

Rising Mortality Rates in Women in the U.S.
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2168 Rayburn House Office Building
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I wished we had reached Melissa sooner.

When I read the article discussed today I was not surprised. I see the people represented in these statistics every day. They are real people, real women. Women I have known in both my personal life and professional career in my home state of SC.

I grew up in a small, rural community in SC. I saw the daily struggles that women faced – raising children, paying the bills, putting food on the table, and caring for elderly or ill family members. These women often put their own health care needs on the back burner because they didn't have the time, the money, or access to health care. As a result, I watched many of them succumb to preventable and manageable diseases.

These early experiences drove me to become a health care provider focused on health promotion and the elimination of health inequities. I wanted to bridge the gap in understanding and respect between patients and providers. Years ago, while working as a staff nurse in a local community hospital, I saw myself caring for patients who came back over and over again for the same health issues. These often poor, uneducated patients did not understand their diseases or issues of prevention; let alone how to navigate the complex healthcare maze. One who particularly stands out in my mind is a woman who constantly returned with complication from diabetes. Other family members diagnosed with the disease did not understand how to live with it and others at risk for diabetes did not know how to avoid getting it. These patients taught me that today's healthcare challenges require new solutions to improve outcomes – particularly for women. Women just like those I am going to tell you about today.

First, let me tell you more about what I do. Much of my work involves directing a mobile screening van and navigation program. This is a safety-net system designed to address cancer disparities among racially diverse and medically underserved populations. The program also leads education and awareness efforts designed to lower risk of chronic disease, provides cancer screening and prevention service, and ensures that clients receive appropriate diagnostic and treatment care. The desired outcome is to provide services along the continuum from prevention, to early detection, and through the diagnosis and treatment. In the program, 92% of our clients are women, 57% African American and 5% Hispanic. 19% report having less than a high school diploma and 60% report having less than adequate health insurance. Additionally, 80% report that they would not have sought cancer screening service if not for the mobile van coming to their community.

Many of the stories I encounter are heartbreaking and frustrating, but all of the stories underscore the challenges facing women today and the need to provide practical solutions for women in need. The lives of the women in my program are REAL. Their faces represent an inescapable public health crisis of our time. Our job is finding solutions. In my program, we deploy highly trained “lay” navigators who are experienced in local ethnic and rural cultures and low health literacy. These navigators help clients overcome contextual and systemic barriers to health care. The names of the clients in these cases have been changed to protect identities. Consider Melissa, a 35 year old, uninsured African American woman, 6 months pregnant with her 5th child at the time of her breast cancer diagnosis. Her care was delayed because her family planning Medicaid did not cover other medical conditions and the new Medicaid application process was delayed because the required documentation was not readily available. My navigation team was with Melissa through the birth of her new baby and cancer treatment, but unfortunately we did not reach her in time. The cancer was aggressive and her condition deteriorated. My team could only offer support to Melissa and grieve with her family when she passed away.

For other patients, my team has had to address the intersection of poverty combined with physical and mental illness. Consider Mary. At age 51, she was diagnosed with locally advanced breast cancer. We discovered that she was homeless. In addition to her own history of mental illness, Mary was responsible for the care of her adult son who suffered from bi-polar disorder and several learning disabilities. Mary was unwilling to go to a shelter because she would have been separated from her son, and she feared for his safety. Coordinating health care was just one piece of the puzzle of ensuring that Mary received the treatment she needed. Basic needs such as food, shelter, and clothing needed to be addressed for both Mary and her son. We arranged a temporary hotel room prior to her surgery, but all of our careful planning was nearly ruined when Mary and her son overslept and missed her initial surgery time. You see, it had been some time since Mary and her son took a hot shower and slept in a bed in an air-conditioned space protected from SC’s hot, humid summer nights. One day following surgery, Mary was released from the hospital into temporary housing with 4 surgical drains from her mastectomy site. Yes, the hospital stay is more often 2-3 days in these types of cases, but only for the insured. Mary’s recovery continues and my team connects with her often. Without our help, Mary’s story would have turned out much differently.

These stories only scratch the surface. I have seen it all...myth and misconception both inside and out of the healthcare system: doctors who immediately stereotype a patient as non-compliant and dismiss certain treatment options or referral to clinical trials; a patient who believed her breast cancer was a curse from God because she allowed her husband to touch her breast; and yet another, so fearful of the healthcare system, that she planned what she called natural radiation therapy by lying on the metal roof of her mobile home.

Despite these challenges, I believe that when we build a culture of health, positive outcomes are within reach. At age 46, Maria a machine operator, mother of two grown sons, and one grandson, let too many years slip by between mammograms. A screening mammogram was initiated when the mobile van parked on site at the local federally qualified health center. An abnormal mammogram triggered a call from a navigator that a biopsy was needed. Initially, Maria surrendered to denial when she learned she had breast cancer. That denial turned into fear. She recalls the paralyzing sensation of hearing the diagnosis and trying to comprehend all that was said shortly after she received the devastating news. "It was like someone had just given me a death sentence," she recalled.

Although Maria was among the working class, she was uninsured. Navigators offered emotional reassurance and guided her through the complex health care system by helping her complete financial paperwork, arrange reliable transportation, schedule appointments, and communicate with her primary provider. The navigator walked her through the process to a successful surgery to remove the cancer while in its early stage. Maria said, "My navigator and the entire healthcare team made my burden much lighter. They were like my family and I didn't have to worry about anything." Maria returned year after year for the recommended follow-up care and when the cancer returned, again at an early stage, Maria was well positioned to receive the care she needed including access to a clinical trial.

We have abundant evidence of the value of our navigation program. The program has decreased the number of at risk patients who do not return for care following an abnormal mammogram from 11% in 2009 to fewer than 5% since 2010.

Of course, the context of women's mortality is multifaceted. We live in a world troubled with health challenges complicated by the stress of social pressures, poverty, fear, and a complex health care environment. However, my experience has taught me that improved results are not only possible, but likely, when adequate infrastructures designed to address unique situations and challenges are in place.

I am thrilled to be here today amongst a group of like-minded people who want to know more about the challenges facing women today---people who want to see and address the people behind the numbers and who are committed to DOING something to help -- so that tragedies can be avoided and successes can be repeated. I believe that we are in a position to make a difference in the lives of women like Melissa, women like Mary, and women like Maria.

Thank you.