Published in final edited form as:

Med Care. 2014 October ; 52(10 0 3): S32–S39. doi:10.1097/MLR.0000000000000194.

Disparities in Health Care Utilization by Race Among Teenagers and Young Adults With Muscular Dystrophy

Orgul D. Ozturk, PhD[*], **Suzanne McDermott, PhD**[†], **Joshua R. Mann, MD, MPH**[‡], **James W. Hardin, PhD**[†], **Julie A. Royer, MSPH**[§], and **Lijing Ouyang, PhD**[‖]

[*]Department of Economics, Moore School of Business, University of South Carolina

[†]Department of Epidemiology and Biostatistics, Arnold School of Public Health, University of South Carolina

[‡]Department of Family and Preventive Medicine, University of South Carolina School of Medicine

[§]Division of Research and Statistics, South Carolina Budget and Control Board, Columbia, SC

[‖]Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Atlanta, GA

Abstract

Background—For people with muscular dystrophy (MD) health care access is crucial and utilization is expected to be high. A multidisciplinary approach is needed for optimal management of symptoms of this rare condition. Regular primary care, specialty care, therapy, and medicine use can improve quality of care and reduce need for emergency treatment and hospitalization. We analyzed health insurance and administrative data to test for racial disparities in regular care use among teenagers and young adults with MD.

Methods—We used South Carolina Medicaid and other administrative data for individuals aged 15–24 years to determine annual health care utilization patterns for individuals with MD by race. We studied adolescents and young adults with MD because this age group represents a time when the condition is typically intensifying and the transition from pediatric to adult care is expected. We used Generalized Estimating Equation models to analyze longitudinal utilization data conditional on other factors that may lead to utilization differences.

Results—Race is correlated with health care utilization among adolescents and young adults with MD. Blacks have lower overall utilization, and less primary care, therapy, and specialist care use but higher incidence of hospitalization and emergency treatment use compared with whites and also to other races. The most striking disparity was the use of outpatient services. Blacks utilized these services 50% less compared with whites and 70% less compared with others. Even in regression analysis, where we take into account individual unobserved factors and allow

---

Reprints: Orgul D. Ozturk, PhD, Department of Economics, Moore School of Business, University of South Carolina, 1705 College Street, Columbia, SC 29208. odozturk@moore.sc.edu.

The authors declare no conflict of interest.

Supplemental Digital Content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Website, www.lww-medicalcare.com.

clustering at the individual level, these differences remained and were in most cases statistically significant.

Conclusions—Our results indicate that there are differences in health care utilization by race even when individuals have access to the same health care benefits. This means simply offering coverage to individuals with MD may not be sufficient in eliminating health disparities. Future studies will be needed to examine other possible sources of these racial disparities, such as resource awareness, health knowledge, or access barriers such as transportation.

Keywords

rare conditions; disability; muscular dystrophy; health care use disparity; racial disparity

The lives of people with muscular dystrophy (MD) are seriously impacted by their ability to pay for services and supports and their access to the latest developments in care technology. Kenneson et al[1] in their studied showed that African Americans with MD live 10 to 12 years shorter than their white counterparts. During their study period (1986–2005), among other things, improvements in treatment of cardiomyopathy, such as ventilation and prescription corticosteroids, increased survival probability of White patients significantly, where rates for black patients barely changed. Most of these differences can be explained by differences in access to health care but inequities in health care delivery systems also play a significant role as Mejia and Nardin[2] point out. They noted, for example, that blacks are more likely to rely on Medicaid and although Medicaid compares favorably to private insurance in terms of primary care, it tends to fall short in providing access to standard-of-care treatments for conditions like MD. In our study, we document discrepancies in care by race even when health coverage is the same, that is, among Medicaid recipients.

Insurance status and access barriers are often studied as reasons for disparities in the general population and for groups of individuals with certain health issues. Many of the published studies use self-reported measures of access and unmet needs and may not necessarily be capturing actual use differences.[3–8] There are a number of studies that look at differences in hospitalization rates by demographic background, but these studies use aggregate data and cannot control for unobserved heterogeneity.[9–12]

We analyzed administrative data with a panel of individuals' detailed health care utilization information combined with receipt of food stamps [or recently known as Supplemental Nutritional Assistance Program (SNAP)], a measure of SES not usually available in (non–self-reported) health care utilization data. Moreover, we are looking at a panel of individuals with MD who have Medicaid coverage but possibly with variation in SES because of the Katie Beckett rule of Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 (Pub.L. 97–248). The Katie Beckett (under §134 of the TEFRA) rule enables children with severe disabilities to be covered irrespective of parents' income. States are allowed to make Medicaid benefits available to children (aged 18 years or under) at home who qualify as disabled individuals under §1614(a) of the Social Security Act as long as they would qualify for institutional care. Those with significant impairments are eligible to continue receiving Medicaid benefits if they meet severity and income criteria. Likewise, young adults with substantial disability qualify for Medicaid irrespective of their parent's income and assets, as long as their own income and assets are below poverty levels. South Carolina is one of the 12 states that extend Medicaid coverage to people with disabilities who work. Under Section 4733 of the Balanced Budget Act of 1997, South Carolina provides Medicaid to working people with disability whose earning below 250% of the federal poverty level. Thus, for children and some adults with MD we cannot assume Medicaid enrollment is synonymous with poverty. Eligibility for SNAP is therefore a potentially better indicator than Medicaid for poverty. Households must meet the national poverty level gross and net income tests unless a household member receives disability payments, in which case only the net income test ($1963 per month for a family of 4) applies (gross income minus allowable disability expenses). This creates a unique opportunity to study differences in health care utilization by racial groups that is not captured by access differences or general differences in health conditions related to SES.

BACKGROUND: MD AND MEDICAL CONDITIONS

MD are a group of rare disorders that result in progressive myopathies in which muscle biopsies demonstrate replacement of muscle fibers by adipose and connective tissue.[13] The etiology of MD is an abnormality in the genetic code for specific muscle proteins.[14] The key clinical feature of MD is muscular weakness; most MD cases have a limb-girdle pattern of weakness with proximal leg and arm muscles weaker than distal muscle groups.[13] The 2 most common types of MD from childhood to young adulthood are Becker and Duchenne MD (DMD). These 2 conditions are clinically similar and are both transmitted via X-linked inheritance (meaning they are more common in males) but differ in terms of onset and severity.[15] For individuals with DMD muscle weakness appears in childhood and progresses rapidly with loss of mobility in early adolescence and high risk of mortality from respiratory and cardiac failure; for individuals with Becker MD, muscle weakness progresses less rapidly and is generally less severe. The prevalence of DMD/Becker MD in male patients 5–24 years old is estimated to be 1.3–1.8 per 10,000.[16]

A multidisciplinary approach to management is needed for individuals with MD.[17] Important goals for management include maintenance and support of muscle strength and function; prevention and treatment of spinal deformity; treatment of respiratory complications; and prevention and treatment of cardiomyopathy.[18] Optimal outpatient and home-based management of these complications should result in improved quality of life and reduced need for emergency treatment and hospitalization.

METHODS

Data

Medicaid data and state level linked administrative data from the South Carolina Budget and Control Board, Division of Research and Statistics (DRS), the central repository for the state's health and human service data in South Carolina, were analyzed. Linked individual records using a unique number in lieu of personal identifiers were merged as described in detail in a methods paper.[19] For this study, we included MD patients who were enrolled continuously in Medicaid for each year and the same individuals were included in multiple years, if they were between 15 and 24 years of age. We identified individuals with MD based on the presence of the appropriate ICD-9 code (359.0 and 359.1) at any time during this 11 year study period. To be included in our sample an individual had to have the ICD-9 code during the 2000–2010 study period (have at least one other occurrence of the code at any time) and had at least 1 year of eligibility when he/she was 15–24 years old. Codes 359.0 and 359.1 include congenital hereditary MDs and hereditary progressive MDs (such as DMD and Becker MD), respectively. There was a different code (359.21) for myotonic dystrophy, which was often diagnosed in individuals who are older than our study population and was very rare in our cohort except in combination with 359.0 and/or 359.1. Therefore, we limited our analyses to the first 2 MD codes. As an indicator of poverty, food stamp receipt data from State Department of Social Services was utilized. This measure was calculated for each year a person was included in the cohort. Therefore, if an individual was on food stamps for a limited time, this would be captured in the data. We also used data from the State Department of Education to track entry into 12th grade, for all the cases, even those who were 15 years of age during the study period, using a prospective search and applying the entry status. The high school variable is defined by the eventual entry into the 12th grade during our data period. Data usage approvals for the project were obtained from participating providers from whom the data originated. All data linkages were performed at DRS and a deidentified dataset was used for the analyses.

Measures

Counts of Health Care Utilization—For each individual in our data we created counts of times they recorded certain health encounters. Inpatient Care, Primary Care, Emergency Room, Therapy, Specialist, Develop Rehabilitation/Intellectual Disability, and Home Health/CLTC (encounter code 13) were subcategories of interest in addition to total encounters, which corresponds to encounters with all observed codes. Identification of these encounter types in the data is described in the Appendix (Supplemental Digital Content 1, http://links.lww.com/MLR/A773). These counts are of all-cause utilizations and we cannot know if they were directly related to MD on all occasions.

Race—We had 2 binary race indicators: black, other races, with whites as the reference group.

Age Group—We had 2 age groups, teenagers and young adults. In our regressions we used young adult, which was a binary indicator equaled 1 if the individual is aged between 19 and 24 years.

High School Graduate—We tracked entry into 12th grade, for all the cases, even those who were 15 years of age during the study period, using a prospective search and applying the entry status. The high school variable was defined by the eventual entry into the 12th grade during our data period. Data was collected on the “last grade enrolled,” thus, we cannot be sure that they actually completed high school. Conditional on enrollment into 12th grade, graduation probability is high, although South Carolina has one of the highest high school dropout rates. In our regressions we used a binary indicator, no high school completion, which was equal 1 if the individual did not enter the 12th grade).

Food Stamps Receipt—We used a binary indicator to capture Food Stamps/SNAP receipt (Food Stamps Recipient). This measure was calculated for each year a person was included in the cohort. Therefore, if an individual was on food stamps for a limited time, this would be captured in the data.

Urban County—We used a binary indicator, *Lives in an Urban County*, which equaled 1 if county of residence is mostly urban.

ANALYSIS

Descriptive Statistics

We compared the differences in health care utilization among teenagers and young adults across 3 racial groups: blacks, whites, and others. For each subgroup, we reported annual averages of total number of encounters, ER visits, inpatient and primary care, specialist visits, therapy, surgeries, developmental rehabilitation, and home care use.

We used a 2-sided t test to assess the significance of the differences in means. We considered difference in means with P-value ≤ 0.05 as statistically significant.

Model

In our regression analysis we included race categories, Food Stamps receipt, and enrollment into 12th grade as independent indicator variables. We also suspected access and utilization vary by county type; thus, we included an indzicator for urban residence. We were also interested in the transition from pediatric to adult care; therefore, we included a young adult dummy as well as interaction of the race variables with this dummy.

Generalized estimating equation (GEE) models[20,21] were used to assess comparisons among the MD patients by encounter type while adjusting for repeated observations (annual averages of above-listed health care encounter types) from each of the same individuals during the study period. The GEE approach extends generalized linear models to account for within-group correlated data. A model with fixed individual effects would have been ideal in controlling for unobserved heterogeneity; however, most of our variables are time invariant and we are interested in predictors such as race, which makes fixed effects model unsuitable. To guard against misspecification of the particular within-person correlation structure, inference of GEE parameters was performed using test statistics based on the modified sandwich variance estimator. As with generalized linear models, GEE models allow us to analyze the relationship between dependent variables and one or more predictors. The population-averaged models are estimated using Stata version 13 with robust (modified sandwich—to account for within-person correlation) standard errors and the equicorrelation (exchangeable) working correlation structure.

Our utilization counts did have evidence of over-dispersion. Thus, we estimated population-averaged negative binomial GEE models using a dispersion parameter estimate obtained from a cross-section negative binomial model with clustered standard errors. We also considered zero-inflated models; zero-inflated model estimates were very similar to our population averaged negative binomial estimates when inference was based on modified sandwich variance estimates. However, there is no panel data version of these models. Moreover, some of the zero-inflated negative binomial models failed to converge, and among the models that successfully converged only a few had Vuong[22] tests statistics favoring the zero-inflated model over regular negative binomial. As estimates were very similar we opted for consistency and have presented the simpler population-averaged negative binomial models.

RESULTS

Table 1 presents the basic descriptive statistics including the health care utilization variables by age group and race. In our study sample the average age is around 19 years. Most of the individuals live in urban counties (81%), and about 35% of them are black, 51% are white, and 14% are other race/ethnicity.

In Table 1, we provide annual counts of select medical encounter types (emergency room, inpatient stay, primary care, specialist care, therapy, surgery, developmental rehabilitation, and home care) as well as an overall count of all encounters. An average person in our data will have 1 ER visit over 2 years and 1 inpatient stay every 4 years. Annually, they will average about 3 primary care doctor visits, 2 visits to a specialist, 1 surgery over 5 years, 2 therapies, 10 developmental rehabilitation, and 47 uses of home health services per year.

Among teenagers (top portion of the table), those who are black race compared with all others had significantly fewer total professional and facility encounters. They had less overall use, including significantly less specialist visits compared with everyone else and less therapy use, but only significantly so compared with those who identify as other. They also had significantly less developmental rehabilitation (DR) and used less of home care [community long-term care (CLTC)]. In contrast, blacks had more inpatient stays than everyone else and this difference is significant compared with the other race group.

Moving to young adult years we still see significantly less overall utilization and therapy use among blacks, but they use significantly more specialist care compared with their counterparts among whites but not other races. Moreover, blacks utilized emergency rooms more than whites. We also see that black and other races have significantly more surgery compared with whites. Black young adults also use significantly less DR compared with whites and less CLTC compared with both whites and others.

Table 2 shows differences in SES across races that may be able to explain the disparities in utilization. We see that majority of beneficiaries (about 73%) recorded entry to 12th grade and there are not significant differences across racial groups in this regard. Only about 5% received food stamps over the study period; significantly more black teenagers received food stamps compared with whites and others. We also see that other racial groups live in urban areas significantly more compared with blacks among teenagers and compared with both black and whites among young adults. We control for these factors in our analysis to be able to isolate racial differences from disparities due to SES differences.

Table 3 reports the incidence rate ratio estimates for 9 different outcome measures and the 95% confidence interval for these estimates. We note that once we control for individual unobserved heterogeneity, food stamps receipt, education, and age, differences by race disappear in some cases. Another way to interpret the results is by producing the predicted means from coefficient estimates for these models. In Table 4, we give these predicted values by race and age group for easy comparison. Blacks have overall about 56 less encounters than whites and 65 less than other races, with everything else held constant. People who report black race have on average about 1.5 times as many ER encounters as whites and other races. They are also twice as likely to be hospitalized as the other race groups. On average, they also have undergone surgeries than everyone else except young adults who are non-black and non-white. However, they use less therapy and primary care than all others. They also have significantly less DR and CLTC use compared with the other race groups.

Our estimates suggest that although overall young adults are expected to have about 20 more encounters per year compared with teenagers, there is a large utilization gap by race. Total number of encounters is expected to be higher in young adulthood for whites compared with their teenage years by about 46%, whereas for blacks the expected number only increases by 10%. For other R/E there is an increase of only 2% in use, but as they were very intensive users to begin with this still implies much higher utilization than blacks and similar amount of utilization as whites. Moreover, although they have overall less utilization, black young adults use ER services about 90% more than their teenage years and 70% more than white young adults and 30% more than young adults of all other races.

Discussion of Results

Our results indicate there are racial disparities in overall health care utilization among teenagers and young adults with MD who are on Medicaid. Although some of the differences in types of care utilized are explained by SES differences, after controlling for SES some differences persist and remain significant. We also show that the utilization differences become more significant as the patients leave pediatric care to adult care, comparing 15–19 year olds to 20–24 year olds. These figures may be capturing racial differences in ease of transition from pediatric care to adult care. Transition from teenage years to adulthood corresponds to the period of increased medical problems for MD patients, making it even more crucial to understand race disparities regarding transition from pediatric to adult care.[23,24] There are significant differences in inpatient care, ER visits, therapy services, DR, and home care use that may be interrelated. Differences in health care use may be resulting from disparities in resource awareness, health knowledge, cultural preferences, and access barriers such as transportation.[23–25] Some individuals with MD are probably inclined to get home and community-based services to keep them out of the hospital or a nursing home; these services include nurse visits, home health aides, respite care for the primary caregivers, respiratory therapy visits, and medical equipment. Some of these services, such as DR, require transport to and from a center and there could be a racial difference in access to transportation that accounts for lower utilization by people who are black compared with the other racial groups. For other services, such as CLTC, which are provided within the home, there could be differences in knowledge of availability of these resources or there might be different cultural values related to having strangers in one's home.

Limitations

The limitations of our study are related to the restrictions of insurance and administrative data. We cannot identify if individuals have another payer that supplements Medicaid and if individuals who were qualified for SNAP based on income actually enrolled in the program. To identify possible bias this may have on our estimates, we utilized the medical claims data from the privately insured State Health Plan, which is managed by SC Blue Cross/Blue Shield, for those who were also enrolled in this insurance plan and updated the number of encounters. Our robustness checks indicate most of these individuals (individuals with additional insurance) are from the higher SES groups identified in our data (white race, other race, completed high school, did not use food stamps), and inclusion of their additional encounters does not change our conclusions. In fact, it increases the magnitude and strengthens the significance in some cases. Thus, we believe our estimates may be understating the disparities that exist in health care utilization by SES.

We also cannot identify Hispanic ethnicity separately from race indicators. Although South Carolina does not have a large Hispanic population, given disparities recorded in the literature regarding this ethnic group,[26] this is a dimension of great interest left to be explored.

Finally, there are likely residual confounding factors because elements of individual demographics and services were not collected in these administrative data.[27] Our measures of SES—high school graduation and food stamps usage—may be correlated with other determinants of health care use, such as overall health condition. Moreover, food stamps take up is very low in our data indicating individuals who may be eligible not receiving food assistance—due to, for example, stigma or lack of resource awareness—underestimating the share of low SES individuals.

CONCLUSIONS

In this study, we find evidence of differences in care seeking behavior across race, education, and food stamp receipt groups, that are indicators of SES, that are not related to lack of coverage but potential indicators of other access barriers for teenagers and young people with MD. We only examined individuals on Medicaid and we controlled for socioeconomic status, which may affect access to care in ways that go beyond insurance coverage and type. However, we still found disparities by race. We looked at total encounters, ER use, inpatient care, primary care, specialists and therapy use, and home and rehabilitation services, and we show that the utilization differences become more significant as the patients leave pediatric care to adult care, comparing 15–19 year olds to 20–24 year olds.

Our results indicated that there are differences in health care utilization by race even when we control for SES measures and individuals have access to the same health care benefits. This indicated simply offering coverage to individuals with MD or other rare conditions may not be sufficient in eliminating health disparities. Differences in health care use may be resulting from disparities in resource awareness, health knowledge, cultural preferences, and access barriers, such as transportation. Understanding group differences in preference for type of health care and the way services are delivered will require qualitative studies. Our models are suggestive of the need for further study with richer data sources.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention, the South Carolina Budget and Control Board Division of Research and Statistics, the South Carolina Department of Health and Human Services, the South Carolina Public Employee Benefits Authority, the South Carolina Department of Education, or the South Carolina Department of Social Services.

Supported by a grant from CDC and results are presented in the Health Disparities at the Intersection of Race, Ethnicity, and Disability: A National Conference.

REFERENCES

1. Kenneson A, Vatave A, Finkel R. Widening gap in age at muscular dystrophy-associated death between Blacks and Whites, 1986–2005. Neurology. 2010; 75:982–989. [PubMed: 20837966]
2. Mejia NI, Nardin R. Dying young: eliminating racial disparities in neuromuscular disease outcomes. Neurology. 2010; 75:948–949. [PubMed: 20837962]
3. Zuvekas S, Weinick R. Changes in access to care, 1977–1996: the role of health insurance. Health Serv Res. 1999; 34(part II):271–279. [PubMed: 10199674]
4. Brown, RE.; Wyn, R.; Yu, H., et al. Children of Immigrants. Washington, DC: National Academy Press; 1999. Access to health insurance and health care for children in immigrant families; p. 126-186.
5. Newacheck PW, Hughes DC, Stoddard JJ. Children's access to primary care: differences by race, income, and insurance status. Pediatrics. 1996; 97:26–32. [PubMed: 8545220]
6. Gornick ME, Eggers PW, Reilly TW, et al. Effects of race and income on mortality and use of services among Medicare beneficiaries. N Engl J Med. 1996; 335:791–799. [PubMed: 8703185]
7. Hahn BA. Children's health: racial and ethnic differences in the use of prescription medications. Pediatrics. 1995; 95:727–732. [PubMed: 7724312]
8. Cornelius LJ. Barriers to medical care for white, black, and Hispanic American Children. J Nat Med Assoc. 1993; 85:281–288.
9. Billings J, Zeitel L, Lukomnik J, et al. Impact of socioeconomic status on hospital use in New York City. Health Aff. 1993; 12:162–173.
10. Bindman A, Grumbach K, Osmond D, et al. Preventable hospitalizations and access to health care. JAMA. 1995; 274:305–311. [PubMed: 7609259]
11. Billings J, Anderson G, Newman L. Recent findings on preventable hospitalizations. Health Aff. 1996; 15:239–249.
12. Pappas G, Hadden WC, Kozak LJ, et al. Potentially avoidable hospitalizations: inequalities in rates between US socioeconomic groups. Am J Public Health. 1997; 87:811–816. [PubMed: 9184511]
13. Amato AA. Other limb-girdle muscular dystrophies. Handbook Clin Neurol. 2011; 101:119–124.
14. Bushby K. Genetics and the muscular dystrophies. Dev Med Child Neurol. 2000; 42:780–784. [PubMed: 11104352]
15. Mercuri E, Muntoni F. Muscular dystrophies. Lancet. 2013; 381:845–860. [PubMed: 23465426]
16. Centers for Disease Control and Prevention. Prevalence of Duchenne/Becker muscular dystrophy among males aged 5–24 years—four states, 2007. Morb Mortal Wkly Rep. 2009; 58:1119–1122.
17. Bushby K, Finkel R, Birnkrant DJ, et al. DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 2: implementation of multidisciplinary care. Lancet Neurol. 2010; 9:177–189. [PubMed: 19945914]

18. Bushby K, Bourke J, Bullock R, et al. The multidisciplinary management of Duchenne muscular dystrophy. Curr Paediatr. 2005; 15:292–300.

19. Royer J, Hardin JW, McDermott S, et al. Use State Administrative Data Sources to study adolescents and young adults with rare conditions. J Gen Internal Med. 2014 [Epub ahead of print].

20. Liang K-Y, Zeger SL. Longitudinal Data Analysis Using Generalized Linear Models. Biometrika. 1986; 73(1):13–22.

21. Hardin, JW.; Hilbe, JM. Generalized Estimating Equations. 2nd ed.. Boca Raton: CRC Press; 2013.

22. Vuong QH. Likelihood ratio tests for model selection and non-nested hypotheses. Econometrica. 1989; 57:307–333.

23. Lannin DR, Mathews HF, Mitchell J, et al. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. JAMA. 1998; 279:1801–1807. [PubMed: 9628711]

24. Adams SHI, Newacheck PW, Park MJ, et al. Medical home for adolescents: low attainment rates for those with mental health problems and other vulnerable groups. Acad Pediatr. 2013; 13:113–121. [PubMed: 23375459]

25. Lotstein DS, Kuo AA, Strickland B, et al. The transition to adult health care for youth with special health care needs: do racial and ethnic disparities exist? Pediatrics. 2010; 126(suppl 3):S129–S136. [PubMed: 21123475]

26. Magaña S, Parish SL, Rose RA, et al. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. Intellect Dev Disabil. 2012; 50:287–299. [PubMed: 22861130]

27. Iezzoni LI. Using administrative data to study persons with disabilities. Milbank Q. 2002; 80:347–379. [PubMed: 12101876]

TABLE 1

Utilization Differences by Race for Teenagers and Young Adults With Muscular Dystrophy in South Carolina 2000–2010

	All		**Whites**		**Blacks**		**Other Race**		**Blacks vs. Other Race**		**Blacks vs. Whites**		**Whites vs. Other Race**	
Encounter Type	**Mean**	**SEM**	**Mean**	**SEM**	**Mean**	**SEM**	**Mean**	**SEM**	***P***	**|*t*|-stat**	***P***	**|*t*|-stat**	***P***	**|*t*|-stat**
Ages 15–18 (y)														
ALL	69.03	0.23	72.36	0.39	24.28	0.25	113.12	1.58	0.00	5.45	0.00	6.82	0.02	2.35
Emergency department	0.47	0.00	0.47	0.00	0.54	0.01	0.38	0.01	0.15	1.43	0.46	0.74	0.38	0.88
Inpatient	0.20	0.00	0.19	0.00	0.30	0.01	0.11	0.00	0.05	1.95	0.25	1.16	0.14	1.49
Primary care	3.39	0.01	3.57	0.02	3.02	0.03	3.34	0.05	0.59	0.55	0.28	1.09	0.70	0.39
Specialist	1.74	0.01	1.79	0.01	1.22	0.02	2.25	0.03	0.00	2.89	0.05	1.97	0.17	1.38
Therapy	2.65	0.03	2.01	0.05	0.72	0.04	6.61	0.25	0.02	2.31	0.17	1.38	0.08	1.75
Surgery	0.18	0.00	0.18	0.00	0.22	0.01	0.13	0.00	0.25	1.15	0.62	0.49	0.35	0.94
Developmental rehab	14.42	0.08	10.96	0.12	4.13	0.08	35.75	0.64	0.00	4.83	0.00	3.23	0.00	3.67
Home health/CLTC	32.92	0.17	40.39	0.33	1.90	0.14	49.78	1.00	0.00	4.65	0.00	6.84	0.42	0.81
N	503		276		123		104							
Ages 19–24 (y)														
ALL	84.49	0.27	99.52	0.41	34.05	0.57	85.03	3.68	0.03	2.15	0.00	6.70	0.55	0.60
ER	0.67	0.00	0.56	0.00	0.99	0.02	0.74	0.04	0.42	0.81	0.02	2.34	0.48	0.71
Inpatient	0.26	0.00	0.19	0.00	0.44	0.02	0.38	0.02	0.80	0.26	0.19	1.30	0.15	1.44
Primary care	2.28	0.01	2.26	0.01	2.34	0.03	2.26	0.06	0.87	0.16	0.85	0.19	0.99	0.01
Specialist	1.66	0.01	1.29	0.01	2.83	0.06	1.87	0.08	0.23	1.21	0.02	2.43	0.26	1.13
Therapy	0.79	0.01	1.02	0.02	0.04	0.00	0.69	0.06	0.09	1.70	0.02	2.26	0.57	0.56
Surgery	0.26	0.00	0.17	0.00	0.40	0.01	0.79	0.05	0.27	1.10	0.06	1.89	0.07	1.84
Developmental rehab	5.77	0.05	6.32	0.08	2.83	0.11	8.79	0.68	0.17	1.37	0.07	1.84	0.58	0.55
Home health/CLTC	61.32	0.24	76.54	0.37	12.56	0.50	55.44	2.96	0.03	2.23	0.00	7.37	0.29	1.07
N	508		361		108		39							

On this table, mean value for per person annual counts of each encounter type and standard errors for these means (SEM) are reported. *P*-values are given for the differences between mean utilization levels of each encounter type across racial groups as specified.

ALL indicates All Encounters; ER, Emergency Room Encounters; IP, Inpatient Care; PC, Primary Care; SP, Specialist Care; TH, Therapy; SUR, Surgery; DR, Developmental Rehabilitation; CLTC, community long-term care and Home Care.

TABLE 2

Socioeconomic Status and Urban Location Differences by Race* for Teenagers and Young Adults With Muscular Dystrophy in South Carolina 2000–2010

	All		Whites		Blacks		Other Race		Blacks vs. Other Race		Blacks vs. Whites		Whites vs. Other Race	
Variables	**Mean**	**SEM**	**Mean**	**SEM**	**Mean**	**SEM**	**Mean**	**SEM**	***P***	**|*t*|-stat**	***P***	**|*t*|-stat**	***P***	**|*t*|-stat**
Ages 15–18 (y)														
Received food stamps	0.10	0.00	0.06	0.00	0.20	0.00	0.09	0.00	0.02	2.40	0.00	3.56	0.36	0.92
High school graduate†	0.71	0.00	0.68	0.00	0.75	0.00	0.74	0.00	0.90	0.13	0.17	1.38	0.25	1.15
Urban	0.81	0.00	0.82	0.00	0.76	0.00	0.87	0.00	0.05	1.98	0.26	1.13	0.22	1.22
N	503		276		123		104							
Ages 19–24 (y)														
Received food stamps	0.01	0.00	0.01	0.00	0.01	0.00	0.03	0.00	0.55	0.60	0.93	0.09	0.51	0.66
High school graduate	0.76	0.00	0.78	0.00	0.70	0.00	0.74	0.01	0.63	0.48	0.10	1.63	0.59	0.54
Urban	0.81	0.00	0.79	0.00	0.81	0.00	0.92	0.01	0.04	2.04	0.76	0.30	0.01	2.71
N	508		361		108		39							

On this table, mean value for per person annual counts of each encounter type and standard errors for these means (SEM) are reported. *P*-values are given for the differences between mean utilization levels of each encounter type across racial groups as specified.

[*] According to 2000 census 68% of SC population identify their race as white and 29.9% as black. Remaining 2.1% consists of American Indian or Alaska Natives (0.7%), Asians (1.1%), Native Hawaiian or Other Pacific Islanders (0.1%), and some other races (1.3%). In 2010 Census, share of whites is 67.6% and blacks are 28.8%. Asians increase to 1.6% and American Indians and Alaska Natives to 0.9%. Native Hawaiian and Other Pacific Islander share did not change and remaining 2.8% consists of variety of other races with smaller shares.

[†] Data is collected on the “last grade enrolled.” Thus, we cannot be sure that they actually completed high school. Conditional on enrollment into 12th grade, graduation probability is high, although South Carolina has one of the highest high school dropout rates.

TABLE 3

Incidence Rate Ratios[†] From Generalized Estimation Equations Models Estimated Using Data From Teenagers and Young Adults With Muscular Dystrophy in South Carolina 2000–2010

	ALL	ER	IP	PC	SP	TH	SUR	DR	CLTC
Black race	0.371[***] (0.243–0.566)	0.998 (0.661–1.508)	1.623 (0.871–3.025)	0.838 (0.532–1.319)	0.697 (0.415–1.171)	0.647 (0.107–3.898)	1.299 (0.558–3.026)	0.441[*] (0.178–1.091)	0.0634[***] (0.00985–0.407)
Other race and ethnicity	1.377 (0.765–2.477)	0.779 (0.451–1.343)	0.602 (0.237–1.534)	0.872 (0.492–1.545)	1.352 (0.879–2.080)	3.623 (0.518–25.34)	0.723 (0.301–1.735)	3.463[***] (1.516–7.911)	1.143 (0.483–2.704)
Young adult	1.397[***] (1.090–1.791)	2.049[***] (1.333–3.150)	2.078 (0.852–5.072)	0.99 (0.694–1.414)	0.621 (0.318–1.215)	0.174[***] (0.0485–0.624)	1.233 (0.564–2.695)	0.344[**] (0.127–0.934)	0.427 (0.0934–1.955)
Black young adult	0.933 (0.632–1.378)	2.011[***] (1.381–2.930)	3.043[***] (1.648–5.618)	1.145 (0.803–1.633)	1.284 (0.866–1.906)	1.048 (0.202–5.449)	1.658[*] (0.917–2.997)	0.793 (0.325–1.937)	0.684 (0.356–1.314)
Other R/E young adult	0.749 (0.470–1.194)	0.665[**] (0.443–0.999)	0.744 (0.404–1.369)	0.771 (0.537–1.108)	0.609[***] (0.421–0.881)	2.796 (0.490–15.94)	0.716 (0.420–1.219)	0.561 (0.191–1.652)	0.88 (0.448–1.729)
Food stamps recipient[‡]	1.461[***] (1.147–1.861)	1.351[**] (1.045–1.746)	1.464 (0.820–2.614)	0.617[**] (0.414–0.918)	0.786 (0.545–1.134)	0.882 (0.186–4.192)	1.055 (0.607–1.835)	0.781 (0.390–1.565)	1.718[***] (1.232–2.397)
No high school completion[§]	0.823 (0.477–1.419)	1.628[*] (0.939–2.824)	1.236 (0.405–3.766)	1.146 (0.664–1.978)	2.581[***] (1.396–4.773)	0.222[*] (0.0394–1.255)	1.648 (0.546–4.976)	0.713 (0.0990–5.131)	3.206 (0.514–20.00)
Lives in an Urban County	0.728 (0.483–1.097)	1.681[*] (0.994–2.842)	3.094[**] (1.037–9.231)	0.902 (0.274–2.966)	0.906 (0.425–1.933)	0.605 (0.126–2.915)	5.967[**] (1.505–23.66)	0.555 (0.152–2.022)	0.661 (0.348–1.256)
# of observations	1011	1011	1011	1011	1011	1011	1011	1011	1011
# of individuals	208	208	208	208	208	208	208	208	208

[*] Significant at 10%.

[**] Significant at 5%.

[***] Significant at 1%. In parenthesis, 95% confidence intervals for the incidence rate ratio (IRRs) are reported.

[†] All models are estimated using population averaged GEE model with equal correlation and robust standard errors assuming a negative binomial distribution. Coefficient estimates (β_i) in a negative binomial regression are not directly interpretable; thus one needs to make the transformation e^{β_i} to get the incidence rate ratios (IRRs); the rate the outcome event happens as the control variable of interest changes by one unit, everything else constant. For example, looking at the first column (ALL) and comparing white teenagers to black teenagers incidence rate ratio is 0.371, which means black teenagers are 37% as likely to use care as white teenagers, that is, they are 63% less likely than their white counterparts. When comparing across multiple categories, say black young adults who received food stamps to white teenagers who did not receive food stamps incidence rate ratio (IRR) is 0.71 (0.371 × 1.397 × 0.933 × 1.461), that is the first group will be 29% less to use care compared with the latter group. GEE negative binomial population averaged model assumes as a default dispersion parameter is equal to 1. We estimated dispersion parameters for each model using cross section negative binomial estimation with clustered standard errors and used the estimated dispersion coefficient in XTGEE command to alter the default.

[‡] Food stamp receipt measure was calculated for each year a person was included in the cohort separately.

[§] No recorded entry into 12th grade.

ALL indicates All Encounters; ER, Emergency Room Encounters; IP, Inpatient Care; PC, Primary Care; SP, Specialist Care; TH, Therapy; SUR, Surgery; DR, Developmental Rehabilitation; CLTC, community long-term care and Home Care.

TABLE 4

Average Yearly Utilization Estimates by Race and SES Measures From GEE Models Using Data From Teenagers and Young Adults With Muscular Dystrophy in South Carolina 2000–2010

Group	ALL	ER	IP	PC	SP	TH	SUR	DR	CLTC
White race	84.61	0.53	0.20	2.73	1.61	1.32	0.18	8.28	57.89
Teenagers	67.23	0.48	0.18	3.50	1.83	1.39	0.18	9.13	39.33
Young adults	97.90	0.56	0.21	2.14	1.44	1.26	0.18	7.63	72.07
Black race	28.11	0.73	0.39	2.53	1.88	0.50	0.31	3.10	7.89
Teenagers	26.86	0.52	0.30	2.94	1.22	0.77	0.23	3.78	2.34
Young adults	29.54	0.98	0.48	2.07	2.64	0.18	0.40	2.33	14.20
Other R/E	93.06	0.46	0.19	2.61	2.13	4.54	0.29	25.71	47.09
Teenagers	92.58	0.36	0.10	2.98	2.32	5.12	0.12	30.40	45.03
Young adults	94.32	0.74	0.42	1.63	1.64	2.98	0.74	13.22	52.56

This table reports the number of events predicted by the GEE models for each listed subgroup of our sample. These predictions are generated using post-estimation command predict with option rate in Stata 13. Estimations used independent variables Black, Other R/E, Food Stamps Recipient, No High School Completion, Lives in Urban County, Young Adult and interactions of Young Adult Indicator with Black and Other R/E indicators as regressors.

ALL indicates All Encounters; ER, Emergency Room Encounters; IP, Inpatient Care; PC, Primary Care; SP, Specialist Care; TH, Therapy; SUR, Surgery; DR, Developmental Rehabilitation; CLTC, community long-term care and Home Care.