and history intertwined with reservations, the cancer-related challenges that people face in these communities are vastly different from the issues that people in more urban areas are confronted with. This is reflected in the differing levels of cancer incidence and mortality, along with the discrepancies in what types of cancer are most prevalent among different nations when compared to the rest of the United States. Studies have investigated cancer incidence in Native American individuals living in Contact Health Service Delivery Area (CSHDA) counties, which contain federally recognized nation land and the adjacent areas. This designation is used to determine eligibility for IHS services. It was found that liver and kidney cancer have a two-fold increase in incidence in Native American individuals living in CSHDA regions when compared to Caucasians in CSHDA regions (White et al., 2014). Across the country, death rates for stomach, liver, and kidney cancers are higher in Native American populations than those seen in Caucasians (White et al., 2014). Some of these differences in mortality and incidence vary by geographical location. The rate of lung cancer deaths in Native American individuals is highest

in the Northern Plains, while uterine cancer rates are higher in the Southern Plains (Plescia et al., 2014). Not only can the information gleaned from studying causes of cancer on reservations be used to improve the healthcare for the 1.1 million Native Americans who live in these areas, but understanding the effects of differences in exposure will help the medical field to understand the impacts of the presence and absence of different contributory factors (“Profile: American Indian/Alaska Native.”, 2018).

Socio-Economic Factors

One of the largest contributors to disparities in cancer incidence and mortality on Native American reservations is tobacco use. Many nations regularly use tobacco for ceremonial purposes and have done so for thousands of years. The people of the Lakota Nation in North and South Dakota traditionally used tobacco pipes for seven rites, which included purification and releasing one’s soul (Godlaski, 2012). However, the detrimental health effects of traditional tobacco use pale in comparison to those caused by habitual smoking. While a vast number of Native Americans use tobacco solely for traditional purposes, many do smoke recreationally. The differences between nations in the attitude towards smoking tobacco outside of ceremonial use has resulted in disparities in the number of lung cancer diagnoses and ultimately the death rates in populations in different parts of the country. In some areas, such as the Lakota Nation in the Northern Plains, the history of the religious use of pipe tobacco has contributed to making tobacco an integral part of social interaction. Other parts of the country, such as the Southwest, do not share the Northern Plains’ history of pipe ceremonies, and thus lack the same societal acceptance of tobacco use (Kunitz, 2016). These areas often have a lower percentage of the population smoking habitually. A longitudinal study conducted from 1990 to 2009 found that Native Americans in the Northern Plains region of the United States had a lung cancer death rate

of 94 per 100,000 people, while in the Southwest region, the rate of lung cancer death was significantly lower: 15.2 per 100,000 (Plescia et al., 2014). The differences in death rates correlated with differences in smoking behaviors between Native American in these two regions. When compared to nations in other regions of the country, the Northern Plains has the highest percentage of smokers, with 40% of the population smoking habitually, while the Southwest has the lowest, at 21% of the population smoking habitually (Plescia et al., 2014). Smoking and other forms of tobacco use are well established as a major factor that increases the risk of lung cancer due to the carcinogenic chemicals in tobacco (“Cancer Causes and Prevention”). However, one can still be exposed to these chemicals even if they don’t smoke. Secondhand smoke is another potential source of carcinogen exposure. One of the largest employers of individuals on reservations is the gaming industry, with over half of Native Americans belonging to nations that operate casinos (Evans, 2002). Because a vast majority of these casinos and gaming parlors are not smoke free, this results in a disproportionately greater possibility that employees will be regularly and continuously exposed to secondhand smoke in their workplace (Espey et al., 2014). Many people are employed in these establishments for years on end due to the narrow field of career opportunities available to them, thus allowing the secondhand smoke effects to compound dangerously.

The lack of high paying work available to people living on reservations has drastic effects on Native Americans’ daily lives, and consequently, their health. Native Americans are twice as likely to live in poverty compared to the rest of the United States (Krebs et al., 2014). With this comes a multitude of other factors that have adverse consequences to their health, such as limited access to healthy food and safe water. This contributes to many Native Americans’ dependence on subsistence living. As part of subsistence living, people source their food from the

environment around them and often hunt locally and grow their own crops. While most see this as an important part of their culture heritage, some depend on it as their primary source of food (Gochfeld et al., 2011). Depending on what region of the country a reservation is in, people often rely on food sources such as wild fish and game, and the blubber of sea mammals (Cobb, 1998). However, this further increases their exposure to environmental contaminants, many of which are carcinogenic. When sourced from contaminated environments, these meats have all been found to contain trace levels of pesticides, heavy metals, and polychlorinated biphenyls, known carcinogens (Cobb, 1998). Ingesting these carcinogen-containing substances regularly will put individuals at a greater risk for mutations that could eventually lead to cancer. Americans who source their food at a retail store are less likely to consume the same amount of these particulates, thus putting them at lower risk for developing cancer than Native American individuals.

By definition, families living in poverty also have lower income levels, and often have little, if any, disposable income. This makes it more difficult to pay for healthcare or insurance because the cost of care has become prohibitory. As a result, many avoid seeing a doctor until their condition has progressed to the point where it is debilitating. For cancer, 'debilitating' usually means that a tumor has formed, and that it is large and metastatic, or it has possibly even metastasized. What could have been a minimally invasive surgery had it been caught early will require chemotherapy, or an equivalent, at this stage in the cancer's progression.

The differences in culture and socioeconomic status in reservation communities factor into disparities in exposures that lead to higher rates of cancer incidence in Native American communities on reservations. Out of all of these factors, tobacco usage is possibly the largest contributor to these disparities (Espey et al., 2014). Poverty also plays a critical role in increasing

the incidence and mortality rates of cancer on reservations. The increased carcinogen exposures that are due to subsistence hunting are a result of living in poverty, and lead to increases in cancer incidence. The limited budget that comes with living in poverty creates a further barrier to care and prevents many from seeking treatment, ultimately contributing to cancer higher mortality rates in these population.

Quality Healthcare Access

The care an individual receives significantly impacts the outcome of their diagnosis and disease. It was found that patients who are treated in National Cancer Institute-designated comprehensive cancer centers (NCICCCs) hospitals, designated for their commitment to providing high-quality care, see mortality rates decrease by up to fifty percent and higher five-year survival rates (Wolfson et al., 2015). Unfortunately, it's difficult for most patients to seek treatment in such centers due to distance, cost, or lack of insurance. Instead, most Native American individuals who live on or near reservations have their healthcare provided by the Indian Health Service (IHS). Established in 1955, the IHS now has 25 hospitals and 55 health centers, which serve the 2.3 million people who reside on reservations in the United States ("IHS Profile", 2018). The per capita expenditure on healthcare for the average American is \$5,755, while the amount spent Native American health is a mere 40% of that (Goodkind et al., 2011). This varies across the country as well. While the IHS spends upward of \$6,000 yearly for healthcare for the residents of remote Alaskan Native villages, individuals in some parts of the Navajo Nation receive less than \$800 of per capita funding every year (Alba et al., 2003). For comparison, even federal prisoners receive more funding for their medical needs (Goodkind et al., 2011). While funding for the IHS is increasing, it is failing to increase at a rate fast enough to make up for medical inflation, so the IHS's funding deficit has grown larger and larger each year

(Warne et al., 2014). Ultimately, this severe lack of funding has led to subpar healthcare for a vast majority of people on reservations, which has adverse effects on cancer outcomes. Many newer treatments for cancer have higher efficacies than some traditional treatments, however, the IHS cannot afford to offer these to their patients due to their limited budget. This leaves patients with fewer options for their treatment, and some treatments which may work for their type of cancer may be entirely out of their reach. Patients' inability to access more effective treatments can prevent their recovery, thus increasing cancer's mortality rate.

The IHS's insufficient funding also affects patients' access to primary care, where a majority of vaccinations and pre-cancer screenings take place. For decades there has been a shortage in the number of medical professionals serving on reservations (Holm et al, 2010). While 229 doctors serve every 100,000 people in most of the United States, only 90 serve the same number of Native Americans (Holm et al., 2010). Many of these doctors work in IHS or tribally-run clinics, which focus on patients who reside on reservations. The Indian Health Service, while attempting to provide primary care to Native Americans on and near reservations, is ultimately better set up to provide acute care instead of the day-to-day medical services that individuals sorely need (Watson et al., 2014). This lack of primary care increases cancer mortality and incidence on reservations in multiple ways. First, a lack of primary care results in fewer people receiving routine cancer screenings. It was reported that for Native Americans, "screening rates were significantly lower than for the US population as a whole with only 59% of [Native American] women receiving Pap smears, 45% of eligible [Native American] women receiving mammograms and only 33% of eligible [Native American] men and women receiving colorectal cancer screening," (Krebs et al., 2014). This has a substantial impact on survivorship outcomes for many of these types of cancer. While Native Americans have a higher mortality-to-

incidence ratio than Caucasians for nearly all cancers, the difference is especially pronounced in cancers that have effective early detection and screening tests (White et al., 2014). A delay in detection ultimately results in an increase in the likelihood that Native Americans will die of the disease, because the cancer is often diagnosed when in later, more aggressive stages that are accompanied by poorer prognoses.

This lack of primary care also increases cancer incidence in less direct ways. There are multiple types of cancer where a disease is a contributory cause, and without access to primary care, less people receive routine vaccinations against these diseases. One such disease is, “Human papillomavirus (HPV)[,] the primary cause of nearly all cervical cancer”, but there are vaccinations that help to reduce its spread (Watson et al., 2014). However, many Native American children aren’t being vaccinated against it. Studies found that Caucasian children living near, but not on reservations, are more likely to receive the vaccine (Watson et al., 2014). If more people were vaccinated for this disease, this would serve to a lower incidence of HPV, and therefore reduce women’s risk of developing cervical cancer. Since cervical cancer affects Native American women at a rate higher than it does Caucasians, the use of vaccinations would drastically impact the rate of cancer incidence.

Not only does the IHS’s lack of funding affect patients, but the remote location of many reservations adds further challenges to obtaining healthcare. These areas are so far removed from populous locations that it is difficult to attract specialists to work there. Without local options for specialized care, patients must travel much further to obtain treatment. For instance, there are no gynecologic oncology surgeons currently working with the IHS, meaning that any patient who would require their care must receive a referral to an outside surgeon (Singh et al., 2014). This may lead to an even greater delay in diagnosis, and thus it will take longer for the patient to

receive proper treatment. These delays are detrimental to the survival of many Native American women after their diagnosis with gynecological cancer. Studies found that Native American women suffer disproportionately high rates of cervical cancer incidence and mortality, which are often 1.5 to 2 time higher than what is observed in Caucasian women (Watson et al., 2014). This lack of specialists also impacts cancer screening. Some procedures, such as colonoscopies, must be performed by a specialist, in this case a gastroenterologist. However, it is often difficult for men to get referred for these since many health programs consider this to be a lower priority procedure, and thus deny the request (Warne et al., 2014). Without specialists on reservations, people are receiving neither the treatment nor the screening they need to stay healthy, thus contributing to higher levels of cancer incidence and mortality.

The extensive healthcare limitations in reservation communities continue to create barriers to care for people who are seeking treatment. The shortage in primary care providers working with the IHS results in fewer individuals receiving regular vaccinations and cancer screenings, the lack of which cause an increase in the incidence of cancer. The IHS's insufficient funding also forces patients to travel for most specialized care, an issue that is compounded by the remote locations of most reservations. This leads some to delay in seeking care, and consequently, present with a more advanced stage of cancer. Because these stages are more difficult to treat successfully, this results in a higher likelihood that patients will die of the disease, thus increasing cancer's mortality rate.

Environmental Contributions

The environment in which a person spends their time has significant effects on one's exposure to carcinogens. These are often the result of mining and drilling, which may leave both the nearby topsoil and groundwater contaminated with cancer-causing substances. Currently, 2.1

million acres of Native American land are being used as an energy resource, and there are still another 15 million acres of untouched tribal land that contain deposits of gas and oil (Grogan et al., 2011). While reservations in the United States only make up 2.3% of land area, they hold nearly 20% of the country's natural gas and oil reserves (Grogan et al., 2014). This has resulted in a disproportionate amount of oil drilling being done on or near Native American reservations. Studies suggest a relationship between a community's proximity to oil fields, and the cancer incidence for community members (Hurtig et al., 2002). Men in these areas near oil fields are 40% more likely to develop cancer compared to men in outlying areas, while women are 63% more likely (Hurtig et al., 2002). This increases the risks for rectal, kidney, and soft tissue cancer in men, while women have a heightened risk for cervical cancer (Hurtig et al., 2002). The amount of oil drilling that takes place in close proximity to reservations puts the people residing in these areas at a disproportionate risk of developing cancer.

Native Americans are no strangers to the idea of environmental racism, the effects of which have a lasting impact on their health. Environmental racism includes acts of intentional and unintentional exploitation of resources that have adverse effects on the health of minority populations (Brook, 2006). Because many nations lack the resources to police their lands, their natural resources are exploited and often contaminated for the financial gain of others. In the past, a large uranium mine was operated on Navajo Nation lands. Although it has long since been closed down, those living on the reservation are still experiencing its effects. A vast majority of the former mine entrances are unsealed, and the government is still working to clean up the radioactive waste that remains (Tauli-Corpuz, 2017). In addition, many former Native American uranium miners have since developed lung cancer due to their prolonged exposure to radioactive radon while in the mines, and babies have been found to contain uranium in their blood (Tauli-

Corpuz, 2017). Radionuclides from mining have also been known to leach into groundwater, where they can cause bone cancer if a population uses the contaminated water as a source of drinking water (Tauli-Corpuz, 2017). This prolonged exposure to carcinogenic materials puts populations at significantly higher risk of developing cancer.

Aside from uranium, there are a number of other carcinogenic substances found on Native lands as a result of environmental racism. In the past, government agencies, the IHS included, used tribal lands to discard hazardous chemical and medical waste (Ortiz, 2003). Even today, “midnight dumpers,” which range from individual people to corporations, continue to leave waste on reservation lands (Brook, 2006). Much of this waste contains known carcinogens such as pesticides and asbestos, which are costly to dispose of properly (Haner, 1994). Even designated dump sites on tribal lands are problematic because a majority of these sites, which contain hazardous chemicals intermixed with household trash, do not conform to federal standards (Ortiz, 2003). Oftentimes this leads to groundwater pollution in these areas, with substances such as arsenic and mercury contaminating the water table (Ortiz, 2003). The infrastructure in these areas is substandard to non-existent, so there are no filters or testings done to ensure that the water is safe to drink. This means that there is no way to monitor levels of contaminants in the water. Because a majority of people rely on the contaminated ground water as their primary source of drinking water due to a severe lack of infrastructure on many reservations, people unknowingly ingest carcinogenic substances which may later lead to cancer. (Ortiz, 2003). In comparison, less than 1% of non-reservation homes in the United States lack safe drinking water, whereas 12% of homes on reservations lack safe drinking water (Krebs et al., 2014). This exposes communities, including highly susceptible children, to unsafe levels of carcinogens, which will ultimately result in more people developing cancer during their lifetime.

Native Americans on reservations face a variety of other hazards that are rarely seen in other parts of the United States. Some of this has to do with the nuclearization encroaching in the areas surrounding their homes. For the nations in Oregon and Washington who depend on the Columbia River for water, the former Hanford Nuclear Weapons Plant is of great concern (Brook, 2006). The plant is upstream from many of them, and there is worry that compounds from the factory may still be leaching into the water. A majority of people from these nations are subsistence hunters, and rely on the river as a source of fish. If the river is contaminated, then the food they source from it will be as well. In Nevada, the Western Shoshone nation had their land used, against their will, for nuclear testing during the 1950's and 1960's, which exposed them to levels of radiation that were known to cause thyroid cancer and leukemia (Frohberg et al., 2002). While rare in the rest of the United States, these unique issues have profound effects on health in reservation communities.

The effects of environmental racism result in continued carcinogen exposure due to resource exploitation on or near reservation land. Mining and drilling both increase carcinogen levels in the environment, while the disregard for the health of other humans that is intrinsically linked to the unsafe dumping of hazardous waste and the presence of nuclear industry and testing in these areas is reprehensible. The lack of modern infrastructure in these communities only serves to perpetuate many of these problems, as it allows for higher levels of exposure than would be seen in other areas. All of these factors contribute to heightened levels of cancer incidence on reservation land.

Relationship with Western Medicine

For most minorities, the healthcare system is viewed as being part of a larger, oppressive political structure, and Native Americans are no exception to this. This has led to widely

pervasive feelings of mistrust for medical practitioners and researchers, who are viewed as perpetrators of this unjust system (Canales et al., “Multi-Generational”, 2011). These views come from a long history of medical trauma at the hands of people who are supposed to “do no harm”. One of the most extensive violations of doctor-patient trust in Native American history was the practice of forced sterilization. During the 1960’s and 1970’s, the IHS sterilized Native American women without their consent or knowledge (Lawrence, 2011). Studies show that anywhere from 25% to 50% of Native American women had been subjected to this practice (Lawrence, 2011). Since then, many are wary of trusting medical professionals for fear that something will be done to them without their consent. Like many other minority groups, Native Americans have also been used for medical testing in the past. In the late 1970’s, there was an investigation into the possible use of experimental drugs on reservations (Lawrence, 2011). Native American populations were viewed as expendable in the pursuit of medical knowledge. All of this has led to a continuing mistrust for the medical community, which has been shown to dissuade people from seeking medical care. A grounded theory study interviewed Abenaki, Mohawk, Lakota, and Cheyenne women in Vermont revealed that “the level of trust and mistrust women had in the health care system often influenced their decisions regarding participation in routine mammography screening. Heightened mistrust of providers led participants to avoid screening mammography,” (Canales, “Connecting to Nativeness”, 2004). As discussed previously, without screenings, individuals are more likely to succumb to a cancer if it is diagnosed at later stages. The traumatic legacy left behind by these practices continues to affect Native American health, manifesting in increased cancer mortality rates.

Another issue Native Americans face when seeking medical care is language barriers. A lack of effective patient-physician communication is detrimental when trying to provide

healthcare. While nearly all Native Americans speak English, more than 20% of Native Americans over the age of 65 speak a native language, such as Navajo, in their home (Seibens et al., 2011). This indicates that they feel they have more control using this language than they would with English, thus suggesting that many of these people may not have the comprehension of the language required to explain the intricacies of medicine. Patients are able to request an interpreter; however, many are unaware that this is available to them (Krebs et al, 2014). Also, the incidence of cancer in a population increases with age, so this age group would be more likely to seek treatment for cancer than others would. If a patient is unable to fully understand their diagnosis, then they are less likely to conform to the treatment regimen, decreasing the likelihood of a favorable outcome. Even if a translator is used, the languages themselves have an effect on how patients understand their diagnosis. Most Native American languages don't have a word for cancer, and even those that do can further the disconnect between Native Americans and Western medicine. For instance, the word for 'cancer' in the Navajo language translates to "sore that does not heal" (Iammarino, 2008). The implications of this translation lead some to believe that cancer cannot be treated, thus preventing them from seeking cancer care. In reality, many could achieve remission if their cancer was diagnosed early enough. This disconnect only leads to more preventable deaths.

The relationship with Western medicine that has resulted from a history of trauma is something that is unique to each minority group, and it profoundly affects Native Americans in how and when they choose to seek care. After extensive violations of trust over generations, many are rightfully wary of the medical care provided to them. Most fear that their medical autonomy will be disregarded, and consequently avoid seeking treatment. If individuals do choose to pursue medical care, language barriers may hinder communication between medical

professionals and patients. This makes it more difficult for patients to conform to treatment regimens, and results in an increase in cancer mortality.

Conclusion

There are many incredibly varied influences on the disparities of incidence of cancer on Native American reservations and on its resulting mortality, which can be attributed to the ways in which communities and cultures on reservations differ from those in other areas, along with the continued effects of racism in the United States. Rates of smoking, one of the largest contributory causes of lung cancer, are higher on reservations and need to be addressed in order to decrease lung cancer mortality. The Indian Health Service requires more funding and trust than it currently has in order for it to be able to provide services that its patients will fully use. Also, reservation lands are prone to being exploited in ways that expose people who live nearby to higher levels of carcinogens. All of these factors compound each other, and lead to not only higher rates of cancer on reservations, but also later diagnoses and therefore higher mortality rates.

However, it doesn't have to stay this way. It's important to address the habitual usage of tobacco due to its significant contribution to heightened rates of cancer incidence. Tobacco-cessation campaigns aimed at the general population focus on eliminating all tobacco usage, and usually evoke feelings of shame to do so. However, these campaigns fail to address the cultural importance of tobacco in several Native American nations. Smoking cessation programs targeted specifically at Native American populations may have a larger impact than the current, widely implemented ones due to the fact that they will be able to focus specifically on the cultural importance of tobacco. Interventions that appeal to an individual's understanding of the sacred

nature of the tobacco plant are more effective than other attempts at intervention, and more emphasis needs to be put on these programs (Daley, 2011).

To improve the quality of healthcare on reservations, the IHS needs to be vastly overhauled. It requires more funding, and a better grasp on cultural intricacies that impact how care is received. This increase in funding will allow them to invest in newer cancer therapies, and work towards making cancer care more accessible for their patients. Once this happens, IHS doctors will be able to treat their patients with the full range of resources that modern medicine has to offer. In order to achieve culturally-competent care, it is important that IHS decision makers collaborate with tribal leaders to determine how to best overlap Western medicine and Native American life experiences and cultural history. This will help to close the gap between medical providers and their patients that has contributed to increased mortality rates.

Lastly, Native American governments need to be given the authority to properly patrol their own lands and enforce their laws, so that they can improve infrastructure and prevent illegal dumping. This is a much larger, more complicated issue that will require a united effort from multiple sectors in order to overcome. The limitations set on law enforcement officers operating on reservations undermines any changes that could be made. Without widening the scope of offenses these officers are able to address, any other changes being implemented will only maintain the current levels of cancer incidence and mortality due to environmental carcinogens. In order to have a measurable decrease in these rates, the laws regarding policing on reservation land need to be changed. Once Native American Nations have the power to police their own lands, criminal dumping and other harmful activities will begin to have consequences. This will aid in decreasing the levels of environmental carcinogens people are exposed to on reservations, thus lowering the incidence of cancer.

These are just a few of the many steps that need to be taken in order to end cancer being the leading cause of premature death on reservations, but it can be done, and as a nation, it's important that it happens (White et al., 2014). It's not enough to address only one issue affecting cancer rates on reservations; it's important that a coordinated effort is made to address the problem as a culmination of many contributory factors. The elimination of just one element furthering these disparities will only yield minimal change if other reforms are not simultaneously implemented. Otherwise, the rates of cancer incidence and mortality on reservation land will remain unchanged as these rates continue to decline in the rest of the country (Canales et al., "Multi-Generational", 2011). All American citizens have a part in this issue, and the country as a whole needs to take responsibility for the way it is affecting people.