

FINAL – 3/5/2020

March is Multiple Myeloma Awareness Month

The theme is: Resilience

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Shine a Light on Multiple Myeloma

There is some good news in cancer!

According to the American Cancer Society (ACS), the death rate from cancer in the United States has declined steadily over the past 25 years. As of 2016, the death rate for men and women combined had fallen 27% from its peak in 1991. This translates to more than 2.6 million fewer cancer deaths between 1991 and 2016 (ACS, 2019). This is most certainly good news.

The drop in cancer mortality is mostly due to steady reductions in smoking and advances in early detection and treatment (Siegel, Miller, and Ahmed, 2019). All populations are not benefitting, however. Although racial gap in cancer deaths is slowly narrowing, socioeconomic inequalities are widening (Siegel, Miller, and Ahmed, 2019)

The most notable gaps are for the most preventable cancers. For example, compared with the most affluent counties in the U.S., mortality rates in the poorest counties were 2-times higher for cervical cancer and 40% higher for male lung and liver cancers during 2012-2016 (Siegel, Miller, & Ahmed, 2019). This could be an opportunity for more equitable strategies for dissemination of effective cancer prevention, early detection, and treatment. An application of existing cancer control knowledge with an emphasis on disadvantaged groups could accelerate progress against cancer.

We hear the most about the top four contributors to cancer deaths – cancers of the lung, breast, prostate, and the colon and rectum. In this article, we will focus on a blood cancer that affects only about two percent of the population – a cancer that few have ever heard of until they are diagnosed. We will focus on Multiple Myeloma. This cancer is the second most common blood cancer (after leukemia) and the most common blood cancer in African Americans.

What is Myeloma? You may hear Multiple Myeloma also referred to as just “myeloma” or “plasma cell myeloma.” They are all the same thing. The International Myeloma Foundation (IMF) launched Myeloma Awareness Month or Myeloma Action Month (MAM) in March 2009 to encourage patient advocates, caregivers, and healthcare professionals to empower patients and increase knowledge about myeloma. The theme for the 2020 Awareness Month is **Resilience** in the survivorship of myeloma patients. Another purpose of the intense focus on myeloma is to drive actions

towards early detection, appropriate and equitable treatment, research, including clinical trials, and a cure.

The Biology. Myeloma is a cancer of a type of white blood cell called plasma cells. Normal plasma cells are found in the bone marrow and are an important part of the immune system. Bone marrow is the soft tissue inside the bone. When plasma cells become cancerous or malignant and begin to grow in an uncontrolled manner this is called multiple myeloma. The main job of plasma cells is to create antibodies (a protein) to help us fight off infectious agents like viruses or bacteria. Myeloma is called “multiple” because there are frequently multiple patches or areas in bone marrow where the cancer grows (ACS, Myeloma Definition).

Myeloma affects the bones, the blood, the kidneys, and the immune system. There are not always symptoms in the early stages of myeloma, but some common symptoms include back pain, bone pain, and unexplained fatigue. Symptoms may fall under what is called the **CRAB** Criteria: Too much **Calcium** in the blood or urine; **Renal** or kidney damage; Unexplained **Anemia**; **Bone** pain or unexplained fractures; and recurring and persistent infections.

By the numbers: There are an estimated 124,733 people living with myeloma in the U.S., and an estimated 32,111 new cases were diagnosed in 2019. Men are 1.5 times as likely to be diagnosed as women. It is most frequently diagnosed in those who are older (aged 65 -74). However, myeloma is now being diagnosed in people younger than 50 years of age. It is no longer considered a disease of the elderly (ACS, 2019). According to myeloma data from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program, both the myeloma precursor, MGUS (Monoclonal Gammopathy of Undetermined Significance) and active myeloma are 2-3 times more common in people of African descent (14.8/100,000 in men) versus other races (7.2/100,000 in Caucasian men; 4.3/100,000 in Asians and American Indian men) (NCI).

Causes and Prevention: There are no known causes of myeloma but is generally caused by genetic mutations. Risk factors that can slightly increase someone’s chance of getting myeloma include increasing age, male gender, African American race, family history of MM, and being overweight or obese (ACS). Occupational exposure to asbestos, benzene, pesticides, or chemicals from rubber manufacturing has been associated with an increased likelihood of developing multiple myeloma. A decline in the immune system, exposure to radiation, and previous diagnosis of MGUS are also risk factors. (Mayo Clinic, Risk Factors). Agent Orange in Vietnam and those exposed to pollutants as 9/11 first responders had a disproportionate increase of myeloma cases. Military veterans and first responders are at higher risk of getting myeloma than the general population. In addition to environmental toxins are the chemicals in our foods. To reduce the risk of cancers, including myeloma, the recommendation is to eat a diet heavy in antioxidants (fruits and vegetables), to maintain a healthy weight, and to get regular exercise (IMF, Myeloma Causes). Colorful fruits and vegetables are generally the

most nutrient dense, and can help us to fight most chronic diseases, including cancers, heart disease and diabetes (Hung, Joshipura, Jiang, et al). While there is no cure for myeloma, it is highly treatable, and outcomes continue to improve.

Diagnosis and Treatment: Primary care physicians diagnose at least half of myeloma patients (IMF). In many instances, diagnosis is made through blood or urine tests during regular, annual doctor's visits. If there are symptoms, primary care doctors diagnose, treatment is often delayed by about six months, usually because the symptoms of back pain or fatigue are so nonspecific. The delay in diagnosis is associated with a greater incidence of secondary complications, like kidney issues. Early diagnosis can lead to earlier treatment and fewer secondary complications. This is a good reminder for primary care providers consider myeloma when nonspecific symptoms are reported. This is also a reminder to patients that they are their own best advocates, and to pay attention to regular laboratory tests and to changes in their body or how they feel.

Research and Survivorship: There has been great progress in the treatment for myeloma. As recently as the late 90s, there were only two drugs that were specifically available to treat myeloma, and five-year survival anticipation was low. In 2015 alone, there were a record five new drugs approved by the Food and Drug Administration (FDA) to treat this heterogeneous disease (Helwick, 2016). Successful clinical trials are responsible for these new therapies. In more recent years, new classes of drugs and more targeted therapies have been developed. Life expectancy has increased dramatically in the past decade (1999 -2019) from less than 5 years to about 10 years (Helwick, 2016).

An innovative, longitudinal myeloma study called iStopMM was initiated in 2016 for the entire country of Ireland. Project aims are to **Screen, Treat, Or Prevent Multiple Myeloma in Iceland**. This is a Black Swan Research Initiative® (BSRI®) for finding a myeloma cure, was developed to determine whether lifestyle changes, dietary recommendations, or occupational exposures can make a difference. The study is also looking at genetic sequencing among the 140,000 Icelanders who are over the age of 40. Only through clinical trials has so much progress been made to date to treat myeloma. Unfortunately, though myeloma is more than twice as likely to occur in blacks as in whites, blacks represent just 8% of participants in myeloma clinical trials.

In the Support Groups in Atlanta, we have welcomed researchers from Morehouse School of Medicine, Emory University, and Grady Memorial Hospital to discuss clinical trials and to respond frankly to any questions and concerns patients, caregivers, and supporters might have about participation and how to find available clinical trials. Since myeloma is so different in each patient, and because there is currently no cure, it is imperative that more blacks participate in clinical trials to benefit from more targeted therapy or from precision medicine in myeloma. In Georgia, we are fortunate to have a Myeloma specialist research center at the Emory Winship Cancer Institute. Myeloma is such a different disease in each person and there are new medications and regimens each introduced every year. They work readily alongside oncologists and patients locally

and from across the State to help with the best possible outcomes for both newly diagnosed and those who may have relapsed or have difficult to manage myeloma.

Georgia CTSA and Myeloma. There are two Myeloma Support Groups in metro-Atlanta and one in Columbus. There is a need for Support Groups in other regions of the State. Support Groups and the approach to Myeloma treatment is patient - and caregiver-centered. Researchers, providers and patients/caregivers in the myeloma world have built a foundation for patient empowerment. Webinars, seminars and monthly meetings are offered to provide education about possible options for treatment, patient-provider communication, drug toxicity and side effects, and financial toxicity as nearly every cancer patient experiences. Through Georgia CTSA, we can share and strengthen the sharing of resources across other regions of the state about this disease so that no patient or caregiver suffers unnecessarily.

One of Georgia CTSA's members is helping to spread the word about myeloma in general and about myeloma and its impact on African Americans. Myeloma occurs earlier in blacks, and mortality is higher in blacks. Studies have shown that "with timely, appropriate, and access to high quality of care to, African Americans can have superior outcomes to whites." (Filmore, et al.). (*See one of our team, Gail McCray, as one of the faces featured in the publication, Standing in the GaAP: for African Americans living with Myeloma.*)

https://media.myelomacentral.com/wp-content/uploads/CGAA1507_US-CLG-19-1185_Gaap-Patient-Brochure_2019_v17_DIGITAL3.pdf

Resources: Get more information about Multiple Myeloma from: IMF (International Myeloma Foundation) (www.myeloma.org); the Leukemia and Lymphoma Society (www.lls.org); and the Multiple Myeloma Research Foundation (www.mmr.org). Please contact Gail McCray if you have specific questions about myeloma resources: gmccray@msm.edu OR 404.752.1645.

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