# The State of Multiple Myeloma Care

## An Evaluation of Access to Medical Care

**EXECUTIVE SUMMARY** An access to care research survey of 239 multiple myeloma (MM) patients showed that a large majority (70%) of patients experienced at least one access to care issue related to care coordination/physician knowledge, medical costs or insurance, or transportation issues. Based on survey findings, we propose several opportunities to improve access to medical care for MM patients. These include increased physician education about signs and symptoms of MM, improved care coordination among providers, and improved options for transportation to medical appointments. It is imperative to address the unmet needs of MM patients through additional research and healthcare policies that will result in equal access to care for all patients.

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## Introduction

Multiple Myeloma (MM)—a rare cancer of the plasma cells—is an incurable, but treatable disease. Although it is most common among African-American males age 50 and older, MM affects all races and both men and women.[1] MM can lead to impaired immunity, pain and numbness in hands and feet, bone erosion and fractures, kidney damage, and anemia. Today, MM patients have a range of treatment options available to them that vary based on individual symptoms and experiences.

Access to appropriate medical treatment is important for all diseases, but is particularly salient for MM patients. Because MM is a rare disease, patients may have difficulty finding an appropriate provider. Sometimes general oncologists and hematologists do not have substantial experience treating the disease, and MM specialists often practice at specialized treatment centers that may be too far away for many patients to reach.[2] MM tends to affect older and minority patients, further heightening access problems. Studies have shown that increased age, minority race, and low socioeconomic status are associated with increased access to care issues for several types of cancer.[3] Research has also shown that cancer patients with inadequate health insurance coverage experience greater access to care issues and poorer health outcomes.

Little is known about the specific barriers MM patients experience in obtaining healthcare services. Avalere Health, engaged by The Leukemia & Lymphoma Society (LLS), designed and conducted the largest study to date examining access to care issues among MM patients to better understand these issues among this patient population.

## Study Methodology

**Patient Survey //** We developed a patient survey intended to capture MM patients' experiences with access to care issues through all phases of the disease: diagnosis, treatment, and maintenance/follow up. The survey, designed to be completed in 45 minutes, included 105 questions. Patients could complete the survey online or over the phone. Survey questions focused on access barriers related to insurance coverage and the costs of treatment; transportation to medical appointments; and experiences with healthcare providers. The survey also solicited demographic information, disease stage, and treatment history from participants. The survey was developed using a modified version of a widely accepted conceptual framework that specifically addresses access to care issues for cancer patients.[4]

We attempted to include a representative sample of MM patients in the study. We tracked participant demographics (e.g., race, gender, age, location, income/education level) during fielding of the survey and amended our recruitment approach as needed. Initial recruitment efforts included targeting MM patients who signed up to receive invitations to online surveys and LLS networks. We supplemented this approach with outreach through community cancer organizations and clinics, MM providers, and support groups. Patients who completed the survey were offered a $45 honorarium.

**Study Outcomes/Analysis //** We defined "access barriers" as factors that 1) slowed or prevented an MM diagnosis; 2) prevented patients from receiving care from their current MM physicians; and 3) prevented patients from taking a medication or treatment that they wanted to take. These factors were further grouped into four categories of access issues:

**TRANSPORTATION:** a lack of transportation to medical services and/or significant distance to a healthcare provider.

**INFORMATION/CARE COORDINATION:** problems communicating with or obtaining information from physicians or gaps in physician knowledge.

**COST/INSURANCE:** problems related to the cost of treatment or health insurance coverage for diagnostic tests or treatments.

**TREATMENT/OTHER:** treatment-specific and miscellaneous access barriers identified by patients unrelated to above factors. For example, 'stopped treatment due to side effects', 'not eligible for clinical trial', 'homeless', and 'age restrictions on medication'.

PATIENT SURVEY

- 105 questions
- Patient demographics, symptoms, disease information and provider data collected
- Examined access barriers related to insurance coverage, treatment costs, transportation, and interactions with healthcare providers
- $45 honorarium offered as patient incentive to complete survey

We evaluated the proportion of patients who had access to care barriers at the diagnosis and treatment stage of their MM. We further evaluated the types of specific access issues these patients experienced. We used logistic regression analysis to examine possible associations between patient sociodemographic and clinical characteristics and access to care barriers.

## Study Results

Patient Characteristics // The 239 patients who completed the survey were included in the analysis. Table 1 summarizes demographic and clinical characteristics of the patient sample. The average age of patients participating in the study was 60, just over half (57%) were male, and the majority (83%) of patients were Caucasian (Table 1). Although the incidence of MM is higher among African Americans than Caucasians, only 10% of our patient sample was African American. The relatively low percent of African Americans in our study is consistent with previous research on the MM patient population.[5] Our study suggests that previously documented difficulties with minority patient recruitment for studies[6,7] may still exist. A single provider (e.g., oncologist, hematologist, or MM specialist) managed the care of approximately 43% of patients in the study. For the remaining 57% of patients, a team of providers managed their MM care.

TABLE 1: PATIENT CHARACTERISTICS

| | Patient Sample (n=239) |
|---|---|
| **Mean Age (years)** | 60 |
| % of patients < 65 yrs | 69% |
| % of patients ≥ 65 yrs | 31% |
| **Gender** | |
| Male | 57% |
| Female | 43% |
| **Race** | |
| White | 83% |
| African American | 10% |
| Other Minority | 6% |
| **Locale** | |
| Rural | 31% |
| Suburban | 50% |
| Urban | 19% |
| **Geographic Region** | |
| Midwest | 25% |
| Northeast | 21% |
| South | 31% |
| West | 23% |

| | Patient Sample (n=239) |
|---|---|
| **Household Income** | |
| $0-20k | 11% |
| $21-40k | 16% |
| $41-75k | 38% |
| $76k+ | 36% |
| **Health Insurance Status** | |
| Public only | 23% |
| Private only | 56% |
| Public and Private | 17% |
| Other | 4% |
| None | 1% |
| **Presenting Symptoms** | |
| Back Pain | 50% |
| Fatigue | 50% |
| Bone lesions/Bone Pain | 47% |
| Anemia | 38% |
| Broken bones/fractures | 23% |
| **Marital Status** | |
| Separated or Divorced | 15% |
| Married | 74% |
| **Management of Multiple Myeloma** | |
| Single Provider | 43% |
| Team of Providers | 57% |

Patients reporting transportation access barriers also report gaps in their support systems. Specifically, they need more emotional support, help with medication costs, and help in identifying MM resources, in addition to assistance securing transportation.

**Access to Medical Care //** Overall, 70% (n=167) of patients in our sample reported at least one access to care barrier related to their MM diagnosis and/or care, and 30% of respondents reported they had never experienced a barrier. Thirty-seven percent of patients experienced two or more access barriers.

Information/Care Coordination issues were the most commonly reported access barriers for our patient population, with 46% of respondents citing this type of issue (Figure 1). Thirty-five percent of patients reported access issues related to Cost/Insurance factors. Twenty percent of patients reported Transportation issues, and 28% reported treatment/other access to care issues.

FIGURE 1: PROPORTION OF MM PATIENTS REPORTING ACCESS TO CARE ISSUES

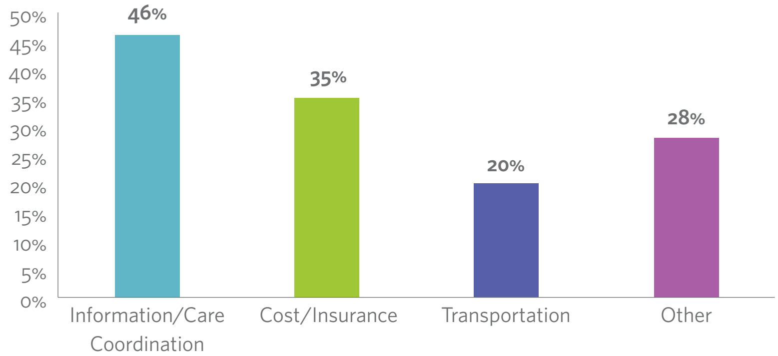


Table 2 provides a summary by category of the top responses reported by patients who had access to care issues. Notably, 41% of patients who had an information/care coordination issue reported that their physician lacked information and 39% of those patients reported that they had communication problems and difficulties getting appointments with their physician. In addition, of those who reported a transportation issue, distance to provider was a much more significant issue (91% of patients) than was the availability of transportation (26% of patients) or an inability to travel (9% of patients). When asked about MM provider location, 38% of these patients reported that the distance to their MM physician was more than 100 miles, and 21% of patients reported that it was more than 200 miles. We looked at the locale of those patients reporting a transportation issue. Approximately 27% of rural patients reported a transportation barrier to care compared to 16% and 18% of patients living in suburban and urban areas, respectively.

TABLE 2: MOST COMMONLY REPORTED ACCESS TO CARE BARRIERS

| Information/ Care Coordination Issue (n=111) | Cost/Insurance Issue (n=83) | Transportation Issue (n=47) | Treatment/ Other Issue (n=68) |
|---|---|---|---|
| Healthcare provider lacked info (41%) | Costs of co-pays and/or deductibles (66%) | Distance to physician (91%) | Stopped treatment due to side effects (75%) |
| Communication problems (39%) | Insurance coverage issues (64%) | Lack of transportation (26%) | Not eligible for clinical trial (13%) |
| Problems getting an appointment (39%) | Other financial concerns (37%) | Not able to travel (9%) | Frequency/ duration of treatment (9%) |

MOST COMMONLY REPORTED ACCESS TO CARE BARRIERS AT DIAGNOSIS AND DURING MEDICAL CARE/TREATMENT

**Diagnosis Phase**

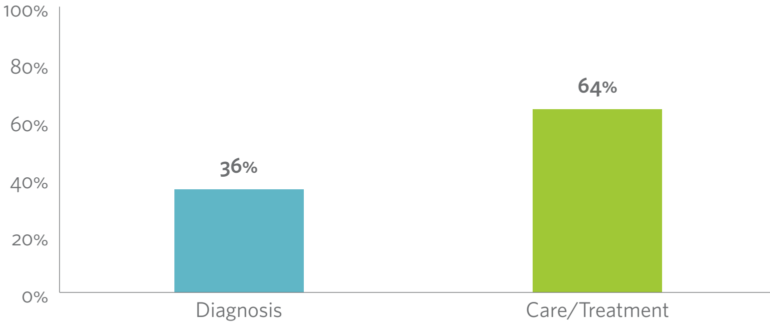
- Healthcare provider lacked specialized information/knowledge on MM (54%)
- Error with lab testing (e.g., wrong test ordered, incorrect results) (22%)
- Problems getting an appointment (22%)
- MM signs and symptoms difficult to recognize (22%)

**Care/Treatment Phase**

- Copay too expensive (36%)
- Treatment side effects (33%)
- Not covered by insurance (33%)
- Distance to physician (27%)

Access Barriers at Diagnosis // When we looked more closely at specific access to care issues reported by patients during the diagnosis phase of their MM compared to the care/treatment phase, approximately 36% (n=85) of patients reported access to care issues related to obtaining their MM diagnosis (Figure 2).

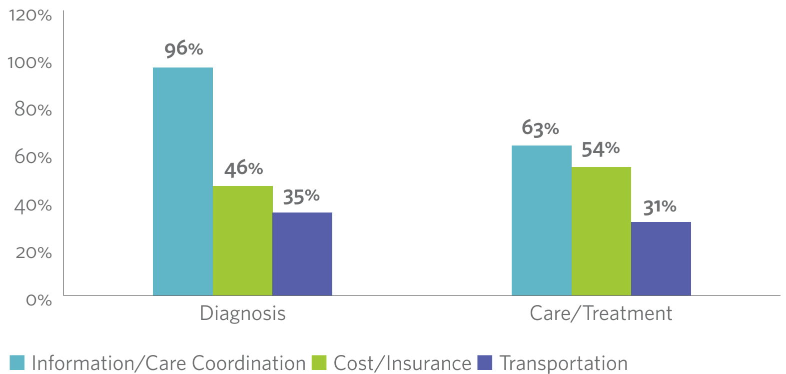
FIGURE 2: ACCESS BARRIERS AT DIAGNOSIS VS. CARE/TREATMENT



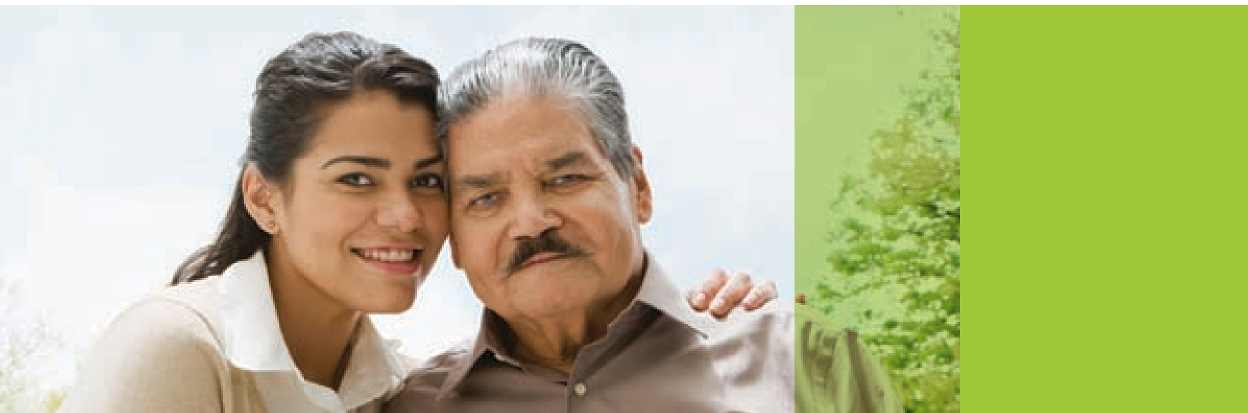

Of patients reporting access barrier at diagnosis, 96% experienced information/care coordination barriers, 46% reported cost barriers, and 35% reported transportation barriers (Figure 3). The most commonly reported access barrier at diagnosis was lack of specialized information/knowledge on MM by healthcare providers (54%). In addition, providers did not initially recognize signs and symptoms of MM, 22% of patients reported. Other issues reported at the diagnosis stage were problems getting an appointment (22%), errors with lab testing (22%), and communication issues with healthcare providers (18%).

Access Barriers During Care/Treatment // Sixty-four percent of patients reported an issue with accessing medical care and/or treatment following their MM diagnosis. Of those, 63% experienced information/care coordination barriers, 54% cost barriers, and 31% transportation barriers (Figure 3). Specifically, the most common access to care barriers that patients reported during medical care and/or treatment were costs of insurance co-pays and/or deductibles for treatment (36%), treatment side effects preventing them from taking a treatment or medication (33%), insurance coverage issues (33%), distance to physician (27%) and communication problems with physician (22%).

FIGURE 3: ACCESS BARRIERS AT DIAGNOSIS VS. CARE/TREATMENT




Predictors of Access to Care Issues // We examined several demographic, clinical, and disease management factors to determine which ones were associated with having an access to care issue. Our analysis showed that patients who were separated or divorced were nearly four times more likely to report having an access to care issue than patients who were not separated or divorced. Age was also significantly associated with having an access to care issue. People under age 65 were nearly 3 times more likely to experience access to care issues as patients ages 65 and older (44% versus 32%, $p<0.05$). Although patients under 65 years of age were more likely to have private insurance than those over the age of 65, insurance status was not a significant predictor of access barriers in our study.



PREDICTORS OF ACCESS ISSUES

- Marital status: separated or divorced
- Age < 65 years
- Back pain reported as a symptom at the time of initial MM diagnosis
- Annual household income between $40–75K
- MM care managed by team of physicians rather than single doctor

Our analysis showed that patients with back pain at the time of diagnosis were twice as likely to experience barriers to medical care as those without back pain. Of the 119 patients who reported back pain, approximately 44% (n=52) reported an access to care issue with diagnosis. Notably, 54% of those with an access issue around diagnosis reported that their healthcare provider lacked information to make an accurate diagnosis, and 23% of these patients reported that they initially received a misdiagnosis.

Patients with annual household income levels between $40–75K were twice as likely to experience an access to care issue compared to patients with other income levels. Few patients in our sample had incomes below $40K. Those few patients may have been more likely to receive financial assistance through Medicaid or other low income health programs and as a result, less likely to report access to care issues.

The patient's care team was also associated with barriers to care. Our analysis showed that patients receiving MM care from a single provider were 68% less likely to experience access barriers to care compared to patients receiving MM care from a team of physicians, suggesting issues with care coordination among multiple providers.

Race, gender, geographic region, locale, and health insurance status were not associated with access to care issues. Patients who reported that they were receiving adequate emotional support and did not require assistance with transportation, costs, or in locating physicians or MM resources were significantly less likely to have access to care issues.

## Potential Policy Options to Address MM Access Issues

The findings from this analysis should be used to help inform healthcare policies aimed at improving accessibility to medical care for MM patients.

Transportation Assistance Program for Cancer // Many patients reported having to travel long distances to see a physician with expertise in MM care. When travel plans fall through or are unaffordable, the result could be gaps or delays in care. Providing transportation assistance to cancer patients to enable them to receive necessary care will undoubtedly improve outcomes for these patients.

Medical Home for Cancer // Patients in our population who saw multiple physicians for treatment of their MM reported more access to care barriers than those who saw one. However, multiple physicians are often necessary for patients who do not have a nearby physician who specializes in treatment of MM. The Patient-Centered Medical Home is a model for improved care coordination and strengthened physician-patient relationships through improved access (e.g., e-visits, telephone consults), patient engagement, coordination of specialist care, and use of health information technology. For MM and other cancer patients who see multiple specialists in different settings, this model could be particularly helpful to ensure coordinated, high quality, and less costly care.

MM Educational Programs for Oncologists // One-quarter of patients reported difficulty obtaining a diagnosis because their physicians lacked knowledge of their rare disease. This underscores the importance of physician education on MM. Our research patients reported that physicians missed signs and symptoms; so educational programs should focus on recognition of signs and symptoms of MM.

## Conclusions

This study represents the first in-depth analysis of access barriers experienced by MM patients. Our findings showed that a majority of patients experienced at least one access to care barrier related to care coordination, physician knowledge, costs/insurance, or transportation issues. Unlike previous studies on access to medical care among oncology patients, our analysis indicated that race and insurance status were not associated with access barriers among MM patients. And while other studies of oncology patients have shown that increased age may be associated with barriers to care, older patients in our sample were actually shown to be less likely to have access to care issues. Previous research shows that with equitable access to care, MM patients have similar outcomes[8], which underscores the importance of implementing solutions to mitigate these access issues.

Despite our aggressive recruitment efforts, there are likely patients who were unable to participate in our study because they were not connected to the healthcare system for treatment or support of their MM. Many of the oncologists and support group leaders we spoke with throughout our recruiting process indicated that they see very few African American patients. It is possible that the reason these patients were not receiving treatment for their MM was in and of itself an access to care issue. As a result, because we were not able to identify and recruit these types of patients into our study, it is possible that the access issues described herein may actually underestimate the true access to care issues among MM patients.

In summary, the results from the study suggest the following:

- Transportation is an access to medical care barrier for MM patients. Improved options for transportation, particularly for those patients whose physicians are located outside of their immediate area, may help decrease barriers to receiving care.
- Improved care coordination for MM patients is essential, particularly for those who require or choose to see multiple physicians to manage their disease. We have proposed considering a Medical Home for cancer patients to improve care coordination and strengthen the patient-physician relationship for these patients.
- More research is warranted on why MM patients younger than 65 years of age and those with middle-income levels were more likely to have access issues.
- Many patients in our research reported that their diagnosis was prevented or delayed due to missed signs and symptoms or lack of knowledge about their rare condition. Increased physician education about signs and symptoms of MM may help to mitigate these issues.
- Finally, African American MM patients appear to be less engaged in the healthcare system compared to Caucasian MM patients. Previous research shows that African American patients are less likely to receive stem cell transplants, which also demonstrates a potential disconnect with the healthcare system.[9] These findings together may signal more significant barriers to seeking and receiving care among African American patients, and should be explored in future research.

This study highlights key access to care issues among MM patients that may affect their outcomes. It is imperative to address these unmet needs through additional research and healthcare policies that will result in equal access to care for all patients.

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