A microscopic image showing several large, round cells with prominent, dark purple nuclei and lighter blue cytoplasm, characteristic of multiple myeloma cells. The cells are arranged in a cluster, with some overlapping. The background is a light, pale blue.

Overcoming Barriers to Effective Treatment and Enrollment in Clinical Trials for Black and Underserved Patients with Multiple Myeloma

Focus Group Panel Discussion

© Trustees of Boston University, 2023



Boston University Chobanian & Avedisian School of Medicine
Barry M. Manuel Center for Continuing Education



Faculty

J. Mark Sloan, MD

CME Course Director

Associate Professor

Boston University Chobanian &
Avedisian School of Medicine,

Hematology

Boston, MA

Camille Edwards, MD

CME Co-Course Director

Assistant Professor

Boston University Chobanian &
Avedisian School of Medicine,

Hematology

Boston, MA

Lynnette Henshaw, PharmD, BCOP

Clinical Pharmacy Specialist,

Hematology/Oncology

Boston Medical Center

Boston, MA

Natasha Gross-Jean, RN

NCPD Course Advisor

Registered Nurse

Member, Hematology & Oncology

Diversity and Inclusion Committee

Boston Medical Center, Hematology

Boston, MA

Natalie Sanfratello, MPH, CHCP

Moderator

Senior Program Manager—Quality
Improvement, Educational Programs,
and Contracts

Barry M. Manuel Center for

Continuing Education

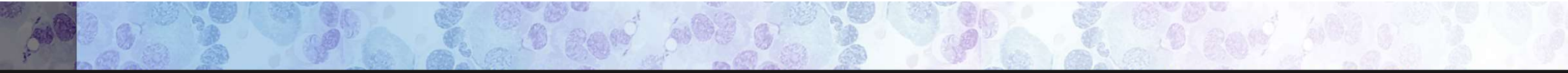
Boston University Chobanian &
Avedisian School of Medicine

Boston, MA



Goals and Objectives

- Explore the impact of multiple myeloma (MM) and race-associated barriers to appropriate care.
- Discuss how and why there are racial disparities in participation in clinical trials.
- Implement a team-based approach to improve MM care and overcome racial disparities.



Multiple Myeloma

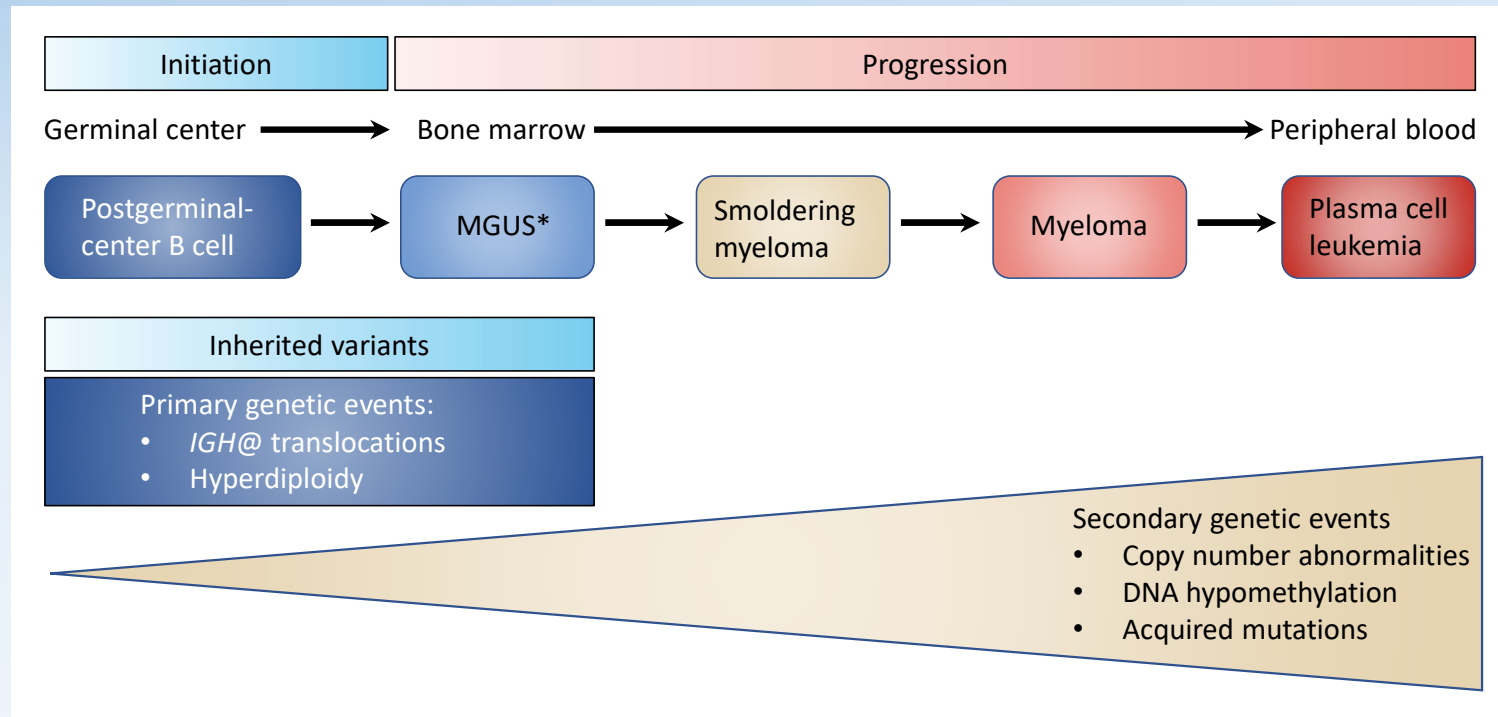
Introduction and Background



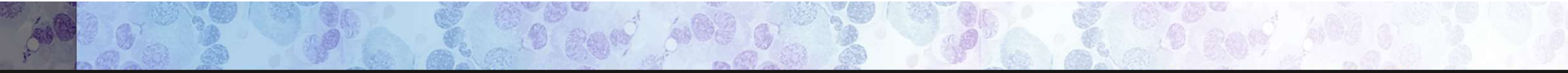
Multiple Myeloma

- Multiple myeloma is a plasma-cell malignancy occurring in more than 34,000 people in United States annually.
- It is responsible for more than 12,600 deaths each year in United States alone.
- Median age at diagnosis is 69 years, with most patients presenting between the ages of 65 and 74.
- Common characteristics
 - Bone pain (often affecting the back)
 - Malaise
 - Anemia
 - Renal insufficiency
 - Hypercalcemia
 - Bone disease
 - Bone marrow infiltration

Multiple Myeloma is a Multistep Progression Disease



*MGUS = Monoclonal gammopathy of undetermined significance



Racial Disparities in Multiple Myeloma

Incidence and Death Rates of MM by Ethnicity

Incidence rates, 2015–2019

By race and ethnicity, for myeloma

Non-Hispanic Black

14.3

American Indian and Alaskan Native

8.1

Hispanic

6.8

Non-Hispanic White

6.2

Asian and Pacific Islander

3.9

Death rates, 2016–2020

By race and ethnicity, for myeloma

Non-Hispanic Black

5.9

American Indian and Alaskan Native

3.7

Hispanic

2.9

Non-Hispanic White

2.6

Asian and Pacific Islander

1.5

Multiple Myeloma Racial Disparities in Blacks

- Difference in biology
 - 10% of Blacks over age of 40 have MGUS
 - Diagnosed 5 years younger than white counterparts
 - More likely to have standard risk cytogenetics and less likely to have high-risk cytogenetic features (del17)
- Racial/socioeconomic status
 - Distrust in the health care system due to systemic racism
 - Less access to full testing and issues of financial toxicity
 - Delayed diagnosis due to confounding diseases (e.g., diabetes), access to care, and slower referral
- Access to innovative treatment
 - Less likely to get aggressive therapy (triplet or quadruplet therapy, stem cell transplants, access to innovative clinical trials, and CAR T-cell therapies)

Racial Disparities in Treatment and Access to Care

- Treatment with novel agents and use of autologous stem cell transplantation (ASCT) has become standard of care for fit patients with newly diagnosed MM¹
 - Racial/ethnic minorities receive these at a lower rate than whites^{1,2,3}
- Black patients: fewer ASCT; more blood product transfusions; fewer palliative care consults; less inpatient chemotherapy; higher intensive care utilization⁴
- Black patients with MM have the potential to experience similar or better survival than white patients^{5,6}
- Black patients have similar response rates/survival to white patients when enrolled in clinical trials^{7,8}

ASCT, autologous stem cell transplant; SMM, smoldering multiple myeloma.

1: Fiala MA, et al. *Clin Lymphoma Myeloma Leuk*. 2020;20(10):647-651.

2: ASH 2021, Abstract 4118. <https://www.myeloma.org/blog/studies-disparities-myeloma-presented-ash>

3: ASH 2021, Abstract 566. <https://www.myeloma.org/blog/studies-disparities-myeloma-presented-ash>

4: Al Hadidi S, et al. *Leuk Lymphoma*. 2021;62(13):3256-63.

5: Marinac CR, et al. *Blood Cancer J*. 2020;10(2):19.

6: Joseph N, et al. *JCO*. 2020;38(17):1928-37.

7: Ailawadhi S, et al. *Blood Cancer J*. 2018;8(7):67.

8: Ailawadhi S, et al. *Blood Adv*. 2019;3(20):2986-2994.

Boston Medical Center

*Our Patient Population Is Racially, Culturally, and Linguistically Diverse:
Promotion of Health Equity Is Imperative*

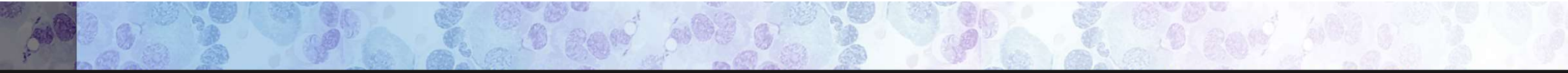


~70% of our hospital patients identify as **people of color**

~50% of our hospital patients live at or **below the federal poverty level**

~50% of our health plan members have a **mental health and/or substance use disorder**

Nearly 60% of our patients with MM are Black; ~20% are White; ~20% other



Focus Group Discussion



Focus Group Report

Goals

- Identify the perceived needs for underserved patients with MM and their caregivers.
- Gain insight into engagement in decision-making and care for underserved patients with MM.
- Gain an understanding of patient facilitators and barriers to managing MM and how those barriers can be addressed.
- Gain an understanding of patient facilitators and barriers to enrollment in clinical trials as part of their MM care.

Participants: 12 (11 patients and 1 caregiver) at Boston Medical Center

Timeline: Focus groups conducted in January 2023, three in-person sessions and one via zoom



Issue 1

*The Impact of MM and Race-Associated
Barriers to Appropriate Care*

What Affects Access to Treatment and Treatment Outcomes in MM?

Patient Factors

- Age
- Comorbidities
- Gender
- Year/Period of Diagnosis

Disease Factors

- Disease Stage
- Prognostic Risk Category
- Disease Subtype
- Presence of Kidney Dysfunction
- Presence of Bone Disease
- Associated Amyloidosis

Socioeconomic Factors

- Race/Ethnicity
- Health Insurance
- Geographical Location
- Socioeconomic Status
- Access to Health care
- Housing Insecurity
- Medical Literacy
- Language Barriers

What Affects Access to Treatment and Treatment Outcomes in MM?

Patient Factors

- Age
- Comorbidities
- Gender
- Year/Period of Diagnosis

Disease Factors

- Disease Stage
- Prognostic Risk Category
- Presence of Kidney Dysfunction
- Presence of Bone Disease
- Associated Amyloidosis
- Disease Subtype

Socioeconomic Factors

- Race/Ethnicity
- Health Insurance
- Geographical Location
- Socioeconomic Status
- Access to Healthcare
- Housing Insecurity
- Medical Literacy
- Language Barriers



Testimonial

“...I used to have pain on my shoulder. When they did an exam for me...they found out I have multiple myeloma. And then when they called me in the office to tell me the result, it was so sad. I was crying and then the nurse said, ‘If you want to cry you can cry’ because I was by myself and had nobody with me at that day.”



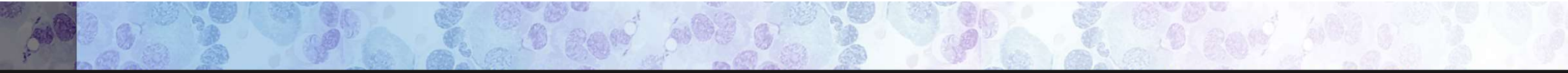
Testimonial

“...They [doctors] just don’t know how to approach you because of the things that they read, the things that they’ve seen on television, the things that they heard on the news. So, they stereotype you with that and it’s a stigmatization. And that has a lot to do with African-Americans, and most people of color have a hard time going to a hospital. I’d rather use my grandmother’s remedies. I mean my grandmother was from Jamaica; my grandfather from Africa. And all the remedies, they were passed down to their kids...”

Testimonial

“But I say hospital transportation is not perfect because sometimes I had some trouble. The driver would come and they didn’t call me. The driver didn’t see me because I wasn’t outside...it’s really cold. The driver just left.”

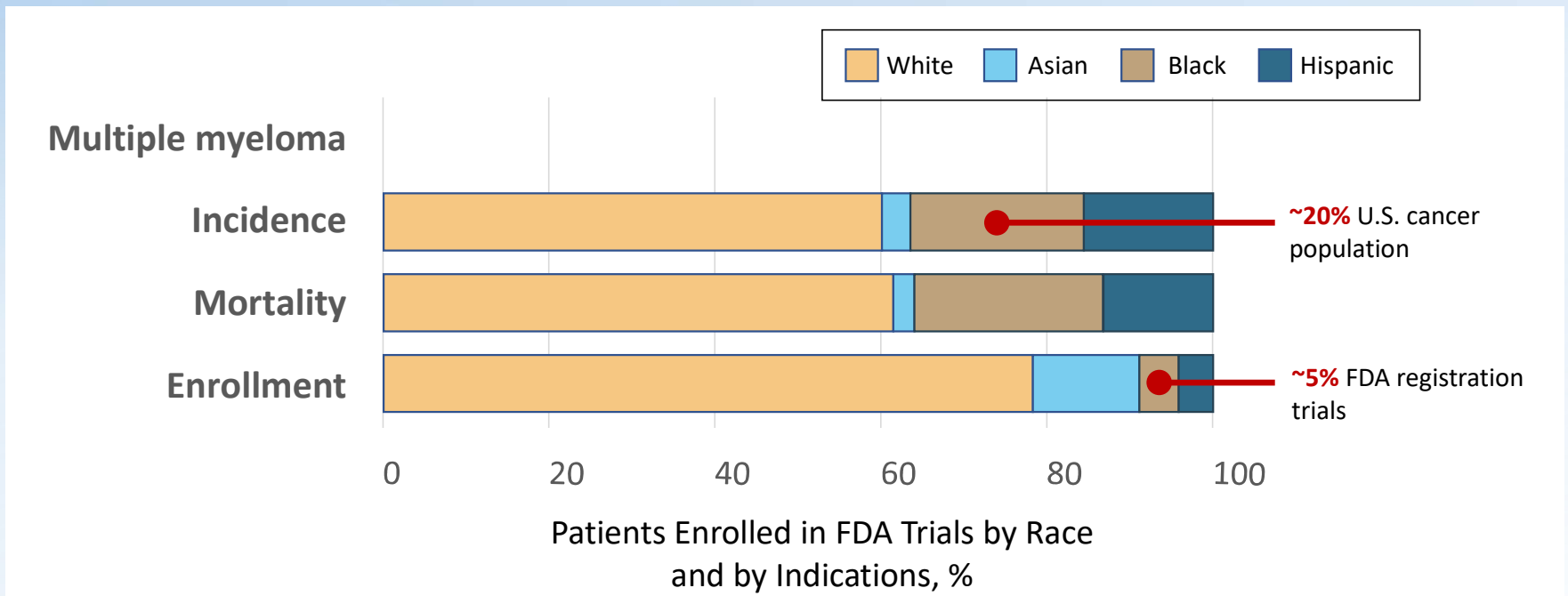
“And not only that too, they hooked me up with care outside of that where I needed to deal with some problems. I couldn’t work so, I want to make sure I kept my lights and gas on. So, they hit me up with a navigator. They hooked me up with how I could get extra food, take care.”



Issue 2

Addressing Participation in Clinical Trials

Realities of Clinical Trial Enrollment





Patient-Reported Suggestions to Promote Greater Participation in Clinical Trials

- Communicate with a trusted medical professional.
- Talk about the benefits and drawbacks to them and their families.
- Address concerns.
- Address culture and health system barriers.



Testimonials

“Well, for me, my doctor had to sit down and talk to me clearly...we think you ought to consider participating in this trial because they offer new medicine for your disease and it’s possible that there’s one that can help you live longer. And if I trust the doctor, I would say, ‘okay.’ If I don’t, I would say, ‘Well, I don’t want to do that. I’m just going to finish this out this way now.’”

“...I think if the person has the disease, the best way to let them know about the trial would be through their doctors that they dealing with. If not the doctors, they should have somebody that the doctor appointed to say, ‘Listen, you should talk to me about this...’”



Issue 3

*Team-Based Approach to Overcoming
Racial Disparities*



Testimonial

“If I had to rate this hospital (Boston Medical Center) from 1 to 10, it would be 11.”



Testimonial

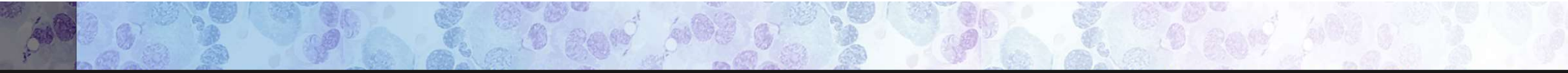
“... Medically speaking I’m sure most of the doctors know how to treat multiple myeloma. The problem is treating the individual. We’re talking about people of color...we can talk about how almost fifty percent of the country feels that there’s certain people that have no value. Now this attitude comes in with...doctors, nurses, and lawyers. The bedside manner is very, very important. The health team and BMC...I’ve observed the way they treat me and it’s like they’re treating their brother or their father...they treat each person like their own child, and here that’s what they do.”



Testimonial

“They know your name. They don’t start looking at the chart to find out what your name is.”

“They treat me with respect, kindness, compassion, tolerance, and so much love.”



Patient-Reported Facilitators of Trust in the Care Team

- Being treated with kindness
- Being treated like family
- Being treated with respect, free of discrimination
- Creating a cheery, positive atmosphere
- Professionalism and expertise
- Providing contact information and permission to “call anytime”
- Keeping the patient up to date with information
- Educating on side effects, medication, what to expect from the disease and the various treatments



Summary

- MM disparities in care exist along racial lines due, in part, to differences in biology, socioeconomic status, and health care access
- Higher representation of Blacks in clinical trials is needed because the medications studied may affect them differently
 - e.g., skin hyperpigmentation, benign neutropenia, peripheral neuropathy
- The team-based approach to improving care informed by our patient focus groups:
 - Treat patients like they are your family.
 - Take time to listen to their concerns.
 - Provide contact information where they can reach you if necessary or respond quickly to built in systems.
 - Utilize the entirety of the care team.
 - Explain the benefits of trials for your patient and for those with MM at large.
 - Help overcome barriers through addressing social determinants of health (SDoH).



Thank you for your attention.

Please complete the evaluation and posttest in order to claim your statement of credit.