Impact of Social Needs and Identity Experiences on the Burden of Illness for Patients with Multiple Myeloma: A Mixed-Methods Study

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Key Takeaways

- Participants report substantial **ongoing mental and physical health burdens** as they navigate the MM disease journey.
- **Social and identity-related factors** play an important role in MM diagnosis, treatment decisions and burden of illness.
- **Lack of Health Knowledge is prevalent** among MM study participants.

Conclusions

- Study reveals important areas for future MM work in the domains of patient education, access to oncology care, mental health assessment and the role of multi-disciplinary care teams and social support

"Myeloma lives with me. I don't live with myeloma."
Black patient, 50s

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Introduction

- Multiple Myeloma (MM) is a highly heterogeneous disease; characteristics pose unique challenges to patients and healthcare providers
- Cumulative evidence suggests that social determinants of health are largely responsible for widespread disparities
  - Known disparities exist in healthcare resource access and utilization
  - Hispanic and Black patients with MM tend to be younger than White patients at the time of diagnosis
  - Black MM patients more likely to experience myeloma-defining events (eg, hypercalcemia, anemia, and kidney dysfunction) and have a higher mortality rate
- Understanding the unique social needs and identity experiences is a critical gap needed to explore to improve health equity

Methods

Study Design

- A mixed-methods study design was utilized consisting of:
  - An online 45-question survey adapted from the Accountable Health Communities screening tool
  - Semi-structured focus group discussions

Participants

- Adult (≥18 years) US residents with MM
- Existing members of the sponsor's Multiple Myeloma Patient Engagement Research Council (PERC) program
- Patients who received a stem cell transplant >5 years from time of PERC initiation were excluded

Data Collection

- PERC members were first invited to participate in the online survey (March-April 2023)
- Subsequently invited to participate in 1 of 4 online, semi-structured focus group discussions conducted May-June 2023

Data Analysis

- Survey results were summarized using descriptive statistics
- Focus group transcripts were transcribed and analyzed:
  - Narrative thematic analysis to identify and organize themes
  - The research team met to debrief and identify and validate final themes and codes for analysis
  - Code saturation was deployed to identify a range of themes after each focus group discussions

Results

Participants

- Among all 23 PERC members who were invited to participate in the study, 21 members completed the survey, and 20 members took part in the focus group discussions
- Among survey participants, the majority (71.4%) were female, 42.9% were over 60 years of age, and more than half (52.4%) were Black, Indigenous, or People of Color (BiPOC)
- Among focus group participants, 60.0% were female, 10% were over 60 years of age, and 60% were BIPOC.

Survey Results (Table 1)

- 90.5% report mental health concern(s) ; 42.9% report food and housing concerns; 28.6% report transportation issues; 24% report financial instability

Focus Groups results (Table 2)

- Social and identity factors play an important role in impacting the disease journey (Table 2)
- Limited understanding of how social and identity factors interact (Figure 1)

"It took quite a bit of time to understand the relationship of the numbers that you would see in your labs, what was good, bad, stable…. A lot we had to go research for ourselves." ***White patient, 50s***

"There really isn't an end game. I was at the oncologist's office getting an injection yesterday, and someone was able to ring the bell. … For multiple myeloma individuals, we never really get the chance to ring that bell because we can't say there's a cure at this point." ***White patient, 40s***

Table 1. Survey Results: Patient perspectives on social determinants that negatively affected their health (n = 21)

Social Determinants	n (%)
Mental Health Determinants	
Felt at least somewhat stressed due to own health	18 (85.7)
Felt at least somewhat stressed due to health of friends/family	13 (61.9)
Feel lonely or isolated at least sometimes	8 (38.1)
Felt at least somewhat stressed due to family dynamic/wellbeing	8 (38.1)
Felt at least somewhat stressed due to financial strain	8 (38.1)
Felt at least somewhat stressed due to food insecurity	6 (28.6)
Felt at least somewhat stressed due to transportation problems	4 (19.0)
Little interest or pleasure in doing things at least half the days	3 (14.3)
Feel down, depressed, or hopeless at least half the days	3 (14.3)
Felt at least somewhat stressed due to housing instability	2 (9.5)
Determinants Related to Housing and Food	
Worried at least sometimes in past 12 months that food would run out	9 (42.9)
Issues with current living situation (eg, mold, pests)	4 (19.0)
Worried about losing stable housing	2 (9.5)
Transportation Determinants	
Travel more than 30 minutes to healthcare appointments	6 (28.6)
Lack of transportation led to missed healthcare appointment in past 12 months	2 (9.5)
Determinants related to Financial Instability	
Filed for personal bankruptcy in part due to health	1 (4.8)
Currently receiving Supplemental Security Income (SSI) or disability	2 (9.5)
Had utility companies threaten to shut off services in last 12 months	4 (19.0)

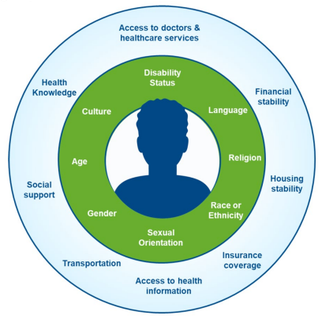
91% of participants report experiencing mental health concerns.

Table 2. Focus group results: Social needs and identity experiences which negatively impact participants' MM disease journey (N = 20).

Determinants	n (%)
Social Needs with Negative Impact[a]	
Lack of health knowledge	10 (50.0)
Financial instability	5 (25.0)
Lack of insurance coverage	3 (15.0)
Lack of transportation	3 (15.0)
Lack of social support	3 (15.0)
Lack of access to doctors and services	2 (10.0)
Lack of housing	1 (5.0)
Inability to access health information	0 (0.0)
None of the above	7 (35.0)
Identity Experiences with Negative Impact[b]	
Race or ethnicity	4 (20.0)
Age	4 (20.0)
Culture	4 (20.0)
Disability status	3 (15.0)
Gender	2 (10.0)
Religion	1 (5.0)
Sexual orientation	0 (0.0)
Language	0 (0.0)
None of the above	11 (55.0)

65% of participants report experiencing ≥1 social needs which negatively impact health outcomes.

Figure 1. Dimensions of social needs and identity experiences used to visually depict the concept of "Intersectionality" for participants in the focus groups.



Participants report limited examples of how social and identity factors interact.

"It's really difficult to be able to leave and go to another job because I don't know what protections I'll have in place. You have to be employed in most places for a year to get FMLA. … I have doctor's appointments three to four times a month. … So I feel kind of trapped financially because I have to stay in this job." ***Hispanic patient, 40s***

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