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## Hospitalizations and Emergency Room Visits for Adolescents and Young Adults with Muscular Dystrophy Living in South Carolina

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### Abstract

**Introduction**—Transitioning from adolescence to adulthood can be problematic for individuals with rare disabilities such as muscular dystrophy (MD).

**Methods**—We identified a cohort of 220 individuals with MD and 440 matched comparison individuals and measured emergency room (ER) and inpatient (IP) encounters for the years 2000 through 2010, using all-payer hospital discharge uniform billing data. We compared ER and IP use rates for people with and without MD, and for 15 - 19 year-olds with MD to 20 - 24 year-olds with MD.

**Results**—ER and IP use rates were significantly higher among individuals with MD than in the comparison group. Additionally, ER and IP use rates were significantly higher in the 20-24 year age group than in 15-19 year-olds.

**Discussion**—Additional research is needed to examine whether increased ER and IP use in young adults is attributable to difficulties in healthcare transition versus increased disease severity.

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*Ethical Approval.* The study was granted exempt status by the Institutional Review Board at the University of South Carolina.

## Keywords

Muscular Dystrophy; Transition; Hospitalizations; Emergency Department; Ambulatory Care Sensitive Conditions

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## Introduction

Muscular dystrophies (MDs) are a group of heterogeneous conditions characterized by progressive muscle weakness and dystrophic changes identified through muscle biopsy.<sup>1</sup> The age of onset for the various types of MDs ranges from infancy to later adulthood and can affect multiple body systems. For childhood-onset MDs such as Duchenne and congenital muscular dystrophies, respiratory and cardiac issues have been the cause of significant morbidity and early mortality; however, multidisciplinary care and interventions such as ventilator use have led to increased survival into adulthood.<sup>2-6</sup>

Improvement in survival of children with MDs has highlighted the need for successful transition from pediatric to adult health care. The goal of transition is to ensure that individuals receive age-appropriate health care services that maximize functioning and prevent adverse health outcomes.<sup>8-12</sup> Transitioning a young adult from pediatric services also demonstrates that there is a realistic expectation of living into adulthood and enhances the individual's sense of responsibility and self-esteem.<sup>13,14</sup> However, numerous barriers inhibit a smooth transition including: lack of pediatric provider support in planning, patient and caregiver apprehension of the different approaches of pediatric and adult providers, failure to involve young people in planning, and a lack of adult providers with adequate training.<sup>8,12,14-23</sup>

Studies have shown higher rates of emergency room (ER) use and hospitalizations for young adults with special healthcare needs.<sup>15, 24</sup> However, research on healthcare use surrounding the period of transition for individuals with MD is limited. Only 1 study has examined healthcare use patterns among children and young adults with MDs.<sup>25</sup> Ouyang et al measured healthcare use and expenditures in patients with MD through a private insurance database and found that children with MDs have higher use and expenditures than children with other special healthcare needs. Additionally, they reported that use and expenditures for 15-19 year olds was higher when compared with adults age 20-24; however, as the percentage of females was higher in the adult group, they postulated that the older age group likely included people with less severe adult-onset MDs who would be more likely to be employed and thereby have better access to private insurance and have lower healthcare use than those with more severe MD.<sup>25</sup> Analyzing data from private and public payers would allow comparisons to be drawn between similar adolescent and adult MD groups to understand healthcare use during the transition period.

Using data from South Carolina Medicaid, State Employee Health plan, and Hospital Discharge Uniform Billing, the purpose of this study was to: 1) compare the rates of ER and inpatient (IP) hospital use for individuals with MD and matched controls without MD age 15 to 24 years old, when transition to adult medical care is likely to occur; and 2) to analyze rates of ER and IP hospitalizations among individuals with MD by age and other socio-

demographic attributes. We hypothesized that young adults (age 20-24 years) with MD would have higher rates of ER and IP use than adolescents with MD (age 15-19 years), due to a combination of worsening health for people with Duchenne MD or Becker MD (DMD; BMD) as well as challenges involved with transition to adult health care providers.

## Materials and Methods

### Study Design and Setting

We conducted a retrospective cohort study using administrative data in South Carolina to describe ER and IP hospital use among people with MD, from ages 15 - 24, and to investigate the association between age (as a proxy for transition from adolescence to adulthood) and use. This study is part of a larger project investigating the transition from pediatric to adult services for adolescents and young adults with rare health conditions. The study protocol was approved by the South Carolina Department of Health and Human Services, the South Carolina Employee Benefit Administration, the South Carolina Data Oversight Council, the South Carolina Department of Health and Environmental Control, and the South Carolina Department of Social Services and was granted exempt status by the institutional review board at the University of South Carolina.

### Data Sources

A cohort was identified from Medicaid, the South Carolina State Employee Health Plan (SHP), and all-payer hospital discharge uniform billing (UB) data. Medicaid is a state-run health insurance program for people with low income; children and adolescents can qualify on the basis of income alone, and individuals under age 18 years with significant disability are eligible regardless of family income. Adults younger than 65 are typically eligible for South Carolina Medicaid only if they have a low income in addition to a significant disability. Individuals who qualify as children because of a disability can remain enrolled in Medicaid if their individual income remains low and if the severity of the disability is sufficient (criteria for disability benefits are not always the same for children and adults with the same condition). The SHP is a self-insured plan, managed by SC Blue Cross/Blue Shield, which includes government workers from all sectors. The UB data includes IP and emergency department discharge billing data extracted from all general, short-term acute care hospitals within the state. These data systems are housed at the South Carolina Revenue and Fiscal Affairs Office, Health and Demographics Section (H&D), the central repository of the state's health and human service data. To "link across" data sources from multiple providers, H&D developed a series of algorithms using source-specific personal identifiers to create a global unique identifier. Using the global identifier in lieu of personal identifiers enables staff to create views of data across multiple providers while protecting confidentiality. This identifier can be unduplicated across data systems to avoid over-counting of individuals. Case and comparison group unique identifiers were linked to vital records for years 2000-2011 to determine if anyone died from any cause.

### Cohort Identification

To be included in the study, individuals were aged between 15 - 24 years for at least 1 year during the 2000 through 2010 time frame. They also were enrolled in the South Carolina

Medicaid program or State Health Plan for at least 1 calendar year during the study period. MD cases were identified from these data sources based on diagnosis with 1 of 3 ICD-9 codes for MD (359.0, 359.1, and 359.21) on at least 2 occasions. For the 2000-2010 study period 220 unique cases of MD were identified. Participants were followed for ER and IP use during the study period until 1 of the following endpoints:

- The end of 2010;
- Attainment of age 25;
- Death

The denominator included person-years, which were calculated as the sum of all the number of years under observation across all of the persons.

### Comparison Group

We created a comparison group, matched on age, gender, and years of insurance coverage, of people from the SHP. We calculated a propensity score based on age, gender, and years of insurance coverage and randomly selected 2 people for each case for comparisons based on propensity score. If 2 people with identical scores could not be identified, an individual with the next closest absolute difference score was identified. We identified 440 unique comparison individuals for our MD cases from the SHP. We excluded from the comparison group people who had spina bifida (741), cerebral palsy (343), spinal cord injury (344.0, 344.1, 767.4, 806, 952, 907.2), intellectual disability (317-319), fragile X syndrome (759.83), autism spectrum disorders (299), or multiple sclerosis (340). This was not intended to be an exhaustive list of exclusions but was done to make the comparison group a relatively “healthy” group rather than comparing adolescents and young adults with MD to those with other significant disabilities.

### Outcome Variables (Use)

ER and IP hospital use was ascertained for everyone in the case and comparison cohort using uniform billing (UB) data for all civilian hospitals located in South Carolina. UB data included the date of service and the primary ICD-9-CM codes for ER and IP hospitalizations. UB data were utilized to capture events that could have occurred when a case or comparison had lost insurance during our study period.

We examined ER visits and IP hospitalizations to evaluate use for any cause, by specific body system conditions (categorized using ICD-9 codes), and Ambulatory Care Sensitive Conditions (ACSC). ACSC are conditions that should be manageable in the outpatient setting, and therefore ER visits or hospitalizations for them would represent a failure or unmet need in terms of the receipt of primary care. ACSC may be particularly relevant for people with MD because: (a) some of the conditions that comprise ACSC (such as bacterial pneumonia) are conditions for which people with MD are at increased risk and (b) an increase in ER and IP use for ACSC as individuals go from adolescence to adulthood could serve as a marker for difficulty in successfully transitioning from pediatric to adult medical care. ACSC were identified and categorized using a data tool developed by the Agency for Healthcare Research and Quality for monitoring the health care safety net using

administrative data (see Supplementary Table S1, available online).<sup>26</sup> We supplemented the original data tool by adding additional codes from the AHRQ prevention quality indicator measures.<sup>27</sup> We also included incidence rates of ER and IP use according to different body systems using ICD-9-CM book chapter groupings (see Supplementary Table S2, available online); these groupings use all encounter data and are not limited to ACSC.

Use rates were calculated in terms of person years. We calculated a total rate that includes both ER visits and IP hospitalizations. We also analyzed separately ER visits and hospitalizations. In addition to comparing MD rates to the comparison group rates, we were also interested in the potential impact of age on use rates. Because care transition from pediatric to adult care is expected to occur in the late teen years, we elected to dichotomize age into less than 20 (ages 15 - 19 years) and 20 or older (20 - 24). For each condition, we compared the use rates for the younger group to the older group.

### Other Data

Other variables analyzed included gender, race, and county of residence (classified into urban and rural). The county of residence was categorized as urban or rural using 2010 Rural Urban Commuting Area (RUCA) Codes. Information on socioeconomic status (SES) was obtained from the South Carolina Department of Social Services Supplemental Nutrition Assistance (formerly food stamps) Program (SNAP); eligibility for this program is dependent on being at or below the federal poverty level and was used as a surrogate marker for SES.

### Statistical Analyses

Inference on Generalized estimating equation (GEE) models<sup>28</sup> assessed differences between the MD group and the comparison group. The motivation for estimating GEE models was the presence of repeated observations from the same individuals during the study period. The GEE approach extends generalized linear models to account for within-group correlated data; in our case, this approach accounts for repeated (correlated) observations from the same person. The GEE model was estimated by specifying REPEATED statement in the GENMOD procedure of SAS 9.3 (SAS Institute Inc., Cary, NC). Each regression model included MD versus comparison group as the key independent variable and assumed a Poisson distribution relationship between the mean and variance for the dependent variables of ER and IP use. We specified the log link function so that incidence rate ratios (IRR) could be calculated as exponentiated regression coefficients. Separate models were run for ER and IP use for any cause, for ACSC, and for each body system listed in the ICD- 9 CM. In each Poisson model, we controlled for age group, gender, race, urban or rural county of residence, and SNAP enrollment as a marker for socioeconomic status. We were unable to control for race in the initial models, because the State Health Plan does not include a race variable. However, when we limited the models to individuals with MD to assess the role of age and other characteristics specifically in this group, we were able to control for race in those models. All variables were assessed using Wald tests based on the empirical standard errors so that inference is robust to misspecification of the within-person correlation structure which was assumed to be exchangeable in our models. Statistical significance was based on a 2-sided p-value of 0.05.

We then stratified each model by limiting to only MD and re-estimated the models with age group as the key independent variable, controlling for the same covariates as before with the addition of race. To ensure adequate sample sizes, we only estimated models for which there were at least 50 observations available. We also tested the effect of stratifying the models, first limiting them only to individuals found to have data during both age ranges (15 - 19 and 20 -24); this was done in order to better evaluate the association between age and use, while minimizing bias due to potentially different characteristics for individuals who were present during only 1 age range. Then we limited the modeling to males, since many types of MD affecting individuals in the age groups being studied (including Duchenne and Becker MD) are transmitted via an x-linked recessive pattern and are, therefore, much more prevalent in males.

## Results

### Descriptive Information

Descriptive information on the MD cohort and the comparison group is shown in Table 1. There were 220 people with MD, and the comparison group included 440 people. As would be expected, a majority of the sample was male. The MD and comparison group were similar on most characteristics, except that race is not available in the SHP data and was therefore missing for the comparison group. Only 10% of the MD group and 3.4% of the comparison received SNAP benefits at any time during the study period.

### Use Rates, Full Cohort

There were 871 person-years of follow-up for people with MD in the 15-19 year age range and 640 person-years for people with MD in the 20-24 age range. Among the comparison group there were 1,733 and 1,393 person-years in the 2 age ranges, respectively. Unadjusted rates of IP and ER use, by demographic and other characteristics, are available in the supplemental online tables (Supplementary Table S3). Compared with the comparison group, people with MD had significantly higher adjusted rates of total ER [incidence rate ratio (IRR) = 2.77,  $P < .01$ ] and IP (IRR = 10.92,  $P < .01$ ) use and ER (IRR = 3.48,  $P < .01$ ) and IP (IRR = 66.58,  $P < .01$ ) use due to any ACSC. Adjusted rates were especially elevated in people with MD for IP use specifically for the ACSC of bacterial pneumonia (IRR = 113.38,  $P < .01$ ) and for IP use for respiratory conditions (IRR = 120.40,  $P < .01$ ). People in the 20-24 age range had significantly higher rates of total ER (IRR = 1.54,  $P < .01$ ) and IP (IRR = 1.64,  $P = .01$ ) use and higher rates of ER use (IRR = 1.72,  $P < .01$ ) for ACSC but not IP (IRR = 1.31,  $P = .33$ ) use for ACSC. Full results for the models that included both people with and without MD are available from the authors upon request.

### Use Rates among People with MD (Table 2)

When modeling ER and IP use only among individuals with MD, older age (20-24) was associated with significantly increased rates of overall ER and IP use and with ER use for any ACSC. IP use for ACSC did not differ significantly by age. Small cell sizes did not permit examination of the association between age group and ACSC use for any condition other than IP admission for bacterial pneumonia, which did not differ significantly by age group. Significantly greater ER use was found among 20-24 year old individuals for the



following types of conditions: digestive, musculoskeletal, respiratory, and ill-defined. No significant differences in IP admission rates were detected for any body system.

There was significantly less IP use for any respiratory condition among individuals who were not white. SNAP use was associated with significantly increased ER use overall and for ACSC, but not for IP use. Specifically, people enrolled in SNAP were significantly more likely to use ER services for any digestive condition or for any respiratory condition. Females experienced higher rates of ER use overall and for ACSC but did not have higher rates of IP use. In fact, the rates of IP use for any ACSC and for the ACSC of bacterial pneumonia were significantly lower in females than in males. By body system, females were significantly more likely to use ER services due to any genitourinary condition or any musculoskeletal condition and significantly less likely to experience IP admission due to any respiratory condition.

### **Use Rates among People with MD, Present in both the 15-19 and 20-24 age ranges (Table 3)**

There were 152 individuals (105 males) with MD who were present in the data for at least 1 year between the ages of 15 and 19 and for 1 year between the ages of 20 and 24. There were 678 person-years of follow-up in the 15-19 year age range and 604 person-years in the 20-24 year age range. The associations between age and use were similar to those shown in Table 2, though in some cases the association was stronger. In addition, although there was not a significant association between age group and IP use for ACSC in the entire cohort with MD, this association was significant for individuals who were present in the data during both age periods.

### **Use Rates among Males with MD, Present in both the 15-19 and 20-24 age ranges (Table 4)**

Among the 105 males with MD who were present in the data for at least 1 year between the ages of 15 and 19 and for 1 year between the ages of 20 and 24, there were 479 person-years of follow up in the 15-19 year age range and 392 person-years in the 20-24 year age range. The association between age and use was found to be very similar to that shown in Table 3.

## **Discussion**

As anticipated, we found that individuals with MD had a higher rate of ER and IP use than those in the comparison group. The increased rates of use in the older age group of individuals with MD may indicate difficulties with access to and quality of adult ambulatory health care, though increasing severity of disability with age (especially for boys and men with DMD or BMD) probably contributes substantially as well. We did not find significant associations between rural/urban county or race and overall or ACSC ER or IP use in general, though there was a significantly lower rate of IP use for any respiratory condition for people with black or other race compared to whites. It is difficult to speculate on the cause of this difference, which was highly significant ( $P = .002$ ). Overall and ACSC ER use was increased significantly for individuals who had ever been enrolled in the Supplemental Nutrition Assistance Program (a marker of lower SES). Evidence from population-based research shows that low income is associated with increased ER use, even when controlling

for insurance status and demographic characteristics.<sup>29</sup> The reasons for this association are not known but may apply to people with MD as well as to the general population.

Girls and women had higher rates of overall ER use but did not have a higher rate of overall IP use. For ACSC, the rate of ER use was similarly elevated, but the rate of IP admission was significantly lower than for males. Females with MD were far more likely to have ER visits due to genitourinary conditions, whereas males were substantially more likely to be hospitalized for respiratory conditions. The increased rate of ER use for genitourinary conditions in females with MD likely reflects differences in anatomic susceptibility to genitourinary conditions that is not related to MD. On the other hand, the increased rate of hospitalization for respiratory conditions in males with MD may reflect the increased risk of pulmonary insufficiency for individuals with Duchenne or Becker MD as they age. When we restricted the models to individuals with MD who were also present in both the 15-19 year old and 20-24 year old time frames, the findings changed little, though a significant elevation in the rate of IP use for any ACSC increased. This likely represents the effects of ensuring that the individuals included in the age group comparison represented the same types of MD, resulting in a “cleaner” comparison with greater power to detect the difference. Again, we hypothesize that some of this difference may be explained by the effects of health care transition, but increasing severity of limitations due to MD is also an important factor.

This study has several limitations. First, we rely on administrative data for all the diagnoses studied, including MD. Since we do not have access to clinical data, it is possible that some of the diagnoses of MD or of reasons for ER or IP use are erroneous (e.g., misdiagnoses or errors in selection of billing codes). We attempted to minimize errors in the diagnosis of MD by restricting cases of MD to individuals who had 2 or more muscular dystrophy codes, but it is possible that some members of the MD group actually do not have MD, and some of the reasons for ER and IP use may have been mischaracterized. In general, such errors would be expected to be non-differential and therefore are likely to bias the results toward the null rather than toward finding erroneous associations. A more significant limitation due to our reliance on billing codes is our inability to distinguish specific types of MD through the use of ICD-9 codes, as 1 code can specify more than 1 type of MD. Ideally, the 3 codes would permit some degree of differentiation among the MD types; however, an exploratory analysis of the data revealed that most of the individuals diagnosed with MD were diagnosed using at least 2 different ICD-9 codes at various times during the study period (data available upon request). Confounding by type of MD should not be a significant problem for our analyses of age in the models limited to individuals present during both time periods. However, the findings of this study represent the “average” effect of age in people with MD, and study data cannot detect differences in use by age by type of MD.

Third, there are limitations related to the selection of an appropriate comparison group for individuals with MD. Since a comparison group drawn from Medicaid is likely to include a large proportion of individuals with disabilities (in the adult age groups), we selected a largely healthy comparison group from the SHP to avoid drawing erroneous conclusions by comparing individuals with MD to people with other (but unidentified) disabilities. However, this means the comparison and MD groups may not be comparable in terms of



socioeconomic and demographic factors. We attempted to account for differences in SES by controlling for SNAP enrollment.

Fourth, while we used commonly accepted definitions for ACSC, it must be acknowledged that some conditions which are ambulatory care sensitive in the general population may not be as amenable to outpatient treatment in people with MD, especially those with more severe disease. It is probably incorrect to assume that all ambulatory care sensitive ER and IP use in people with MD would be preventable via improved ambulatory care.

Finally, while we adjusted for confounding to the degree possible, we were unable to control for all potential confounders. For example, as described above, we used an indicator variable for whether an individual was ever enrolled in the Supplemental Nutrition Assistance Program as a proxy for socioeconomic status; while this variable was a significant predictor in many of our models, it is an imperfect indicator of SES. Race information was available only for individuals enrolled in Medicaid, as the State Health Plan does not collect information on race. For this reason we could not include race as a covariate in our initial models comparing IP and ER use of individuals with MD to the comparison group from the SHP. However we were able to obtain race information for all individuals with MD, as most were enrolled in Medicaid or had encounters of other types, such as hospital admissions, so we controlled for race in the models limited to people with MD.

All the analyses conducted in this study were pre-planned, so we did not adjust *P*-values for multiple comparisons. It might be argued that adjustment is needed for the secondary outcomes (in this case the specific types of IP/ER use). For Table 2, Bonferroni adjustment would reduce the *P*-value needed for statistical significance to 0.0083 or below. If we applied this criterion to the condition-specific associations between age group and IP/ER use, 9 of the 10 statistically significant associations would remain significant. For Table 3, the *P*-value required for significance would be 0.010 or below, and 8 of the 12 significant associations with age would remain significant. For Table 4, the required *P*-value would be 0.017, and all 4 significant associations with age would remain significant.

This study has several strengths. The greatest strength is the ability to use linked data across multiple sources to identify a large cohort of individuals with MD and describe their ER and IP use experiences over time. MD is a rare condition, so it is difficult to conduct sufficiently powered research related to it. Using South Carolina's advanced system of data linkage, we were able to identify 220 people with MD and include them in the study. We found a number of statistically significant associations, which is a testimony to the adequacy of the sample size for the study. The linked data system also permits controlling for a number of important variables, including SNAP enrollment as a proxy for SES and the rural/urban county of residence. We used "uniform billing" (UB: hospital and ER) data for all analyses. UB data are provided from all public, private, specialty, and general hospitals in South Carolina, so they provide a comprehensive picture of hospital use (not including Veterans Administration hospitals). We decided to use UB data because an individual's enrollment in Medicaid or the State Health Plan is not necessarily constant. Only relying on these data sources could result in important information being missed or in biased findings, since people may "save up" their health care use for time periods in which they have insurance

coverage. The strength of the uniform billing data is that they include all hospitalizations in the state regardless of insurance status or payer. A limitation is that they only include hospitalizations/ER visits within the state; if a resident of South Carolina received care outside the state (for example, in a border city such as Charlotte, NC) that information would not be available.

In summary, 15-24 year old individuals with MD living in South Carolina have increased rates of overall and ACSC-related ER and IP use compared to individuals of the same age without MD. Among those with MD, increased age (20-24 versus 15-19 years) is associated with increased IP and ER use, and race and gender also appear to be related to patterns of use. These results identify potential opportunities for intervention to improve the healthcare access of people with MDs by highlighting health conditions that could be managed better through outpatient care. Additional research is needed to investigate the role of transition from adolescent to adult health care, versus increasing severity of MD, as a potential cause of the increase in ER and IP use as people with MD move from adolescence to adulthood. Additional research is also needed to investigate the role of MD type and to clarify the impact of race and gender. Finally, we did not address health care expenditures in these analyses; further study of predictors of health care expenditures in adolescents and young adults with MD are likely to be beneficial from a health policy perspective.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Abbreviations

<b>ACSC</b>	<i>Ambulatory Care Sensitive Conditions</i>
<b>AHRQ</b>	<i>Agency for Healthcare Research and Quality</i>
<b>H&amp;D</b>	<i>Health and Demographics Section (within the South Carolina Revenue and Fiscal Affairs Office)</i>
<b>ER</b>	<i>Emergency Room</i>
<b>GEE</b>	<i>Generalized estimating equation</i>
<b>GU</b>	<i>Genitourinary</i>
<b>IP</b>	<i>Inpatient</i>
<b>IRR</b>	<i>Incidence rate ratios</i>
<b>MD</b>	<i>Muscular Dystrophy</i>
<b>RUCA</b>	<i>Rural Urban Commuting Area</i>
<b>SHP</b>	<i>State Health Plan</i>
<b>SNAP</b>	<i>Supplemental Nutrition Assistance Program</i>
<b>UB</b>	<i>Uniform Billing</i>

**Table 1**  
**Distribution of the number of adolescents and young adults from South Carolina**  
**according to condition and demographic and socioeconomic characteristics (2000 – 2010)**

	Muscular Dystrophy	Comparison Group <sup>1</sup>
<b>Total<sup>2</sup></b>	220	440
<b>Gender</b>		
Male	151 (68.6%)	302 (68.6%)
Female	69 (31.4%)	138 (31.1%)
<b>Age group<sup>3</sup></b>		
15 – 19 years	211 (56.7%)	421 (55.3%)
20 – 24 years	161 (43.3%)	340 (44.7%)
<b>Race</b>		
White	132 (60.0%)	
African American	48 (21.8%)	
Other/Missing	40 (18.2%)	440 (100.0%)
<b>County Description</b>		
Urban	176 (80.0%)	335 (73.1%)
Rural	44 (20.0%)	105 (23.9%)
<b>Food stamps</b>		
Yes	22 (10.0%)	15 (3.4%)
No	198 (90.0%)	425 (96.6%)
<b>Eligibility</b>		
Average Number (SD) of Years <sup>4</sup>	4.1 ± 2.8	4.1 ± 2.8

<sup>1</sup> Comparison group selected from State Health Plan records, which did not record race. Cases were matched on sex, age and years of insurance coverage using propensity scoring.

<sup>2</sup> Total = unduplicated number of persons with muscular dystrophy in Medicaid, State Health Plan, and hospital discharge uniform-billing data and met study definition criteria.

<sup>3</sup> Age groups sum to a number greater than overall total. Age category numbers are based on number of persons in each age group. Therefore, individuals could be in both age categories.

<sup>4</sup> During 2000-2010 study period.

**Inpatient and ER Hospital Discharge Encounter Counts, Adjusted Incidence Rate Ratios for Individuals with Muscular Dystrophy**

**Table 2**

	Age (20-24 vs 15-19)		Race Black/Other vs White		SES (SNAP Enrollment vs Not Enrolled)		Gender (Female vs Male)	
	IRR	P-value	IRR	P-value	IRR	P-value	IRR	P-value
<b>Total Visits</b>								
All Visits	1.66	<0.0001	1.34	0.0983	2.15	0.0001	1.55	0.0100
ER	1.76	<0.0001	1.34	0.1197	2.61	<0.0001	2.17	<0.0001
IP	1.76	0.0163	1.00	0.9929	1.090	0.7668	0.75	0.2594
<b>Ambulatory Care Sensitive Conditions</b>								
All ACSC	ER 1.77	0.0056	1.53	0.1016	3.63	0.0003	3.10	<0.0001
All ACSC	IP 1.33	0.3307	0.87	0.7309	0.95	0.9222	0.42	0.019
Bacterial Pneumonia	IP 1.17	0.6790	0.44	0.0538	0.54	0.5234	0.26	0.0036
<b>ICD-9-CM Book Chapters</b>								
All Digestive	ER 2.46	0.0037	1.78	0.2066	5.96	0.0002	1.93	0.1207
All Genitourinary	ER 1.17	0.6195	1.79	0.0903	0.58	0.3109	9.10	<0.0001
All Ill-Defined	ER 2.53	<0.0001	1.52	0.1121	1.63	0.1164	1.64	0.0607
All Musculoskeletal	ER 1.90	0.0391	0.78	0.5477	2.59	0.1082	4.01	0.0001
All Respiratory	ER 1.77	0.0069	1.27	0.3413	3.94	0.0015	1.42	0.1785
All Respiratory	IP 1.72	0.1010	0.38	0.0023	1.81	0.2419	0.21	0.0003

Note: Only results for outcomes with sufficient cell sizes are shown.

IP = Inpatient; ER = Emergency Room; IRR = Incidence Rate Ratio

Data for ER use for the ACSC of bacterial pneumonia, ER and IP use for the ACSC of epilepsy, IP use for the ACSC of severe ENT, ER and IP use for the ACSC of UTI, IP use for other ACSC, ER and IP use for all circulatory conditions, IP use for all digestive conditions, ER and IP use for all endocrine conditions, IP use for all genitourinary conditions, ER and IP use for all infections, ER and IP use for all mental health conditions, IP use for all musculoskeletal conditions, ER and IP use for all neoplasms, IP use for all skin conditions, and IP use for all ill-defined conditions are excluded from this table because of very small cell sizes.



**Table 3**  
**Incidence Rates and Adjusted Incidence Rate Ratios among Individuals with Muscular Dystrophy, with Data for Both Age Groups**

<i>Muscular Dystrophy Cases in Both Age Groups **2000-2010 Inpatient and ER Hospital Discharge Encounters** Counts, Rates per Person Years &amp; IRR</i>									
	Age		Race		SES		Gender		
	IRR	P-value	Black/Other vs White	P-value	(SNAP Enrollment vs Not Enrolled)	P-value	(Female vs Male)	IRR	
<b>Total Visits</b>									
All Visits	1.80	<0.0001	1.45	0.0581	1.95	0.0028	1.73	0.0044	
<b>ER</b>	1.74	<0.0001	1.52	0.0366	2.44	0.001	2.50	<0.0001	
<b>IP</b>	2.26	0.0005	1.05	0.8906	1.19	0.6271	0.75	0.3190	
<b>Ambulatory Care Sensitive Conditions</b>									
All ACSC	<b>ER</b>	2.09	0.0002	1.83	0.0312	4.11	0.0022	3.72	<0.0001
All ACSC	<b>IP</b>	2.06	0.0092	0.92	0.8545	1.16	0.8012	0.38	0.0271
<b>ICD-9-CM Book Chapters</b>									
All Digestive	<b>ER</b>	3.87	<0.0001	2.39	0.0968	7.25	0.0012	2.45	0.0731
All Genitourinary	<b>ER</b>	1.04	0.9094	2.01	0.0452	0.70	0.4497	11.37	<0.0001
All Ill-Defined	<b>ER</b>	2.48	<0.0001	1.76	0.0457	1.39	0.3787	1.82	0.0375
All Respiratory	<b>ER</b>	1.84	0.0048	1.45	0.1581	3.65	0.0229	1.66	0.0761
All Respiratory	<b>IP</b>	2.75	0.0069	0.37	0.0072	1.81	0.3496	0.23	0.0027

Note: Only results for outcomes with sufficient cell sizes are shown.

IP = Inpatient; ER = Emergency Room; IRR = Incidence Rate Ratio

**Table 4**  
**Incidence Rates and Adjusted Incidence Rate Ratios among Males with Muscular Dystrophy, with Data for Both Age Groups**

<i>Muscular Dystrophy in Both Age Groups; Males Only **2000-2010 Inpatient and ER Hospital Discharge Encounters** Counts, Rates per Person Years &amp; IRR</i>									
	Age		Race		SES				
	(20-24 vs 15-19)		Black/Other vs White		(SNAP Enrollment vs Not Enrolled)				
	IRR	IRR	P-value	IRR	P-value				
<b>Total Visits</b>									
All Visits	2.03	<0.0001	1.28	0.3684	2.09	0.0039			
ER	1.89	0.0001	1.19	0.4816	3.52	<0.0001			
IP	2.91	0.0001	0.99	0.9803	1.26	0.6216			
<b>Ambulatory Care Sensitive Conditions</b>									
All ACSC	IP	2.58	0.0005	0.86	0.7973	1.13	0.8051		
<b>ICD-9-CM Book Chapters</b>									
All Ill-Defined	ER	2.18	0.0034	1.44	0.4011	1.23	0.5937		
All Respiratory	ER	1.70	0.0681	0.93	0.911	0.96	0.9062		
All Respiratory	IP	3.21	0.0047	0.84	0.7958	0.39	0.0146		

Note: Only results for outcomes with sufficient cell sizes are shown.

IP = Inpatient; ER = Emergency Room; IRR = Incidence Rate Ratio