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30-day all-cause readmission rates among a cohort of individuals with rare conditions

Kevin J. Bennett[a,*], **Joshua R. Mann**[b], and **Lijing Ouyang**[c]

[a]University of South Carolina, Department of Family and Preventive Medicine, Columbia, SC, USA

[b]MPH University of Mississippi Medical Center School of Medicine and John D. Bower School of Population Health, Department of Preventive Medicine, Jackson, MS, USA

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

Abstract

Background: There is a need to examine health care utilization of individuals with the rare conditions muscular dystrophies, spina bifida, and fragile X syndrome. These individuals have a greater need for health care services, particularly inpatient admissions. Prior studies have not yet assessed 30-day all-cause readmission rates.

Objective: To estimate 30-day hospital readmission rates among individuals with three rare conditions. Hypothesis: Rare conditions patients will have a higher 30-day all-cause readmission rate than those without.

Methods: Data from three sources (2007–2014) were combined for this case-control analysis. A cohort of individuals with one of the three conditions was matched (by age in 5 year age groups, gender, and race) to a comparison group without a rare condition. Inpatient utilization and 30-day all-cause readmission rates were compared between the two groups. Logistic regression analyses compared the odds of a 30-day all-cause readmission across the two groups, controlling for key covariates.

Results: A larger proportion in the rare condition group had at least one inpatient visit (46.1%) vs. the comparison group (23.6%), and a higher 30-day all-cause readmission rate (Spina Bifida-46.7%, Muscular Dystrophy-39.7%, and Fragile X Syndrome-35.8%) than the comparison group (13.4%). Logistic regression results indicated that condition status contributed significantly to differences in readmission rates.

Conclusions: Higher rates of inpatient utilization and 30-day all-cause readmission among individuals with rare conditions vs. those without are not surprising, given the medical complexity of these individuals, and indicates an area where unfavorable outcomes may be improved with proper care coordination and post discharge care.

* Corresponding author. Department of Family and Preventive Medicine, USC School of Medicine, 3209 Colonial Drive, Columbia, SC, 29203, USA. kevin.bennett@uscmed.sc.edu (K.J. Bennett).

Conflicts of interest

The authors assert no conflicts of interest.

Keywords

Muscular dystrophy; Spina bifida; Fragile X syndrome; 30-day all-cause readmissions

Introduction

There is a growing awareness of the need to examine health care utilization and outcomes of individuals with rare conditions. In the United States, rare conditions are defined as physically or mentally disabling conditions that affect 200,000 or fewer persons. Examples of these conditions include muscular dystrophies, spina bifida, fragile X syndrome, Huntington disease, Guillain-Barre syndrome, Crohn's disease, and cystic fibrosis. Populations affected by a rare condition are typically understudied due to several factors, such as low prevalence, difficulty in identifying cases, and lack of data availability.[1]

Conducting research and implementing programs for those with rare conditions has been a focus of the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities' (NCBDDD) Child Development and Disability Branch. This work has led to a call for better data on rare conditions, and improvements in treatment and services for individuals with rare conditions in the public health context.[1,2]

Three conditions were examined in this analysis: muscular dystrophies (MD), spina bifida (SB), and fragile X syndrome (FXS). These three were chosen for several reasons. First, there is a paucity of information regarding these conditions, so further research on these conditions and the impact of service utilization on those patients is needed. Second, despite the variety of clinical characteristics, these three do represent commonalities as far as patient identification and analysis. Specifically, each is a lifelong condition that can cause significant (though variable) levels of disability, frequently with onset during childhood; each has a genetic or congenital etiology; each can produce a range of different symptom types and severity; and each is a rare condition that is not readily amenable to active surveillance but may have frequent contact with the health care system that makes passive surveillance using administrative data a reasonable approach. Third, both public and private entities, in particular the Centers for Disease Control & Prevention, have identified further research into these conditions as a priority in the field of disability research.[3–7]

Muscular dystrophies include more than 30 genetic conditions that lead to a degeneration of the skeletal-muscular system, resulting in increasing weakness and lack of control.[8] These conditions may present at an early age (e.g. Duchenne MD, the most common form of childhood onset MD), during adolescence (e.g. Facioscapulohumeral MD) or during adulthood (e.g. Myotonic MD)[8,9]. Spina bifida (SB) is a neural tube birth defect, with four variants (closed neural tube defects, Myelomeningocele, Meningocele, and Spina Bifida Occulta). The treatment and long term needs of those with SB vary by variant, and range from surgery, physical therapy, and need for assistive devices and/or durable medical equipment.[10] Fragile X syndrome is a genetic disorder that is characterized by developmental delays, and intellectual disabilities.[11]

Individuals with MD, SB, and FXS tend to have a greater need for health care services, higher levels of outpatient visits, physician services, inpatient stays, and pharmaceuticals filled than individuals without these conditions.[12–17] Higher utilization rates lead to greater health care expenditures and increased overall financial burdens due to the conditions.[16,18–21]

The higher inpatient utilization rate is worth noting, as one measure of adequate inpatient care and adequate follow-up care is the 30-day readmission rate (with some caveats).[22,23] This rate is often used to assess quality, particularly by the Centers for Medicare and Medicaid Services (CMS)[24] and the Readmissions Reduction Program (HRRP).[25]

Factors associated with higher 30-day readmission rates include co-morbidities, type of condition requiring admission, prior admissions or service utilization, personal demographics (age, race and gender), social determinants such as income, education, and resource availability, access to care (insurance coverage an usual source of care), and local supply of services.[26–34]

All of these factors may be related to seeking care post discharge, and ultimately have an impact upon subsequent 30-day readmission rates.

While prior studies have examined inpatient utilization of rare conditions, none has thus far assessed the 30-day all-cause readmission rate. Therefore, the purpose of this analysis is to compare the 30-day all-cause readmission rates between a cohort of individuals with three rare conditions and a matched cohort of individuals without a rare condition.

Methods

The analysis utilized a combined dataset from three sources from the years 2007–2014. The first dataset was the Clinical Data Warehouse (CDW) obtained from Health Sciences South Carolina (HSSC). The CDW is an aggregated dataset using de-identified electronic medical records from seven of the largest hospital systems in South Carolina. The data included clinical data related to inpatient, outpatient, and emergency department encounters from these systems.

The second dataset was obtained from the South Carolina Revenue and Fiscal Affairs (RFA) Office. This dataset included claims for individuals with the three conditions who were enrolled in either the State Health Plan (SHP) or Medicaid (fee for service or HMO). The SHP is an insurance option, administered by Blue Cross/Blue Shield of South Carolina that is offered to state and local government employees and their dependents. Data from these two sources were merged to alleviate privacy concerns. The third dataset utilized in this study was also obtained from the RFA; this dataset included all inpatient encounters, derived from the UB-04 and CMS-1500 billing system. This dataset includes diagnostic information (ICD9-CM), types of services received (ICD-9-CM procedures or HCPCS/CPT procedures), service dates (admission and/or discharge dates), patient disposition, and other visit information for all inpatient and emergency department visits in the state, regardless of payer. Individuals were matched across the sources, resulting in a single dataset with

multiple encounters per unique identifier. The method for combining these data are described elsewhere.[35]

Individuals were included if they had at least one encounter across all claim types with a diagnosis code for Spina Bifida (ICD9 741.xx), Muscular Dystrophy (ICD9 359.0, 359.1, and 359.21), and Fragile X (ICD9 759.83). From the three data sources, a study population of 5400 was obtained (SB n = 3,245, MD n = 1,837, FXS n = 318). In addition, a comparison cohort (n = 10,800) was also derived from two of the data sources e the State Health Plan/ Medicaid data, and the inpatient data. The HSSC data was not utilized as a source for the comparison group due to the ability to obtain adequate data from the other two sources. This cohort was matched (in a two to one ratio) with the study population based upon the following characteristics: age group (in 5-year increments), gender, and race/ ethnicity. The first 30 days of claims for the entire period were excluded to prevent a 30-day readmission to be inaccurately classified as an index admission. Further exclusions based upon missing data were then made, resulting in a final study population of 5389 and a matched cohort of 10,788.

Additional covariates included demographic variables: sex (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, and Hispanic/non-Hispanic Other/missing), payer (commercial, government, other, self-pay), admission and discharge information, and diagnoses associated with the visit. The SHP/ Medicaid dataset did not include race/ethnicity information; when possible, this was obtained from the other data sources, yet still resulted in a large number with missing information for this variable (classified as other/missing). Payer was classified as the payment source for the index inpatient admission, as insurance coverage was included for each claim. Reasons for this hospitalization were derived from the diagnostic related group code.

Initial analysis first compared the demographic characteristics of both cohorts. The distribution of inpatient visits (0, 1, 2, 3 or more) was also compared between the two groups for context. The sample was then subset to those with at least one inpatient visit (5419 total; 2486 in the rare condition group and 2933 in the matched group), and once again demographics and the distribution of inpatient visits (0, 1, 2, 3 or more) were compared between the two groups. Subsequent analyses estimated the proportion with a hospital readmission for all diagnoses that occurred within 30 days of discharge of a prior admission. This calculation excluded admissions that resulted in transfers to another facility or death in the hospital. This analysis was performed at the visit level; that is, all subsequent admissions were examined to identify potential 30-day all-cause readmissions. This rate was also compared between the study and comparison groups. All differences were tested using Wald Chi Square with an $\alpha = 0.05$.

Finally, two multivariable logistic regression models were utilized to determine factors most closely associated with a 30-day all-cause readmission, also at the visit level. The first model included only the indicators for disease (SB, MD, FXS, or Comparison group). The second model also included the indicators for disease, but added age group, gender, race/ethnicity, and payer of the initial admission (commercial/private, government funded, self-pay, or

other). The regression analysis was adjusted to account for the repeated nature of the data, as individuals could have more than one admission or readmission.

Results

As displayed in Table 1, the demographic characteristics of the rare condition group and the comparison group do not differ, indicating a successful match. Overall, both groups were predominately female and non-Hispanic White. Both groups were relatively evenly split between ages younger than 20 years and ages 20–44 years as well.

The rare condition group had a larger proportion (46.1%) of individuals with at least one inpatient visit during the entire study period than the comparison group (23.6%, $p < 0.0001$). A substantial proportion of the rare condition group had three or more visits during the entire study period (17.8%), compared to only 3.9% among the comparison group.

Among those with at least one inpatient admission, differences between the two groups emerge (see Table 2). The rare condition group was younger, with more than two-thirds (67.3%) younger than 45 years old, compared to 61.1% among the comparison group. The comparison group also had a larger proportion over the age of 65 (16.9%) than the rare condition group (10.0%, $p < 0.0001$). The rare condition group also had a lower proportion of other or missing race. The rare condition group had a larger proportion for whom a government payer was the payment source for their index admission than the comparison group (59.3% vs. 42.8%), yet had a lower proportion of self-pay visits (6.2% vs. 12.2%, $p < 0.0001$).

Both groups had a total of 5419 inpatient visits (2486 in the rare condition group, 2933 in the comparison group) (Table 3). Of these hospitalizations, the most common reasons for a visit among the rare conditions group included kidney and urinary tract infections, spinal procedures, cellulitis, pneumonia, and sepsis. Among the comparison group, the most common reasons included birth/delivery, gastroenteritis, joint replacement, and circulatory disorders (data not in table). Due to limited sample sizes, the reasons for a readmission were not able to be subset by specific condition.

Across the conditions, individuals with SB had the highest 30-day all-cause readmission rate (46.7%), followed by those with MD (39.7%) and those with FXS (35.8%, $P < 0.001$). The rare condition group had a significantly higher proportion of inpatient visits that were followed by a 30-day all-cause readmission (44.0%) than the comparison group (13.4%). Within the rare condition group, this proportion was significantly lower among those ages 20 years and under, non-Hispanic White, and self-pay individuals. The rate was higher within all of these categories than the comparison group. Descriptions of the diagnostic reasons for the readmissions were not able to be presented due to a lack of power and concerns for confidentiality.

Table 4 displays the results of the adjusted logistic regression models that estimated the odds of a 30-day all-cause readmission. The first model included only an indicator of which condition or cohort the individual was in; this model indicated a strong relationship among the three conditions for a readmission. Of the three conditions, FXS had the lowest odds

ratio (3.61, 95% CI 2.34–5.56) while SB had the highest (5.67, 95% CI 4.91–6.56). The second model included the demographics of the individual, which reduced the odds for each of the conditions only slightly. Within this model, non-Hispanic Blacks and those with government-funded insurance were associated with a higher odds of a 30-day all-cause readmission, while those aged 20–44 and Hispanics/other/missing race had a lower odds.

Discussion

This analysis examined the 30-day all-cause readmission rate among a sample of individuals with one of three rare conditions, spina bifida, muscular dystrophy, or fragile X syndrome. The finding of a higher readmission rate among individuals with a rare condition than among individuals without a rare condition is not surprising, given the medical complexity of those cases. It does, however, indicate a potential opportunity for improving outcomes with proper care coordination and post discharge care. Such programs to reduce readmission rates have proven successful in a variety of settings, populations, and resources.[36,37] These programs have not, however, been implemented or examined in populations of individuals with rare conditions. Inclusion of such individuals would be vital to understanding the effectiveness of these programs. As the Centers for Medicare and Medicaid Services (CMS) continue to incentivize hospitals for reducing 30-day readmission rates (and penalize hospitals with high readmission rates), identifying patient population groups with elevated rates and developing effective approaches to reduce readmissions will remain vitally important. Hospitalized patients with lifelong disabling conditions such as those included in this study, likely represent opportunities for improvement in readmission prevention.

It is also worth noting the differences in 30-day all-cause readmission rates by race/ethnicity among individuals with rare conditions. In the unadjusted results, there were no significant differences in the rates among those with a rare condition. In the adjusted model, however, non-Hispanic Blacks were found to have a higher odds of readmission, while Hispanic/other/missing individuals had a lower odds of readmission compared to nonHispanic Whites. The reasons for this adjusted difference may be due to a number of factors associated with 30-day all-cause readmission rates that are not included in these data (such as disease severity, personal income, and provider preferences). Previous research has demonstrated some evidence of increased readmission rates in non-Hispanic Blacks, but this finding has not been entirely consistent.[38–41] A recent analysis of multi-state data from 2009 (before CMS initiated its incentive/penalty program for 30-day readmissions) found an overall increase in readmission rate among non-Hispanic Blacks, but this was inconsistent across insurance types.[42] Further, there was a higher readmission risk for non-Hispanic Blacks among those with Medicare or private insurance, but reduced risk of readmission among non-Hispanic Blacks who were uninsured and similar risk among Medicaid enrollees.[42] While specific causes of racial differences in 30-day readmission rates are not known, they are part of an overall picture of racial disparities in health and health care in the United States.[43]

In this study, individuals with government funded insurance had a higher odds of readmission than commercially insured individuals. Again, the reasons for this are unclear, and may be related to factors such as access to care (such as travel distance or provider

supply) and individual resources to obtain care (such as financial resources, social support, or health literacy), all of which are unmeasured in these data. Future work within these populations could be strengthened by attempting to gather such data to better explain these findings.

While these findings are important, it would be appropriate to interpret the results with caution due to several limitations. This is a single-state study, and the results may not be generalizable nationally. In addition, there may be unknown or unmeasured factors across the conditions that bias the results, but which cannot be examined due to the low statistical power of the study. Further, the data do not include adequate information on the need for the readmissions themselves, beyond diagnosis codes. This lack of detailed information about factors such as condition severity, specific complications during hospitalization or after discharge, and quality of health care received probably has the greatest potential to impact our findings. For example, it may be that individuals with the conditions being studied have greater disease severity on admission, a higher risk of complications during hospitalization, and/or receive lower quality of care during the hospitalization or in the first weeks following discharge. Such differences, if present, could account for the findings of our study. Future work that includes a large sample of individuals and more detailed clinical information would be vital to better understand these issues. Finally, this analysis does not present a full examination of a population; rather, the data are drawn from those who utilized the health care system at some point during the study period. Data capturing eligibility or potential for use of the services (not captured in these data), and how these factors impact admissions and readmissions would add to the robustness of future work.

Additional avenues for future research include the investigation of readmission rates in other patient groups with complex, disabling conditions. Inclusion of a wider range of condition types and severity can help inform readmission prevention efforts. Investigation of additional predictors of readmission risk in such population groups, such as geographic location and access to care, may help further identify opportunities for intervention. Finally, evaluation of the effectiveness of targeted interventions to reduce readmissions in specific targeted groups will be important in guiding future health system efforts in this area.

Conclusions

In conclusion, this analysis provides valuable preliminary data regarding hospital readmission rates, and potential factors associated with them, among a population of individuals with rare conditions. Future work that builds upon and improves these findings would be important to the quality of care within these populations.

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Table 1

Rare condition and comparison group characteristics, 2009–2014.

	Rare Condition Group (n = 5400)	Comparison Group (n = 10,800)	
Gender			
Female	54.4%	54.3%	0.9605
Male	45.6%	45.7%	
Age Group			
<20 years	37.4%	36.8%	0.5833
20–44 years	35.1%	36.2%	
45–64 years	19.5%	19.1%	
65 + years	8.0%	7.8%	
Race/Ethnicity			
Non-Hispanic White	54.5%	54.5%	0.9849
Non-Hispanic Black	17.0%	17.0%	
Hispanic/Other/Missing	28.7%	28.5%	
Inpatient Visits			
0	53.9%	76.4%	<0.001
1	18.1%	15.3%	
2	10.2%	4.4%	
3+	17.8%	3.9%	

Table 2

Rare Condition and Comparison Group Characteristics among those with at least One Inpatient Admission, 2009–2014.

	Rare Condition Group (n = 2933)	Comparison Group (n = 2486)	
Gender			
Female	57.9%	61.0%	0.0296
Male	42.1%	39.0%	
Age Group			
<20 years	32.7%	24.4%	<.0001
20–44 years	34.6%	36.7%	
45–64 years	22.6%	21.9%	
65 + years	10.0%	16.9%	
Race/Ethnicity			
Non-Hispanic White	71.0%	67.1%	<.0001
Non-Hispanic Black	22.4%	20.3%	
Hispanic/Other/Missing	6.6%	12.6%	
Payer for Index Admission			
Commercial/Private	27.9%	35.2%	<.0001
Government	59.3%	42.8%	
Self	6.2%	12.2%	
Other/Unknown	6.6%	9.8%	

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Table 3

Proportion of Inpatient Visits for a Rare Disease (RD) Group and a Comparison Group that Resulted in a 30-day all-cause readmission, 2009–2014.

	Rare Condition Group (n = 2933)	Comparison Group (n = 2486)
Overall	44.0%	13.4%
Condition		
Spina Bifida (ref.)	46.7%	
Muscular Dystrophy	39.7%†	
Fragile X Syndrome	35.8%†	
Gender		
Female (ref.)	45.5%‡	12.8%
Male	41.8%‡	14.3%
Age Group		
<20 years (ref)	50.4%‡	7.2%
20–44 years	42.7%†‡	11.0%
45–64 years	38.4%†‡	17.3%
65 + years	39.8%†‡	24.0%
Race/Ethnicity		
Non-Hispanic White (ref.)	42.8%‡	20.7%
Non-Hispanic Black	46.8%‡	20.7%
Hispanic/Other/Missing	46.8%‡	2.1%
Payer for Index Admission		
Commercial/Private (ref.)	44.3%‡	11.4%
Government	44.3%‡	18.4%
Self	33.8%†‡	16.0%
Other/Unknown	48.7%‡	6.3%

†Significantly different from reference group, p <0.05.

‡Significantly different from comparison group, p< 0.05.

Table 4

Adjusted odds of a 30-day all-cause readmission, 2009–2014.

	Model 1	Model 2
Cohort		
Spina Bifida	**5.67 (4.91, 6.56)**	**5.12 (4.39, 5.97)**
Muscular Dystrophy	**4.25 (3.57, 5.07)**	**3.70 (3.08, 4.44)**
Fragile X Syndrome.	**3.61 (2.34, 5.56)**	**3.15 (2.02, 4.89)**
Comparison Group	Ref.	Ref.
Gender		
Female		1.06 (0.92, 1.21)
Male		Ref.
Age Group		
<20 years		Ref.
20–44 years		**0.82 (0.69, 0.96)**
45–64 years		0.90 (0.75, 1.09)
65 + years		1.20 (0.96, 1.50)
Race/Ethnicity		
Non-Hispanic White		Ref.
Non-Hispanic Black		**1.24 (1.06, 1.45)**
Hispanic/Other/Missing		**0.42 (0.32, 0.55)**
Payer for Index Admission		
Commercial/Private		Ref.
Government		**1.18 (1.01, 1.37)**
Self		0.97 (0.74, 1.26)
Other/Unknown		1.20 (0.90, 1.58)

Bold indicates significance, $p < 0.05$.