J Autism Dev Disord (2012) 42:95–104
DOI 10.1007/s10803-011-1217-x

ORIGINAL PAPER

Hospitalization Burden Among Individuals with Autism

Tasneem Lokhandwala · Rahul Khanna · Donna West-Strum

Published online: 15 March 2011

Abstract The objective of this study was to assess the inpatient care burden among individuals with autism using the 2007 Health Care Utilization Project Nationwide Inpatient Sample [HCUP-NIS]). There were ~26,000 hospitalizations among individuals with autism in 2007, with an overall rate of 65.6/100,000 admissions. Rates of hospitalizations were the highest among individuals with autism aged 10–20 years, males, having household income >$63,000, and with private insurance, respectively. In terms of hospital characteristics, rates were the highest in hospitals in large urban areas, located in the Northeast region, and with teaching status, respectively. Individuals with autism had significantly higher LOS (6.5 vs. 4.2; $p < 0.0001$) and total charges ($24,862 vs. $23,225; $p < 0.0001$) as compared to those without autism.

Keywords Autism · Hospitalization · Cost

Introduction

Autism spectrum disorders (ASDs) are a set of disabilities that are neurodevelopmental in nature and characterized by impairments in social interaction and verbal and non-verbal communication, and restricted and repetitive behaviors (American Psychiatric Association 2000). In their analysis of the 2007 National Survey of Children's Health, Kogan et al. (2009) estimated the prevalence of autism to be 110/10,000 among children 3–17 years of age in the US. Besides causing substantial functional and behavioral limitations among individuals with the disorder, autism places a considerable economic burden on families, payers, and society (Creon et al. 2006; Ganz 2006; Liptak et al. 2006; Mandell et al. 2006; Shimabukuro et al. 2008).

In the past few years, several studies have reported higher healthcare utilization and costs among individuals with autism as compared to individuals with typical development or with other developmental disorders (Creon et al. 2006; Liptak et al. 2006; Mandell et al. 2006; Shimabukuro et al. 2008; Wang and Leslie 2010). In their analysis of a private health insurance claims database, Shimabukuro et al. (2008) found medical expenditures for children with autism to be roughly four to six times higher as compared to children with typical development. In a similar study of a managed care population (Kaiser Permanente), Creon et al. (2006) found the average annual healthcare cost to be three times higher among children with autism as compared to children without autism after adjusting for age and gender ($2,757 vs. $892, $p < 0.0001$). Higher healthcare costs among children with autism is reflective of the greater use of inpatient care, office services, and prescription medications in this population as compared to children with typical development or with other developmental disorders (Liptak et al. 2006; Mandell et al. 2006; Shimabukuro et al. 2008). When analyzing a nationally representative database, Liptak et al. (2006) found the average healthcare expenditure to be $6,132 among children with autism. In a more recent study of costs among children with autism enrolled in Medicaid, Wang and Leslie (2010) found the average total healthcare expenditure to be $22,772 (2003 dollars). Further, the authors noted an 8.3% increase in median total healthcare expenditure among children with autism over a four-year period from 2000 to 2003. The total societal cost of caring for an individual with autism is estimated to be $3.2

T. Lokhandwala · R. Khanna (✉) · D. West-Strum
Department of Pharmacy Administration, University of Mississippi, University, MS 38677, USA
e-mail: rkhanna@olemiss.edu

million, and the total economic burden of autism, inclusive of direct medical and non-medical and indirect costs, is estimated to be $35 billion (2005 estimate) in the US (Ganz 2006).

Though several studies have reported the healthcare utilization and costs associated with autism, there is limited information currently available about the inpatient care episodes among individuals with the disorder. Information concerning length of stay (LOS), average hospitalization charge, and mortality rate associated with inpatient episodes in individuals with autism is currently not known. Further, studies of healthcare utilization and costs in the autism literature have primarily focused on children, and have excluded adults with the disorder in their analyses. Among individuals with autism, the cost of care incurred during adulthood represents the largest fraction of the lifetime direct cost of care (Ganz 2007). Studies have shown that with age the healthcare utilization among individuals with autism shifts from the use of outpatient services towards the use of prescription medications and inpatient care (Shimabukuro et al. 2008). Therefore, when studying autism-related healthcare burden, it is essential to include all individuals with the disorder irrespective of age.

The purpose of this study was to determine the hospitalization burden among individuals with autism using nationally representative hospitalization data from the Health Care Utilization Project Nationwide Inpatient Sample (HCUP-NIS) database. The current study describes the patient-, hospital-, and discharge-level characteristics associated with hospitalizations among individuals with autism and compares them to those of a control group of hospitalizations without autism. For hospitalizations among individuals with autism, common comorbid diagnoses and procedures recorded during the inpatient episode were reported. Finally, the factors that predict hospitalization outcomes among inpatient episodes of individuals with autism were studied.

Methods

Data Source

For the purpose of the study, the 2007 HCUP-NIS data were analyzed. Sponsored by the Agency for Healthcare Research and Quality (AHRQ), the HCUP-NIS is the largest all-payer national survey of inpatient care in the US. The HCUP-NIS contains discharge data from more than 1,000 hospitals, representing a 20% stratified sample (multistage cluster sample) of community hospitals. The NIS is discharge-level data, with each line representing a single hospitalization. As a result, individuals may be represented more than once in the data; however, given the nature of the data available to researchers (de-identified), it is not possible to identify duplicate cases. The 2007 HCUP-NIS database contained roughly 8.1 million discharge records from 1,044 hospitals. The database includes information on several patient- and hospital-level characteristics. According to federal regulations (CFR Title 45 Section 46.101 subparagraph(b)(4)), Institutional Review Board approval is not required for research involving the use of HCUP-NIS database, since it is a publicly available dataset and does not contain unique patient identifiers.

Study Design and Sample

A cross-sectional descriptive analysis of the 2007 HCUP-NIS was undertaken in this study. Discharges with length of stay (LOS) greater than 365 days or total charges greater than $1 million were excluded from study analysis. From the remaining set of discharge data, those with a primary or secondary diagnosis of autism (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] code 299.xx) were extracted, and served as autism case records. A total of 5,214 discharges (un-weighted) with a diagnosis of autism were identified. To determine the additional inpatient burden of autism, a control group of discharges without a diagnosis (primary or secondary) of autism were identified. Discharges in the control group were matched to those of individuals with autism based on age and gender using a greedy match algorithm with a 1:4 case–control ratio. Discharge records of individuals with autism without a corresponding control group match were excluded from the study analysis. Because of missing gender information for 28 discharge records of individuals with autism, the matching algorithm was unable to extract the corresponding set of control discharges. These 28 discharges were therefore removed from further analyses. The remaining 5,186 (un-weighted) discharge records of individuals with autism served the sample of interest, for which a matched group of 20,744 (un-weighted) control discharges was identified.

Study Variables

Patient-level variables. Age, gender, income, and type of insurance were studied for both autism and control group. With respect to age, the discharge records were grouped into three categories: <10 years, 10–20 years, and ≥21 years. Gender was classified into male and female. Household income was grouped into four categories: $0–$38,999, $39,000–$47,999, $48,000–$62,999, and >$63,000. For the purpose of the study, we grouped insurance coverage into the following categories: public, private (including health maintenance organizations), self-pay, and others.

Hospital-level variables. Hospital characteristics that were included in the study were hospital size, location, region, and teaching status. With respect to size, hospitals were categorized into small, medium and large based on the number of beds in the hospital. Hospital location was classified into urban and rural. Hospitals were classified into four regional categories: Northeast, Midwest, South and West. A hospital teaching status was coded as either non-teaching or teaching.

Discharge-level variables. Discharge-level variables such as source of admission, discharge disposition, LOS, total hospital charges, and the number of diagnoses recorded were studied. Costs are reported in terms of total hospital charges and not actual amount paid (data unavailable). Admission source was grouped into emergency department, another hospital, another health facility, court/law enforcement, and routine. The discharge status was classified into routine, transfer to a short term facility, transfer to another facility, home health care, discharged against medical advice, died, and unknown.

Statistical Analysis

Given the complex sampling design of HCUP-NIS, study analysis was performed using PROC SURVEY procedures in Statistical Analysis System (SAS) version 9.2. Descriptive statistics were reported for study variables. Mean and standard deviations were calculated for continuous variables, and frequencies and percentages for categorical variables. Hospitalization rates for individuals with autism were calculated overall and by different patient- and hospital-level characteristics. For each category, the numerator used in the calculation of rates was the weighted number of hospitalizations of individuals with autism. The denominator was the total weighted number of hospitalizations associated with the category. For example, to calculate hospitalization rates by different age groups (<10 years, 10–20 years and ≥21 years), we divided the weighted number of hospitalizations of individuals with autism in each of these categories with the total number of hospitalizations within those categories. Common comorbid diagnoses recorded and procedures performed during the inpatient episodes of individuals with autism have been reported. PROC SURVEYFREQ was used to compute weighted frequencies and percentages for categorical variables, and also to determine differences in percentages across categorical variables among autism and control group. PROC SURVEYMEANS with the *t* test option specified was used to determine the difference in average LOS, total charges, and number of diagnoses recorded, respectively, between the two groups. Among hospitalizations of individuals with a diagnosis of autism, factors predicting LOS and total charges were determined using PROC SURVEYREG procedure. Factors predicting mortality among individuals with autism were identified using PROC SURVEYLOGISTIC. All results reported in the study are weighted, unless otherwise noted.

Results

Table 1 compares the patient-, hospital-, and discharge-level characteristics among individuals with and without a diagnosis of autism. Further, rates of hospitalization among individuals with autism are also reported. In terms of age and gender distribution of individuals with autism, roughly 42% were aged 10–20 years and 79% were males, respectively. Since hospitalizations of individual with and without a diagnosis of autism were matched on age and gender, there were no significant differences between the two groups in terms of these characteristics. A significantly greater proportion of hospitalizations of individuals with autism were of those with a household income of >$63,000 (27.7% vs. 20.9%; $p < 0.0001$) and were covered under public insurance (54.0% vs. 38.9%; $p < 0.0001$) than those in the control group. Significant differences were also observed among the two groups in terms of hospital-level characteristics. Hospitalizations among individuals with autism were significantly more likely to have occurred in urban hospitals (92.8% vs. 89.0%; $p < 0.0001$) and in the Northeast region (27.9% vs. 19.7%; $p < 0.0001$) as compared to those in the control group. Hospitalizations among individuals with autism were less likely to be through a routine source of admission as compared to the control group (39.2% vs. 42.2%; $p = 0.0003$). Hospital size ($p = 0.562$) and teaching status ($p = 0.22$) were not significantly different among the two groups.

In 2007, the total length of stay for hospitalizations among individuals with autism was 168,473 days, and the total charges incurred were $638 million. The incremental inpatient burden associated with a diagnosis of autism was reflected in the significant difference in the LOS, total charges, and discharge disposition observed between the autism and matched control group, and is described in Table 1. The LOS was 1.5 times higher for hospitalizations of individuals with autism as compared to the control group (6.5 [±0.37] vs. 4.2 [±0.11]; $p < 0.0001$). In comparison to the control group, the average total hospital charges were higher for hospitalizations of individuals with autism ($23,225 [±$768] vs. $24,862 [±1,106]; $p < 0.0001$). The number of diagnoses recorded was also higher for the hospital stays among individuals with autism as compared to the control group (5.9 [±0.09] vs. 4.37 [±0.06]; $p < 0.0001$). With respect to discharge disposition, a greater proportion of hospitalizations among individuals with autism led to transfer to another health facility

Table 1 Study sample characteristics

Characteristic	Individuals with a diagnosis of autism	Individuals without a diagnosis of autism	*p* value	Rates (/100,000 admissions)[a]
Socio-demographic characteristics				
Age in years, *n* (%)				
< 10	6,859 (26.46)	26,885 (26.42)		114.54
10–20	10,849 (41.86)	42,675 (41.95)		619.59
≥ 21	8,212 (31.68)	32,180 (31.63)		25.82
Gender, *n* (%)				
Male	20,436 (78.85)	80,359 (78.98)		125.91
Female	5,483 (21.15)	21,383 (21.02)		23.63
Median household income, *n* (%)			<.0001*	
$0–$38,999	5,820 (23.58)	32,171 (32.71)		50.59
$39,000–$47,999	5,737 (23.24)	24,238 (24.64)		58.94
$48,000–$62,999	6,294 (25.50)	21,428 (21.79)		70.89
> $63,000	6,833 (27.68)	20,513 (20.86)		81.71
Primary payer, *n* (%)			<.0001*	
Public	13,967 (54.04)	39,420 (38.86)		63.36
Private insurance	10,433 (40.37)	46,666 (46.00)		76.04
Self pay	446 (1.73)	8,897 (8.77)		21.20
Other	999 (3.86)	6,470 (6.38)		62.83
Hospital characteristics				
Hospital size, *n* (%)			0.5622	
Small	3,208 (12.38)	13,488 (13.27)		66.03
Medium	4,933 (19.03)	20,613 (20.28)		51.78
Large	17,774 (68.59)	67,555 (66.45)		70.80
Location of hospital, *n* (%)			<.0001*	
Rural	1,878 (7.25)	11,149 (10.97)		37.18
Urban	24,037 (92.75)	90,507 (89.03)		65.80
Region of hospital, *n* (%)			<.0001*	
Northeast	7,231 (27.90)	20,084 (19.74)		93.26
Midwest	7,273 (28.06)	23,311 (22.91)		79.66
South	7,882 (30.41)	42,902 (42.17)		51.61
West	3,534 (13.64)	15,444 (15.18)		47.85
Teaching status of hospital, *n* (%)			0.22	
Nonteaching	9,544 (36.83)	40,249 (39.59)		46.04
Teaching	16,372 (63.17)	61,407 (60.41)		87.27
Discharge characteristics				
Admission source, *n* (%)			0.0003*	
Emergency department	11,809 (51.88)	46,113 (51.55)		
Another hospital	1,385 (6.08)	4,063 (4.54)		
Other health facility (including long-term care)	444 (1.95)	981 (1.10)		
Court/Law enforcement	211 (0.93)	535 (0.60)		
Routine	8,914 (39.16)	37,760 (42.21)		
Discharge disposition, *n* (%)			<.0001*	
Routine	21,412 (82.63)	90,303 (88.78)		
Transfer to short-term hospital	516 (1.99)	1,709 (1.68)		
Transfer to other facility	2,486 (9.59)	3,767 (3.70)		
Home health care	1,183 (4.57)	4,164 (4.09)		
Against medical advice	101 (0.39)	1,193 (1.17)		

Table 1 continued

Characteristic	Individuals with a diagnosis of autism	Individuals without a diagnosis of autism	*p* value	Rates (/100,000 admissions)[a]
Died	209 (0.81)	560 (0.55)		
Discharged alive to unknown destination	4 (0.02)	18 (0.02)		
Length of stay (LOS), *mean* (SE)	6.50 (0.37)	4.24 (0.11)	<.0001*	
Total charges, *mean* (SE)	$24,862 (1,1105.54)	$23,225 (768.06)	<.0001*	
Number of diagnoses on this record, *mean* (SE)	5.90 (0.09)	4.37 (0.06)	<.0001*	
Total hospitalizations	25,919[b]	101,741[b]		65.55

* $p < 0.01$

[a] Rates were calculated based on the number of hospitalizations (weighted) of individuals with autism in each of the categories divided by the total number of hospitalizations (weighted) within those categories

[b] The total number of hospitalizations across categories of each variable might not add up to the final total due to missing data

as compared to those without autism (9.6% vs. 3.7%; $p < 0.0001$).

The overall rate of hospitalization of individuals with autism was 65.55/100,000 admissions. Hospitalization rate among individuals with autism differed by patient- and hospital-level characteristics. By age group, the highest rate of hospitalization occurred among individuals aged 10–20 years (619.59/100,000 admissions). In terms of gender distribution, males had higher rates than females (125.91/100,000 vs. 23.63/100,000). Hospitalization rates among individuals with autism increased with increasing household income, with highest rate seen among those with income greater than $63,000 (81.71/100,000). As per insurance status, rates of hospitalization were higher among those with private insurance (76.04/100,000) as compared to those with public insurance (63.36/100,000). By hospital size, rate of hospitalization was higher in large hospitals (70.80/100,000). Urban hospitals had higher rates than rural hospitals (65.8/100,000 vs. 37.18/100,000). Hospitalization rates were almost twice as high in the Northeast region as compared to the West (93.26/100,000 vs. 47.85/100,000). Teaching hospitals had a higher rate of hospitalization than non-teaching hospitals (87.27/100,000 vs. 46.04/100,000).

Individuals with autism had several different comorbid conditions. Almost one-fifth of the hospitalization records of individuals with autism also reported a diagnosis of epilepsy. Psychiatric and behavioral disorders including mood disorders (17.74%), hyperkinetic syndrome (16.56%), disturbance of conduct (11.13%), and anxiety (10.26%) were also reported. Non-operative procedures including cardiopulmonary resuscitation, infusions, and blood transfusions were the most commonly reported hospitalization procedures (7.15%). A total of 209 deaths (0.8%; weighted) occurred during hospitalization for individuals with autism. Among those who died during hospitalization, more than half (56.01%) had a comorbid diagnosis of lung disease. Further, almost half (48.78%) of the individuals with autism who died had cardiac dysrhytmias and 39.02% had a diagnosis of fluid electrolyte and acid base balance disorder. The most common procedure reported among individuals with autism who died was non-operative intubation and irrigation (73.17%), followed by incision, excision, and occlusion of vessels (48.78%). The authors can provide additional tables for these analyses on request.

Table 2 presents the results of multiple linear regression analysis conducted to identify the factors predicting LOS associated with hospitalizations among individuals with autism. Individuals with autism aged <10 years ($\beta = -1.46$; 95% Confidence Interval [CI] [−2.27, −0.66]; $p = 0.0004$) had significantly shorter LOS than adults (≥21 years) with the disorder. The LOS was longer for hospitals located in the Northeast region ($\beta = 2.08$; 95% CI [0.81, 3.35]; $p = 0.0014$) as compared to hospitals in the South. The LOS was longer for hospitalizations that took place in large size hospitals ($\beta = 1.16$; 95% CI [0.35, 1.98]; $p = 0.0051$) than hospitals which were small in size. Hospitalizations of individuals with autism who were admitted through an emergency department ($\beta = -0.84$; 95% CI [−1.54, −0.13]; $p = 0.02$) had shorter LOS, while those admitted from another hospital or health facility ($\beta = 2.15$; 95% CI [0.62, 3.68]; $p = 0.0058$) had longer LOS as compared to those with routine admission. Among hospitalizations of individuals with autism, the LOS was longer for those who were discharged to other health facilities ($\beta = 2.52$; 95% CI [1.45, 3.4]; $p < 0.0001$) as compared to those who had a routine discharge. An increase in the number of recorded diagnoses during hospitalization was also associated with longer LOS ($\beta = 0.58$; 95% CI [0.46, 0.7]; $p < 0.0001$).

Table 3 summarizes the results of multiple linear regression analysis aimed at identifying the predictors of total charges for hospitalizations among individuals with

Table 2 Predictors of length of stay for hospitalizations associated with an autism diagnosis

Variable	β	95% CI	p
Age in years			
< 10	−1.46	[− 2.27, −0.66]	0.0004*
10–20	0.45	[− 0.35, 1.26]	0.2703
≥ 21	Ref		
Gender			
Female	−0.67	[− 1.37, 2.25]	0.0589
Male	Ref		
Median household income			
$0–$38,999	0.57	[− 0.42, 1.55]	0.2601
$39,000–$47,999	−0.12	[− 0.95, 0.70]	0.7678
$48,000–$62,999	−0.56	[− 1.27, 0.15]	0.1238
> $63,000	Ref		
Region of hospital			
Northeast	2.08	[0.81, 3.35]	0.0014**
Midwest	0.13	[− 0.84, 1.10]	0.7892
West	−0.06	[− 1.00, 0.87]	0.8936
South	Ref		
Primary payer			
Public	1.14	[− 0.13, 2.4]	0.0792
Private insurance	0.62	[− 0.65, 1.89]	0.3355
Other	0.98	[− 0.61, 2.57]	0.2256
Self pay	Ref		
Hospital size			
Large	1.16	[0.35, 1.98]	0.0051**
Medium	0.86	[− 0.08, 1.80]	0.0739
Small	Ref		
Location of hospital			
Rural	−1.35	[− 3.12, 0.42]	0.1345
Urban	Ref		
Teaching status of hospital			
Nonteaching	−0.06	[− 0.93, 0.81]	0.8951
Teaching	Ref		
Admission source[a]			
Emergency department	−0.84	[− 1.54, −0.13]	0.0206*
Other	2.15	[0.62, 3.68]	0.0058**
Routine	Ref		
Discharge disposition[b]			
Died	−0.99	[− 3.77, 1.78]	0.4811
Other	2.52	[1.45, 3.40]	<.0001**
Routine	Ref		
Number of diagnoses on this record	0.58	[0.46, 0.70]	<.0001**

$R^2 = 0.1061$; Adjusted $R^2 = 0.1061$

* $p < 0.05$; ** $p < 0.01$

[a] Admission source was collapsed into three categories: emergency department, other and routine

[b] Discharge disposition was collapsed into three categories: died, other and routine

autism. Average total charges were higher for hospitalizations of individuals with autism aged <10 years (β = $6,336; 95% CI [$2,746, $9,924]; $p = 0.0006$) and individuals 10–20 years of age (β = $5,008; 95% CI [$1,736. $8,280; $p = 0.0027$), respectively, as compared to those aged 21 year or more. Differences in charges were also observed by payer status, with hospitalizations paid for by private insurance having higher charges (β = $5,487; 95% CI [$979, $9,996]; $p = 0.0171$), when compared to self-pay. Hospitalizations of individuals with autism with household income $48,000–$62,999 had lower charges (β = −$4,050; 95% CI [−$6,967, −$1,134]; $p = 0.0065$) in comparison to those with income $63,000 or more. Charges for hospitals in the Northeast (β = $5,253; 95% CI

Table 3 Predictors of total charges for hospitalizations associated with an autism diagnosis

Variable	β	95% CI	p
Age in years			
< 10	6,335.89	[2,746.82, 9,924.96]	0.0006**
10–20	5,008.27	[1,736.64, 8,279.91]	0.0027**
≥ 21	Ref		
Gender			
Female	1,030.89	[− 1,714.72, 3,776.50]	0.4614
Male	Ref		
Median household income			
$0–$38,999	−213.28	[− 4,132.13, 3,705.56]	0.9150
$39,000–$47,999	−1,892.96	[− 4,789.50, 1,003.59]	0.2000
$48,000–$62,999	−4,050.21	[− 6,966.78, −1,133.64]	0.0065**
> $63,000	Ref		
Region of hospital			
Northeast	5,253.07	[130.98, 10,375.16]	0.0444*
Midwest	−1,107.06	[− 4,933.27, 2,719.14]	0.5703
West	15,462.63	[8,838.34, 22,086.92]	<.0001**
South	Ref		
Primary payer			
Public	3,943.63	[− 612.58, 8,499.84]	0.0897
Private insurance	5,487.24	[978.75, 9,995.73]	0.0171*
Other	1,660.82	[− 3,544.29, 6,865.92]	0.5314
Self pay	Ref		
Hospital size			
Large	439.57	[− 4,721.85, 5,600.99]	0.8673
Medium	−1,019.66	[− 6,620.01, 4,580.68]	0.7209
Small	Ref		
Location of hospital			
Rural	−8,405.96	[− 12,401.48, −4,410.44]	<.0001**
Urban	Ref		
Teaching status of hospital			
Nonteaching	−3,191.25	[− 6,835.36, 452.86]	0.0860
Teaching	Ref		
Admission source[a]			
Emergency department	−2,068.70	[− 4,376.62, 239.21]	0.0789
Other	−132.64	[− 4,610.8, 4,345.52]	0.9537
Routine	Ref		
Discharge disposition[b]			
Died	43,227.63	[9,703.26, 76,752.00]	0.0115*
Other	5,949.89	[2,416.46, 9,483.31]	0.0010**
Routine	Ref		
Number of diagnoses on this record	3,157.60	[2,321.14, 3,994.06]	<.0001**
Length of stay	2,445.14	[1,906.45, 2,983.83]	<.0001**

$R^2 = 0.4481$; Adjusted $R^2 = 0.4481$

* $p < 0.05$; ** $p < 0.01$

[a] Admission source was collapsed into three categories: emergency department, other and routine

[b] Discharge disposition was collapsed into three categories: died, other and routine

[$131, $10,375]; $p = 0.0444$) and West (β = $15,463; 95% CI [$8,838, $22,087]; $p < 0.0001$) were higher in comparison to those for hospitals in the South. Charges were lower for rural ($\beta = -\$8,406$; 95% CI [−$12,401, −$4,410]; $p < 0.0001$) as compared to urban hospitals. Charges were higher for hospitalizations of individuals with autism who died during the hospital stay ($\beta = \$43,228$; 95% CI [$9,703, $76,752]; $p < 0.0115$) and also for hospitalizations of individuals who were discharged to other health facilities ($\beta = \$5,950$; 95% CI [$2,416, $9,483]; $p < 0.0010$) as compared to those who had a routine discharge. An increase in the number of

recorded diagnoses (β = \$3,158; 95% CI [\$2,321, \$3,994]; $p < 0.0001$) and LOS (β = \$2,445; 95% CI [\$1,906, \$2,984]; $p < 0.0001$) were associated with higher charges, respectively.

Though not described in a table, logistic regression analysis to examine the predictors of mortality among individuals with autism was also conducted. Age, gender, household income, hospital region, payer status, hospital size, location, teaching status, admission source, number of diagnoses on record, and LOS were included as the independent variables in this model. Due to insufficient cell size, primary payer was collapsed into two categories namely public and other. Only number of diagnoses emerged as a significant predictor ($p < 0.0001$), with the odds of mortality increasing with the number of diagnoses among individuals with autism (Odds ratio = 1.29; 95% CI [1.16, 1.42]).

Discussion

This study provides a comprehensive description of the inpatient burden among individuals with autism based on cross-sectional analysis of a nationally representative hospitalization database. Using case–control methodology, we determined the incremental burden of autism by comparing outcomes among individuals with and without a diagnosis of autism. Further, we identified the factors that predict hospitalization LOS, charges, and mortality among individuals with autism.

In 2007, there were a total of 25,919 (weighted) hospitalizations among individuals with autism in the US. When comparing the patient- and hospital-level characteristics of individuals with autism to those without the disorder, significant differences were observed. A higher proportion of individuals with autism had public insurance coverage than those without autism, which is likely because Medicaid is a major source of funding for individuals with developmental disorders like autism (Ruble et al. 2005). More individuals with autism had high household income than those without the disorder. Though not conclusively ascertained, some of the literature in autism suggests a positive relationship between household income and autism prevalence (Bhasin and Schendel 2007; Durkin et al. 2010). In a more recent study, Durkin et al. (2010) found increasing socioeconomic status to be associated with increasing autism prevalence. This could also explain the higher proportion of hospitalizations occurring in hospitals in urban area and Northeast, respectively, for individuals with autism than those without the disorder.

Hospitalization rates among individuals with autism varied by patient- and hospital-level characteristics. In terms of patient-level variables, rates were highest for individuals aged 10–20 years, males, with household income greater than \$63,000, and those with private insurance, respectively. Though the rate of hospitalization (25.82/100,000 admissions) was the lowest among adults (21 years of age) with autism, they still constituted almost one-third of the sample. This highlights the need to include this age group when studying health outcomes in this population. Studies that assess autism-related or overall healthcare resource utilization and cost in individuals with autism are likely to underestimate the true burden of the disorder when excluding adults. In terms of gender, the rate of hospitalization among males was five times that among females. The fact that autism is almost three times as prevalent among males as females (Nicholas et al. 2008) could explain the higher rates seen among males. Though a majority of individuals with autism were covered under public insurance, the rate of hospitalization was the highest among those with private insurance. Studies have reported inequality in access to care among children with public insurance as compared to private insurance, which has been attributed to the low reimbursement rates provided by public insurance (Wang et al. 2004). It is plausible that the low rate of hospitalization among individuals with autism with public insurance or self-pay is more so a reflection of limited access to care. We found a gradual relationship between household income and hospitalization rate, with the rate increasing with income level. Both higher prevalence of autism among high household income families (Bhasin and Schendel 2007; Durkin et al. 2010), and the relationship between income and access to care could plausibly explain the relationship between income and hospitalization rate as seen in this study. Differences in hospitalization rate for individuals with autism also occurred by hospital characteristics (size, geographic location, and teaching status). Given the lack of prior literature examining these patterns, it is difficult to interpret this variation in admission rate for individuals with autism by hospital characteristics.

Epilepsy and other psychiatric disorders were found to occur commonly among individuals with autism. This is consistent with previous literature, which has also reported common occurrence of these conditions in this population (Creon et al. 2006; Leslie and Martin 2007). The incremental burden of autism was highlighted when we compared hospitalization outcomes among individuals with and without a diagnosis of autism. At 6.5 days, the average LOS for individuals with autism was 1.5 times than that of individuals without the disorder. In 2007, individuals with autism had a total of $\sim$165,000 days of inpatient stay. Given the longer LOS for individuals with autism, it was not surprising to also see higher total hospital charges among this group in comparison to individuals without autism.

The total charges incurred for hospitalization among individuals with autism was ~$638 million. Having a diagnosis of autism was associated with an incremental charge of $1,637 ($24,862 vs. $23,225). This result is consistent with previous studies which have also found higher inpatient expenditures for individuals with autism as compared to those without the disorder (Creon et al. 2006; Mandell et al. 2006; Shimabukuro et al. 2008; Wang and Leslie 2010). However, the average total hospitalization charge of $24,862 for individuals with autism as observed in our study is substantially higher than cost estimates reported in previous studies. Creon et al. (2006) reported hospital care costs of $550 among children with autism enrolled in a private plan. In another study, Mandell et al. (2006) reported general inpatient cost of $198 and psychiatric inpatient cost of $4,109 paid for by Medicaid for children with autism. In their analysis of the Medical Expenditure Panel Survey (MEPS) data, Liptak et al. (2006) found the average inpatient hospital cost of $734 among children with autism. Differences in study methodology used to assess hospital expenditure and patient populations could explain this variation. In our study, we reported the total hospital charges and not actual amount paid in reporting inpatient expenditure, while cost estimates from these previous studies were based on payer perspective and included actual payments (Creon et al. 2006; Mandell et al. 2006; Liptak et al. 2006). Since several children with autism have both public and private insurance, studies based on privately insured populations do not include the healthcare costs paid for by Medicaid, which could lead to an underestimation of the true economic burden of autism (Shimabukuro et al. 2008). It should also be noted that hospital charges as reported in the current study are generally higher than actual payments made by payers (Riley 2009). Due to lack of information, we were not able to ascertain the actual amount paid for hospitalization in our study. Additionally, it may be noted that almost 60% of individuals with autism in our study had an admission source listed as emergency department, another hospital, other health facility, or court/law enforcement for their hospitalization. These individuals may represent more severe cases, and are likely to have driven the resource use expenditure upwards.

Regression analyses undertaken to study the factors predicting LOS, total charges, and mortality among individuals with autism revealed some interesting results. The LOS was higher among adults (≥21 years) with the disorder as compared to those aged <10 years. Healthcare utilization and cost among individuals with autism increases with age (Creon et al. 2006; Ganz 2007; Shimabukuro et al. 2008), which is likely to translate into greater LOS among older individuals with the disorder as seen in this study. Hospital characteristics such as location (Northeast) and size (large) also had an influence on the LOS for hospitalizations among individuals with autism. When studying regional differences in hospital LOS, studies have found the average LOS to be generally higher in the Northeast (U.S. Congress, Office of Technology Assessment, OTA-HCS-23 1983). Large size hospitals had higher LOS than small size hospitals. The differential resource mix could explain the higher total charges observed among urban hospitals as compared to rural hospitals. Proxy measures of patient severity including discharge disposition and number of recorded diagnosis were associated with both LOS and total charges, respectively. Number of recorded diagnosis was the sole predictor of mortality among individuals with autism. This was likely due to the fact that the number of death events were small (209 deaths out of 25,919 weighted discharge records).

There are several limitations of this study. This study used a publicly available dataset (HCUP-NIS) that could have been subjected to coding errors during claims processing. The HCUP-NIS is a discharge level data, wherein same individuals may be represented multiple times. We considered discharges with a primary or secondary diagnosis of autism, and therefore the findings are descriptive of the hospitalization burden among individuals with autism and could not be attributed directly to the disorder. Given the lack of clinical information, we could not ascertain the level of autism-severity among individuals with autism. Additionally, we could not provide information on the race/ethnicity variation in the patients due to missing data. Future studies of hospitalization among individuals with autism could use hospital chart reviews to gain in-depth information associated with the hospital stay.

To the best of our knowledge, this is the first study to provide information concerning inpatient care among individuals with autism. Unlike previous studies in this area of research, we used a large nationally representative database for our analysis. Further, we included adults with autism to provide a complete picture. Consistent with previous studies of healthcare use and costs in autism, we found incremental hospitalization burden in terms of LOS, total charges, and discharge status associated with a diagnosis of autism. Hospitalization rates among individuals with autism were greatest for those aged 10–20 years, males, of household income greater than $63,000, and with private insurance. Hospitals that were large in size, with urban location, in Northeast region, and of teaching status had greatest rates of hospitalization among individuals with autism. Common comorbid conditions listed during hospitalization among individuals with autism included epilepsy and psychiatric disorders. Different patient- and hospital-level characteristics predicted hospitalization outcomes among individuals with autism.

References

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders fourth edition text revision*. Washington, DC: American Psychiatric Association.

Bhasin, T. K., & Schendel, D. (2007). Sociodemographic risk factors for autism in a US metropolitan area. *Journal of Autism and Developmental Disorders, 37*(4), 667–677.

Creon, L. A., Najjar, D. V., Ray, T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics, 118*, e1203–e1211.

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., et al. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE, 5*(7), e11551.

Ganz, M. L. (2006). The costs of autism. In Moldin & J. L. R. Rubenstein (Eds.), *Understanding autism: From basic neuroscience to treatment*. Boca Raton, FL: S.O. Taylor and Francis Group.

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine, 161*(4), 343–349.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., et al. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics, 124*, 1395–1403.

Leslie, D. L., & Martin, A. (2007). Health care expenditure associated with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine, 161*, 350–355.

Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders, 36*, 871–879.

Mandell, D. S., Cao, J., Ittenbach, R., & Pinto-Martin, J. (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders, 36*, 475–485.

Nicholas, J. S., Charles, J. M., Carpenter, L. A., King, L. B., Jenner, W., Eve, G., et al. (2008). Prevalence and characteristics of children with autism spectrum disorders. *Annals of Epidemiology, 18*(2), 130–136.

Riley, G. F. (2009). Administrative and claims records as sources of health care cost data. *Medical Care, 47*(7), s51–s55.

Ruble, L. A., Heflinger, C. A., Renfrew, J. W., & Saunders, R. C. (2005). Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders, 35*(1), 475–485.

Shimabukuro, T. T., Grosse, S. T., & Rice, C. (2008). Medical expenditures for children with an autism spectrum disorder in a privately insured population. *Journal of Autism and Developmental Disorders, 38*, 546–552.

U.S. Congress, Office of Technology Assessment, OTA-HCS-23. (1983). *Medical Technology and Costs of the Medicare Program.* Health Technology Case Study 24: Variations in Hospital Length of Stay: Their Relationship to Health Outcomes. Washington, D. C.

Wang, E. C., Choe, M. C., Meara, J. G., & Koempel, J. A. (2004). Inequality of access to surgical specialty health care: Why children with government-funded insurance have less access than those with private insurance in Southern California. *Pediatrics, 114*(5), e584–e590.

Wang, L., & Leslie, D. L. (2010). Health care expenditures for children with autism spectrum disorders in Medicaid. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*(11), 1165–1171.