

The Impact of the Affordable Care Act on Disparity in the Care of American Women with Breast Cancer

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We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.

Declaration of Independence of the United States of America

July 4, 1776

A review of early American history reveals that this principle did not apply to all human beings living on this land. This statement holds particularly true when one looks at the delivery of health care. Starting with a system that simply eliminated by drowning the Africans that had been stolen from their homeland and that were deemed too weak or too sickly to survive the “passage” to the “New World.” This differential approach to health care extended to the plantations. The first European physicians are reported to have started tending to the colonists as early as the very creation of the Jamestown colony in 1607. The first contingent of Africans arrived in the American Colonies in 1619, as indentured servants. The first hospital was erected in 1751. At the same time, the Negroes toiling inhumanely on the plantations had to care for their own. They used traditional remedies imported with them from Africa as well as other herbal medicines learned from the Native inhabitants, but had no access to hospitals.

The Civil War of 1861- 1863 officially ended slavery on the land, but this was soon followed by the institution of Jim Crow laws, which essentially created with the backing of state governments, two completely different standards of living for the Caucasians and the Negroes, as well as a two-tier system in health care delivery. For example, the state of Alabama passed a law that prohibited any person or corporation from requiring a white female nurse to work in hospital wards or rooms, either public or private, in which “negro men” were being kept. In Georgia, the Board of Control of Mental Hospitals was instructed to see “that proper and distinct apartments be provided for mental patients”, so that “in no case shall negroes and white persons be together.”

In 1948, the United States of America along with 131 other nations of the world signed the chart of the World Health Organization. It is stated in the Preamble of its Constitution that: “The enjoyment of Health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. Yet, this American Apartheid system did not end officially until the Civil Rights Act of 1964, forced upon the country by the civil rights movement of the 1960s.

At that time, all the vital statistics pointed to a shorter life expectancy and an overall worse health status for the African American population. These dismal numbers were reported in medical textbooks as a given, an expected result of the inherent constitutional inferiority of the Negro. Indeed, in 1975 -1977, the five-year survival for a black woman with breast cancer was 62 %, while it was up to 76 % for her Caucasian counterpart.

Over the past few decades, great strides have been made forward in the understanding and the treatment of breast cancer, the most common cancer found in American women and the second most lethal cancer among women. The incidence of breast cancer has been decreasing steadily, as well as the mortality from that disease. Between 2007 and 2011, the death rate for breast cancer has decreased by 3.2 % and 1.8 % per year for white women and by 2.4% and 1.1 % per year for black women, respectively of less than 50 years of age and more than 50 years of age. By 2010, the disparity was still persistent with an over-all five-year survival of 92 % for the Caucasian woman and 80 % for the black woman.

During the past 20 years, the tone of the debate has changed. A spotlight was directed at the health care disparity observed across the board, in the management of both malignant and benign diseases. As this topic of health care disparity was being dissected both in governmental and academic circles, several contributing factors were identified and efforts have been made to compensate for them or reverse their effects, when and if possible.

First, over the past decade, it has become clear that not all breast cancers are the same. Based on their expression of different hormone receptors and amplification of certain oncogenes, they have been classified into four groups: Luminal A and Luminal B, which have a better prognosis, while the other two, HER2neu (+) and Triple Negative

portend a worse prognosis. For a yet unexplained reason, the last group has been found to be more prevalent in the African American population.

Furthermore, besides being more aggressive, breast cancer tends to develop in the African American population at a younger age. According to the SEER (Surveillance, Epidemiology and End Results) data, from birth to age 24, the African American woman is twice as likely to develop breast cancer as her white counterpart is and between the ages of 25 and 29, the incidence is 50 % higher in the African American group than in the Caucasian group. This finding carries many implications and puts a big question mark on the validity of the screening and therapeutic recommendations offered to the African American women. In the 1980s, the recommendation for screening was that all women should have a baseline mammogram at age 35, and then continue with a yearly mammogram starting at age 40. In the 1990s, the age to start having mammograms was raised to 40. However, most of the early adjuvant studies were carried out in US academic centers where solely women with adequate health insurance were included or in Europe where the non-Caucasian participants were few and far between. Given the more recently discovered biological differences in tumor types, one can call into question the management algorithms and the treatment options uniformly offered to all women with breast cancer.

Access to medical information, medical care and a medical home is another well-established obstacle to proper health care. The women in need of services often must take public transportation and attend hospital clinics where they spend considerably more time in line. They are obliged to take time off from work and that may result in a loss of income. Furthermore, these clinics set up in large academic centers with government funding are used as teaching venues, where students, interns and residents are the first if not the only contact that the patients will have with the medical personnel. These residents rotate through different services and it is not uncommon for patients to be seen by a different person every time, often with a simple nod or a brief check from the senior supervisor.

The prevalence of women reporting a mammogram within the past year increased from 50% in 1991 to 64% in 2000, and has since remained relatively stable (2008: 62%). During this time, mammogram utilization varied considerably by educational attainment. The prevalence of women with less than a high school education reporting a recent mammogram was approximately 13 percentage points lower than the prevalence for all women. Even more striking is that the prevalence for women with no health insurance was approximately 33 percentage points lower than the prevalence for all women.

Even in more affluent neighborhoods populated by minority groups, it is often difficult to find proper technologically advanced services. A simple inspection of the geographic distribution of medical centers, in particular radiology centers where mammographies are performed will show what we can call a technology desert in the poorer or in this case, what is considered a predominantly minority neighborhood. Thus, in the County of Queens, until recently, there was not one single Radiology Center, with mammography capabilities between the Cross Island Parkway to the east and the Van Wick Expressway to the west, between Jamaica Avenue to the north and the Belt Parkway to the south. This area designated as South Queens, is home to a population that is in majority Afro-American or Caribbean. Yet, this population is for the most part educated, holding government jobs, and earning salaries equal to if not higher than that of whites living in the same county (\$51,836 vs \$ 50,960). This population includes also a large population of retirees, covered most of the time with private health insurance or government plans. In comparison, the geographically more or less equivalent area between Northern Boulevard and the Southern State Parkway and between the Cross Island Parkway to the west and the Meadowbrook Parkway to the east, predominantly inhabited by Caucasians, is home to 15 advanced radiology and mammography centers. The asymmetric distribution of these services creates a problem of access. Women that do not drive have to pay two or three fares of public transportation to reach their destination or depend on friends or relatives to keep their medical appointments. For all these reasons, such women would often delay their work up and it has been proven that the longer time from diagnosis to treatment is associated with a worse prognosis for women with breast cancer. The time from screening to diagnosis and to treatment has been found also to be significantly longer for women with Medicaid coverage or no health insurance coverage, when compared to those with private health insurance.

Finally, one cannot omit the role that pure, overt or subliminal racism plays in maintaining health care disparity. For example, minority women are more likely to have a mastectomy, rather than conservative treatment with lumpectomy and radiation, where the breast is preserved. African-American women undergoing mastectomy are less likely to be offered reconstructive procedures. They are also less likely to be referred for adjuvant therapy following

their surgical treatment. A recent modeling study demonstrated that, if the same adjuvant treatment was given to both white and black women, up to 19% of the mortality difference could be erased.

Several of these causative factors are structurally linked to the American society, or elude an immediate or easy solution. However, it seems that the proverbial lower hanging fruit is accessibility to proper care and in our context, it is closely connected to the availability of health insurance.

Over the past 70 years, efforts have been deployed by multiple administrations, starting with President Franklin Delano Roosevelt to provide universal health care to the American people. Although his effort has been nearly a constant preoccupation of consecutive administrations, albeit in varied forms and scopes, it has been impeded by faction politics. Nevertheless, the process of implementing this concept has continued its long and arduous road. Certainly, the military veterans were the first to benefit from government sponsored health benefits, but starting in 1964, incremental sectors of the civilian population have seen medical coverage extended to them, including the poor via Medicaid, the elderly and the disabled via Medicare. Special consideration was given to women's health when under President George H. W. Bush, Congress voted to enact the National Breast and Cervical Cancer Early Detection Program in 1990 providing funding for the screening of women for breast cancer, which was then the number one cause of death from cancer among women and cervical cancer. This program was further expanded in 2000 under President William Jefferson Clinton to provide treatment as well when these cancers were detected. Yet, in the early years of the 21st century, about 50 million American, particularly the poor, minority individuals, were deprived of health insurance benefits.

Universal Health Care

President Barack Obama, after his victory in 2008, decided to use much of his political capital to achieve what so many of his predecessors had sought to achieve but always failed. In 2010, he signed the Patient Protection and Affordable Care Act, more commonly known as ACA, into law, creating a path for all Americans to obtain health insurance.

The Affordable Care Act expanded health insurance coverage to the population through the following initiatives:

- 1- Expansion of Medicaid programs provided by the States with subsidies from the Federal government
- 2- An Employer mandate, through which every person or corporation with a workforce of at least 50 persons had to provide them with medical insurance or face a penalty.
- 3- The individual mandate, whereby every individual with an income up to 400% of the Federal Poverty Level must purchase an insurance plan or face an income tax penalty.
- 4- The establishment of state-based exchanges/purchasing groups or exchanges through the Federal Government. Depending on their income levels, these individuals may qualify for federal subsidies
- 5- Expansion of the coverage to dependent children up to the age of 26

As of December 2016, 13 State-based Marketplaces, 4 federally supported Marketplaces, 7 State-Partnership Marketplaces and 27 Federally-facilitated Marketplaces have been created under the aegis of the Affordable Care Act.

Beyond the numeric expansion of the insured categories in the population, the Affordable Care Act sought to establish certain protective measures, which were being denied to the population and were contributing to the health care crisis.

Indeed, the ACA

- 1- Bans the denial of medical coverage for preexisting conditions.
- 2- Prohibits insurers from setting lifetime spending caps.
- 3- Prohibits insurance companies from canceling coverage
- 4- Improves the efficiency of the health care system through the widespread use of electronic health records.

When it comes to women's health, the ACA takes specific steps to guarantee certain rights to this population. For example, the new private plan coverage requirements in the ACA for well woman visits and for other preventive services could result in greater numbers of women receiving these services at recommended rates. The ACA includes a small financial incentive for state Medicaid programs to provide coverage of all services recommended by the US Preventive Services Task Force (USPSTF) without cost sharing. The ACA specifies also that commercial and individual or family plans must, at a minimum, provide coverage and not impose cost sharing for any evidence-based preventive services that receives a grade A or B from the United States Preventive Taskforce. The law

prohibits insurers from requiring prior authorization before a woman sees an obstetrician/gynecologist. In addition, the ACA prescribes that all women enrolled in the programs that it offers, will be entitled to genetic testing, chemoprevention for women at higher risk for breast cancer as well as breast reconstruction if a mastectomy is recommended.

The ACA provided funding for a vast expansion of community health centers in underserved areas staffed by physicians and other health professionals supplied by the National Health Services Corps. Thanks to the Medicaid expansions and the additional funding available, these health centers will open in many sites where no medical services were previously available.

Finally, the new Law stimulates the creation of Accountable Organizations or ACOs. These ACOs represent a new payment model designed to improve health care outcome, while reducing the cost. Under this program, the patient care is expected to be better coordinated, reducing overutilization, while providing incentives for more preventive services and evidence-based management of chronic illnesses.

While most of the protective measures were progressively implemented following the signing of the Bill in 2010, the major coverage expansion did not take effect until December 2013 – January 2014. Nevertheless, now that some provisions of this law have been in effect for five years, it is legitimate to wonder whether one can anticipate a significant improvement of outcome for minority women dealing with breast cancer.

Given the lag time necessary for the collection of the appropriate data, it is impossible at this time to show already such improvement in survival. However, some surrogate questions may be germane in an effort to ascertain the impact of this law on health care disparity when it comes to breast cancer. These questions will center on the availability of a medical home for all women, the frequency of visits to a physician and the performance of mammography for all the appropriate candidates and at appropriately recommended intervals.

In 2013, investigators from the Kaiser Family Foundation and the Princeton Survey Research Associates International undertook an assessment of the accessibility and affordability of care for women, their connection to health providers and their use of preventive care, by conducting a telephone interview of a nationally representative sample of 2,907 women.

With the passing of the Affordable Care Act, the rate of uninsured individuals has dropped from 17 % in the first quarter of 2013 to 11.4 % in the second quarter of 2015. Nearly 30 million additional Americans are now equipped with some form of Healthcare Insurance. At least in theory, half of these new enrollees are women. This high percentage of insured population should be considered with caution. Indeed, to be effective, an insurance coverage must be affordable and stable. Among women interviewed, while 77 % of them overall reported to have had insurance for a full year, only 53 % of lower income women could make that claim. Insurance can be interrupted because of job loss or because of a job change, since at times the new employee may have to wait three to six months before obtaining an employer-sponsored insurance coverage. The insurance coverage may also lapse because the spouse or parent providing the coverage may have lost his or her job or because of a divorce or the death of the individual providing the dependent coverage.

Furthermore, due to multiple restrictions introduced in the bill because of partisan wrangling in congress, recent immigrants, who on average have a high rate of poverty, do not qualify for Medicaid for at least five years following even a legal entry into the United States. As to the undocumented women, they are plainly barred from Medicaid (except in case of a life-threatening emergency), barred from purchasing a plan or receiving subsidies through the state-based market places. Finally, we must remember that this survey, being conducted by landlines or cell phones could not take into account the extremely poor, not able to afford this commodity or the homeless population, which in April 2015 was estimated by the National Alliance to End Homelessness to number about 578,424 individuals.

Positive Impact of ACA

The survey showed that adults under Medicaid, have access to and use preventive care at rates comparable to their counterparts with employer-sponsored insurance. The overall use of mammography among women aged 40 and above remained steady between 2010 and 2013 (66.5 and 65.7%). The gap between whites and blacks appeared to have narrowed, since the rates for white women aged 40 and above was 67.4 and 66.8, and for blacks, 67.9 and 67.1 respectively in 2010 and 2013. The biggest discrepancy in the mammography rates correlated with income levels. Indeed, for women aged 40 and above, of any race, below the 100% poverty level, the rate was 51.4 % in 2010 and

49.9 in 2013. In contrast, when the income level was at 400 % or more of the federal poverty level, the rate went up to 77.2 %. Beside the income level, the level of compliance with the screening recommendations was closely linked to the level of education and the health insurance status. Regardless of the race, a woman aged 40 and above, both in 2010 and in 2013 with at least some college education was more likely to have had a mammogram in the previous two years (72.1% and 71.6%) than if she were without a high school diploma or GED. The health insurance status was also most significant. Seventy-five and six tenths of one percent and 73.4 % of women aged 40 and above covered with a private insurance plan reported to have had a mammogram within the previous two years, while those covered with Medicaid had mammograms at the rates of 64.4 and 63.5 %. Only 36 and 37.3 % of those who were uninsured reported to have been screened by mammography in 2010 and 2013.

On the other hand, women with Medicaid coverage, despite their lower incomes and constrained provider options, obtain preventive screening and counseling services at rates that are on par with women with private coverage. Indeed, 87 % of women on Medicaid reported that they had a regular place or a medical home where they usually go and 85 % reported that they had a regular clinician they usually see when they are sick. These numbers remained much lower for the uninsured women who had a medical home only in 69 % of the times and a regular clinician only 50 % of the times. In comparison, these numbers were similar to the Medicaid rates at 90 % and 87 % for women equipped with private insurance.

Potential Shortcomings of the ACA

As of the end of 2013, after the initial application of the Employer mandate and the individual mandate, 57 % of American women were covered under an employer sponsored health insurance plan (ESI), 7 % were covered under the individual mandate, and 15 % were covered under Medicaid/CHIP or some other forms of government program while 21 % were uninsured. With the slow but definite improvement of the economy over the past five years, it is probable that more women will benefit from an ESI. It is also likely that a large proportion of women will now be covered by Medicaid or a state-exchange plan. The young healthy individual is also likely to be covered under their parents' plan at least until age 26 or to gravitate toward a lower premium but high deductible plan. Therefore, we can predict that there will be an improvement in most of these data, concomitant to a reduction of the rate of uninsured. More women will have medical homes and more people will be able to obtain screening and preventive services.

However, the Kaiser Family Foundation survey revealed in 2013 that the major difference was in the location of these medical homes. Due to the low level of reimbursement from the Medicaid plans, a large percentage of physicians do not accept Medicaid recipients in their private offices. The percentage of specialists who accept Medicaid is even much lower and oftentimes limited to hospital salaried medical staff. Thus, although the survey confirmed that 82 % of women with private health insurance get their routine care at a doctor's office, this number dropped to 66 % for women with Medicaid and only 45 % for the uninsured women. The Medicaid beneficiaries were much more likely to get their care from government clinics (23%) than the privately insured women (7%).

If physicians in large numbers have joined the employed hospital staff and are salaried based on the number of Relative Value Units produced, they have therefore an incentive to accept as many patients as possible regardless of their types of insurance coverage. However, the so-called Medicaid patients tend to be seen by the more junior staff while the upper crust of specialists find themselves too busy to devote their time to this low paying population.

Two additional groups of individuals, despite adequate health insurance coverage may not benefit from the Affordable Care Act. This vulnerable population can be divided in two sub-groups, the clinically at-risk and the socially disadvantaged. The first group includes individuals with clinical conditions or risk factors, such as obesity, congestive heart failure, diabetes mellitus, severe arthritis etc. that may result in poor health or less than optimal medical outcomes, particularly if timely and high-quality health care is not provided. The ACOs were conceived exactly for these patients, so that they can benefit from protocols derived from evidence-based medicine. Because the care of these patients is more complex and they may consume more resources than the average population, there is a risk of patient "dumping" from the ACOs, a practice that has been known to occur among ACOs who want to meet their metrics requirement and qualify for their bonus subsidies.

The second group of vulnerable individuals consists of the socially disadvantaged. This group shares social, economic and geographic characteristics that may affect their ability to receive high quality care and may directly or indirectly influence their health outcomes. The poor, racial minorities with language barriers and the socially or

financially isolated individuals are overwhelmingly represented in this category. This group tends to receive their care from a subset of providers and hospitals that are lower performing. The community of hospitals and providers may not have the resources to integrate into an ACO or able to achieve high quality and cost savings. Some inner city neighborhoods and some widely spread rural communities may fall into this category and this may require specific governmental intervention to assist in the creation and maintenance of an ACO.

We are also reminded that 20 states have yet to engage in the creation of the state-exchanges. These states are homes for some of the poorest women in this country.

Finally, as demonstrated above, it does not suffice to diagnose a breast lesion. Timely biopsy and definitive multimodality therapy is of the essence. Meaningful metrics must be integrated in the ACO agreements to make every effort to minimize delays and optimize outcome. Otherwise, this will be all for naught, i.e the colloquial window dressing.

Conclusions

Health care disparity is and remains a complex conundrum in the United States. Nevertheless, this complexity should not deter health care officials from tackling this problem, which is both a question of moral and of justice. The Affordable Care Act goes a long way to address health care disparity and represents thus far the best ever attempt to rectify this shameful situation. The ACA law seeks to provide health insurance coverage to all Americans in one form or another. It also seeks to remedy specific shortcomings of the existing situation that have hampered the care of women. In this review, we have endeavored to analyze how the ACA may lead to an improvement in the outcome of breast cancer across the color line in the United States. Although it is too early to demonstrate a significant increase in the survival from breast cancer for certain minority groups, it is becoming clearer that the Affordable care Act has increased the opportunity for screening and proper follow up for breast cancer for both the Caucasian and the African American, as well as the other sectors of the American female population.

Certainly, the country is still faced with a certain degree of uncertainty, given the repeated attempts by the Republican legislators to repeal the Law. However, it is more than likely that the ACA which has withstood several challenges all the way to the Supreme Court will survive in some form. Our review has clearly shown that the Law has its limitations, some known, some yet to be uncovered. Along the way, some adjustments will be required, particularly when dealing with the disadvantaged population. A greater effort will be needed in order to provide these individuals with an effective and supportive navigation system, where no one will be left out. A more balanced reimbursement system will allow physicians and hospitals to survive without being crushed by the insurance company oligopolies. An increase in the reimbursement provided by the Medicaid system will also make it more attractive to private practitioners. Nevertheless, the ACA is a giant step in the right direction toward the resolution of some of the issues that hinder the delivery of health care to minority groups. Will the ACA facilitate the screening process in the detection of breast cancer? The early answer is "Yes." Will the new law lead to a better outcome for all women with breast cancer? The answer is "Too soon to tell." Yearly monitoring of the results will be needed to confirm the concretization of the goals contemplated by the President and the US Congress.

One must however acknowledge the fact that health care disparity is a multifaceted problem that will not be erased until every child has access to a proper education and every adult has an equal opportunity at finding an employment. Ultimately, government programs should be safety nets for the needy population. As the promise of wealth is made to all Americans, private insurance should be more of a norm. Otherwise, some form of "Medicare for all" could eventually be the best solution and hopefully the final chapter of health care disparity.