# Racial Disparities in Health Care Utilization Outcomes Among Patients With Duchenne Muscular Dystrophy

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## Background

- Duchenne Muscular Dystrophy (DMD) is a progressive neurological disease affecting predominantly males. These patients can live into their 40s, but the majority succumb to respiratory and/or cardiac complications earlier in life[1]
- Patients lose the ability to ambulate between 10-13 years and need ventilator support by 20 years, increasing the cost burden along with the progression of the disease.[1] Annual cost is estimated to range from $23,920 to $54,270[2]
- Real world evidence (RWE) of burden and unmet medical needs among patients with DMD is needed to develop more valid & reliable clinical, economic, humanistic, & inpatient quality of care outcome metrics in rare diseases like DMD

## Study Objective

- The aim of this study was to identify racial disparities among a nationally representative sample of hospitalized patients with DMD

## Methods

### Study Design

- A cross-sectional analysis using 2018-2019 hospital discharge data from the Health Care Cost and Utilization Project (HCUP) National Inpatient Sample (NIS)[3]
  - Initial analysis included only 2018 data, however, due to low sample size the analysis was updated with newly available 2019 data
- The sample included hospital admissions identified using ICD-10-CM diagnosis code G71.01. Healthcare utilization (HCU) outcomes were in-hospital mortality, length of stay (LOS), and charges
- Sample weights were applied to generate nationally representative estimates of hospital admissions

### Statistical Analyses

- Descriptive statistics and multivariable regression models (adjusting for age, gender, payer, hospital region, and comorbidity score) were used to examine differences in HCU outcomes between White patients and racial minority patients with DMD

## Results

- A total of 732 inpatient admissions were identified for DMD:
  - 463 (63%) White patients
  - 241 (33%) racial minorities
  - 28 (4%) encounters missing race data
- Nationally representative estimates of hospital encounters were 2315 White patients and 1205 racial minorities
- Median age at admission was 29 (20-46) and 22 (16-29) for White patients and racial minorities, respectively (*P*<0.001)
- The most frequent Medicare severity diagnosis related group code was 871: Septicemia or Severe Sepsis with Major Complications and Comorbidities (7.3%) for White patients and 10.8% for minorities, followed by 207: Respiratory System Diagnosis with Ventilator Support >96 Hours (5.0% for White patients and 4.1% for minorities)
- A comparison of comorbid medical diagnoses is shown in **Figure 1**
- Racial minorities (58.1%) were more likely to have Medicaid as a payer than White patients (30.2%) (**Figure 2**)

**Figure 1: Percentage Comorbid Medical Diagnoses**

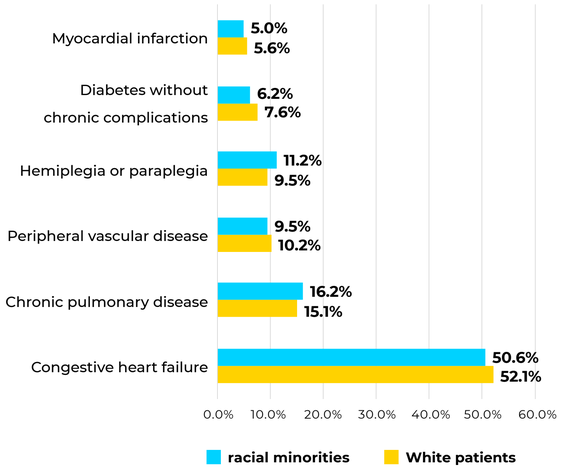
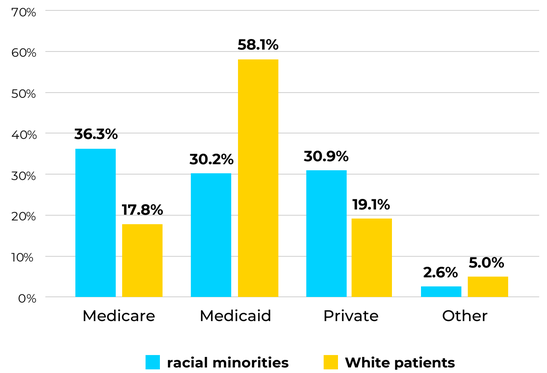



**Table 1: Unadjusted HCU Outcomes**

| | White patients | Racial minorities |
|---|---|---|
| **Died during visit, (n%)** | 25 (5.6%) | 11 (4.6%) |
| **Length of stay, median (Q1-Q3), days** | 4 (2-8) | 4 (2-8) |
| **Charges, median (Q1-Q3), $** | 46,551 (25,254-106,951) | 62,594 (29,546-124,015) |

- Mortality occurred in 25 (5.6%) White patients and 11 (4.6%) racial minorities. Median (IQR) LOS was 4 days (2-8) for both White patients and racial minorities (**Table 1**)
- Median (IQR) charges were $46,551 ($25,254-$106,951) for White patients and $62,594 ($29,546-$124,015) for racial minorities (**Table 1**)
- Racial minorities were not associated with an increased visit charge after adjusting for covariates
- Adjusted regression results revealed no statistical difference in mortality or LOS

**Figure 2: Payer Breakdown of the Sample**




## Limitations

- Limitations of large-scale administrative data include inconsistent coding and billing practices, which often translate to incomplete records
- Settings of care captured in this analysis include inpatient hospitalizations, which do not account for all settings of care required for patient management
- The hospital discharge data used are structured at encounter level instead of patient level, which limits the ability to track patients longitudinally or across hospitals within a region or between regions of the United States.
- Race data are not uniformly available across the HCUP sampling frame and representation of DMD for 2018 was limited because the ICD 10 code did not exist until the end of the year

## Conclusions

- Low sample size initially was due to delayed use of the specific DMD diagnosis code for reimbursement of services in 2018 and created a need to add a year (2019) to the data collection
- Median age was high for White patients (29 y) relative to racial minorities (22 y), perhaps indicative of improved overall survival outcomes among White patients with DMD
- This may also be an indicator that this analysis was most representative of a less severe subgroup of DMD patients
- Racial differences were not associated with in-hospital mortality, LOS, or charges

### Acknowledgments

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### References

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