



Original Contribution

An analysis of ED utilization by adults with intellectual disability^{☆, ☆ ☆}

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Abstract

Objectives: We sought to identify factors increasing the odds of ED utilization among intellectually disabled (ID) adults and differentiate their discharge diagnoses from the general adult ED population.

Methods: This was a retrospective, observational open cohort study of all ID adults residing at an intermediate care facility and their ED visits to a tertiary center (January 1, 2007–July 30, 2008). We abstracted from the intermediate care facility database subjects' demographic, ID, health and adaptive status variables, and their requirement of ED care/hospitalization. We obtained from the hospital database the primary International Classification of Diseases 9 ED/hospital discharge diagnoses for the study and general adult population. Using multivariate logistic regression, we computed odds ratios (OR) for ED utilization/hospitalization in the cohort. Using the conditional large-sample binomial test, we differentiated the study and general populations' discharge diagnoses.

Results: A total of 433 subjects met the inclusion criteria. Gastrostomy/jejunostomy increased the odds of ED utilization (OR, 4.16; confidence interval [CI], 1.64–10.58). Partial help to feed (OR, 2.59; CI, 1.14–5.88), gastrostomy/jejunostomy (OR, 3.26; CI, 1.30–8.18), and increasing number of prescribed medications (OR, 1.08; CI, 1.03–1.14) increased the odds of hospitalization. Auditory impairment (OR, 0.45; CI, 0.23–0.88) decreased the odds of hospitalization. For ED discharge diagnoses, ID adults were more likely ($P < .05$) than the general population to have diagnoses among digestive disorders and ill-defined symptoms/signs. For hospital discharge diagnoses, ID adults were more likely ($P < .05$) to have diagnoses among infectious/parasitic, nervous system, and respiratory disorders.

Conclusion: Among ID adults, feeding status increased the odds of ED utilization, feeding status, and increasing number of prescribed medications of that hospitalization. Intellectually disabled adults' discharge diagnoses differed significantly from the general adult ED population.

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1. Introduction

Intellectual disability, defined generally as significant limitations in cognitive functioning and adaptive behavior originating before age 18 years [1], exists in a significant portion of the general population. In the United States, up to 3.1% of the general population can be characterized as intellectually disabled [2], and the World Health Organization estimates that at least 120 million individuals worldwide may have intellectual disability [3]. With improvements in medical care and resultant longevity for intellectually disabled individuals, this population will only grow in size [2,4]. As a result, emergency physicians are expected to increasingly encounter this patient population in the emergency department (ED) [5].

Despite the growing number of intellectually disabled adults, research has been lacking about their utilization of medical resources in general [2] and emergency services in particular. The literature on ED utilization by intellectually disabled individuals consists largely of review articles, survey studies, or investigations of particular areas of illness among these patients [5-8]. No study has examined in a comprehensive manner the demographic, intellectual disability, health, and adaptive status factors that are associated with ED presentation among intellectually disabled adults. Nor has any study provided prevalence data of disease in this population when presenting to the ED in comparison to the general adult ED population. This paucity of literature may contribute to discomfort among emergency physicians in caring for intellectually disabled individuals that can carry over to their ED management [5] and the difficulties encountered by intellectually disabled individuals when presenting to the ED [9]. Data on whether identifiable factors exist that are associated with ED presentation among intellectually disabled adults as well as prevalence data on disease epidemiology in this population at ED presentation would aid both outpatient caregivers and emergency physicians when encountering such patients. In addition, the identification of factors associated with ED presentation among intellectually disabled adults would open up avenues of investigation as to whether modification of these factors may affect the need for ED and inpatient care.

The purpose of this investigation was to identify factors associated with increased odds of ED utilization by intellectually disabled adults and determine whether and how their primary ED and hospital discharge diagnoses differ from the general adult ED population. We hypothesized that from among demographic, intellectual disability, health and adaptive status variables in intellectually disabled adults, specific factors could be identified that are associated with increased odds of ED utilization and hospitalization through the ED. We also hypothesized that the primary ED and hospital discharge diagnoses of intellectually disabled adults would differ significantly from the general adult ED population in an identifiable pattern of relevance to emergency physicians.

2. Methods

2.1. Study design

This was a retrospective, observational open cohort study of all adult residents of an intermediate care facility for intellectually disabled adults and their ED visits to a single tertiary care center from January 1, 2007 to June 30, 2008 with comparison of diagnoses to a convenience sample of all general adult visits to this tertiary care center concurrently during the study period. The study protocol was approved by the institutional review board of the tertiary center in a data use agreement with the intermediate care facility.

2.2. Study setting and population

This intermediate care facility exclusively serves individuals with intellectual disability and consists of residential arrangements ranging from community group homes to campus living. During the study period, primary care for the identified study cohort was provided largely by a single practitioner (92.6% of all study subjects) who evaluated patients on an annual basis and as needed for urgent or follow-up needs. This intermediate care facility is certified and regulated under the Intermediate Care Facilities for People with Mental Retardation program of the US Department of Health and Human Services. There are more than 7000 such facilities in all 50 states caring for more than 129 000 intellectually disabled individuals [10].

The tertiary care center in this study was contracted by this intermediate care facility to serve as the primary referral center for their residents during the study period. Emergency department evaluation at this center was performed by emergency medicine residents and attending faculty and, if hospitalization was required for medical care, a single group of hospitalists served as attending physicians. Subspecialty admissions were attended by specialists in those areas. Direct admissions are rare from this intermediate care facility to the study hospital because of the difficulties related to assessment of individuals with intellectual disability from communication and physical impairments [5,9].

All adult residents of this intermediate care facility at any point from January 1, 2007 to December 31, 2007 were included in this study as were their identified ED visits from January 1, 2007 to June 30, 2008. The time period extended beyond the 1-year period of 2007 so that ED visits by patients who entered the facility at the end of the year could be observed for at least 6 months. Eligible subjects were identified from a preexisting clinical database maintained by the intermediate care facility for medical care. This database was also used to query the information services database of the tertiary care center to identify all ED visits and the primary International Classification of Diseases (ICD)-9 coded ED or hospital discharge diagnoses for the study

cohort and the convenience sample of all general adult ED visits to this center during the study period.

2.3. Study protocol and measurements

In determining what variables were appropriate for evaluation as possibly being associated with ED utilization and hospitalization among intellectually disabled adults and how their diagnoses might be compared with the general adult ED population, the authors drew upon the existing literature regarding ED utilization in this population as well as literature regarding outpatient care and mortality among intellectually disabled adults. Though limited, this literature had suggested that demographic (age, sex, race), intellectual disability (degree and diagnosis related to intellectual disability, cerebral palsy or autism presence), health (number of medications, tracheostomy presence, hearing and visual impairment, weight level by body mass index [BMI]), and adaptive (feeding and ambulatory ability, bowel and bladder continence) status variables were all potentially associated with either requirements of ambulatory, emergency or inpatient care, or mortality among intellectually disabled adults [5,6,11-16].

Studies on disease epidemiology among intellectually disabled adults have come to differing conclusions as to whether morbidity and mortality in this population are due to similar conditions as the general adult population. In addition, most studies on disease epidemiology among intellectually disabled adults have either not reported or directly compared how this prevalence of disease compares with the general adult population in the same practice setting or have done so in a limited way [7,17-22].

Data regarding the tested variables for association with ED utilization and hospitalization via the ED were downloaded directly from the intermediate care facility's database or abstracted by the investigators from preexisting utilization reviews performed semiannually by the intermediate care facility for its residents. These reviews follow standardized criteria established by the intermediate care facility and are conducted by the primary physician, an outside physician, nursing staff, and administrative staff. The earliest utilization review for each study subject during the study period was used for data abstraction by the investigators.

Age was defined as that on January 1, 2007, whereas sex was dichotomous and race was categorized as white, African American, or other. Intellectual disability was categorized by the intermediate care facility based on the accepted degrees of profound, significant, moderate, or mild from results on standardized testing instruments administered by the intermediate care facility's staff psychologists. The testing instruments used in making this determination of degree of intellectual disability were the Weschler Adult Intelligence Scale-Revised, the Slosson Intelligence Test-1985 Edition, the Leiter Intelligence Performance Scale, the Stanford-Binet

Intelligence Scale-4th Edition, and the Vineland Adaptive Behavior Scales. These instruments allow consideration of both the cognitive and adaptive characteristics that are included in the definition of intellectual disability. Intelligence quotient cutoffs of lower than 25 (profound intellectual disability), 25-40 (significant), 41-55 (moderate), and 56-70 (mild/borderline) provide guidance for classification in this regard but are not exclusive in the determination of degree of intellectual disability both in this study cohort and in general [1].

Diagnosis related to intellectual disability was abstracted as Down syndrome, other identified cause of intellectual disability (Fragile X, tuberous sclerosis, Klinefelter syndrome, nonaccidental trauma, kernicterus, congenital hypothyroidism, Prader-Willi syndrome, leukodystrophy, phenylketonuria et al), or no identified cause of intellectual disability. Autism or cerebral palsy presence was abstracted as tested by the intermediate care facility using the standardized assessment tools available. Though both can be associated with intellectual disability, their presence does not automatically account for an individual's intellectual disability [1].

The health status variable of number of prescribed medications (both regular and as needed) was recorded from the utilization reviews as a continuous variable, given that all members of the study cohort were prescribed at least 1 medication. Hearing or visual impairment of any degree was recorded from the utilization reviews as a dichotomous variable. Body mass index was categorized as underweight (<18.5 kg/m²), normal (18.5-24.9 kg/m²), overweight (25-29.9 kg/m²), or obese (>30 kg/m²) and calculated based on the recorded height and weight in the utilization review using the spreadsheet program into which data were abstracted. Tracheostomy presence was downloaded from the intermediate care facility's clinical database as a dichotomous variable.

Adaptive status variables were categorized by the intermediate care facility using definitions that their staff is trained to apply and abstracted using their formulation, which conforms to previous studies evaluating functional status in intellectually disabled individuals [12], from the utilization reviews. Bowel or bladder continence was categorized by the intermediate care facility staff as continent, occasionally incontinent, or incontinent. Feeding status was categorized as self-feeding, partial help to feed, requires feeding but able to swallow, or gastrostomy/jejunostomy for nutrition. Ambulatory status was categorized as ambulatory, ambulatory with assistance, wheelchair dependent, or completely dependent/unable to move without assistance. These last 2 categories were combined for analysis, given that the distinction for clinical purposes that has been reported in the intellectually disabled population as most relevant is the ability to ambulate or not [12].

The primary ICD-9 coded ED and hospital discharge diagnoses for the study cohort and the convenience sample of the general adult ED population to this hospital during the study period were downloaded directly from the tertiary care

center's information services database. The primary coded diagnosis in this database is that deemed by the treating physician on that visit as the main reason the patient required care in that episode of ED or hospital care. Only one such diagnosis is coded for each visit. The investigators chose to only analyze the primary diagnosis to avoid the confounding issue of comorbid illnesses that might have been coded despite their existence before this ED presentation. These diagnoses were categorized using the preexisting ICD-9 Tabular Index that organizes diagnoses in disease categories used in other studies on intellectually disabled patients [18].

Before data collection, a standardized data collection instrument was prepared and used to construct a Microsoft Excel spreadsheet into which the relevant data were either directly downloaded (if from a preexisting database) or abstracted by 2 investigators at the same time. Age, sex, race, intellectual disability degree, hearing or visual impairment, autism or cerebral palsy presence, and tracheostomy presence were directly downloaded from the intermediate care facility database into the analytic spreadsheet. Data on intellectual disability diagnosis, number of medications, height and weight, and adaptive status variables prerecorded on the utilization reviews were abstracted by the investigators and entered into the spreadsheet. The spreadsheet was programmed to convert, using a standard BMI calculation, the height and weight of each subject into the BMI categories described above. After this abstraction/direct download was completed, 10% of subjects' utilization reviews were then abstracted by 2 investigators with no variations found.

The presence or absence of ED presentation or hospitalization via the ED was downloaded directly from the hospital information services database into the analytic spreadsheet. However, the intermediate care facility did use other nearby hospitals for care on occasion (<10% of ED visits and hospitalizations via the ED). These outside visits were identified by 2 investigators examining ED visit forms completed by caregivers when accompanying residents during these episodes and maintained at the intermediate care facility. The dichotomous variable of ED presentation or hospitalization for those study cohort subjects not captured by the hospital information services database was then inputted into the analytic spreadsheet.

Thirty-two subjects used different primary physicians and thus did not have utilization reviews. For these subjects, 1 investigator and the data management director at the intermediate care facility together directly abstracted the nondatabase available variables of intellectual disability diagnosis, number of medications, feeding and ambulatory ability, bowel and bladder continence, and height and weight from nursing summaries at the intermediate care facility onto the standardized data collection form. The investigators then entered these subjects' variables into the analytic spreadsheet.

The ICD-9 coded primary ED and hospital discharge diagnoses for the study population and the general adult ED population to the tertiary care center during the study period

were directly downloaded from the information services database at this hospital into the analytic spreadsheet.

2.4. Outcome measures

The first outcome measure was the identification of correlates of ED and inpatient utilization among intellectually disabled adults in the study cohort. The second outcome measure was the comparison of ED discharge and hospitalization discharge primary diagnoses between the study cohort of intellectually disabled adults and the convenience sample of the general adult ED population to this tertiary center during the study period.

2.5. Primary data analysis

The statistical investigator used multivariate logistic regression to calculate adjusted odds ratios (OR) and 95% confidence intervals (95% CIs) for the association of particular abstracted variables with ED presentation and hospitalization at the level of the patient. Before the performance of logistic regression, analysis of collinearity between all abstracted variables was performed. It was noted that significant collinearity alone existed between bowel and bladder continence (Pearson $\chi^2 = 577$, significance level <.001; directional measure λ (symmetric) = 0.83). As a result, the regression analysis was conducted with either bowel or bladder incontinence as a covariate and found that the inclusion of one versus the other did not result in any significant change in the results reported. Therefore, the data presented on the association and significance of the remaining abstracted demographic, intellectual disability, health, and adaptive status variables with ED utilization or hospitalization only include that for bowel continence. The model's predictive value for ED utilization and hospitalization was then tested using the Model χ^2 test and the Hosmer and Lemeshow test.

To analyze the variation between the prevalence of primary ED and hospital discharge diagnoses in the study cohort versus the convenience sample of the general adult ED population to this center during the study period, the statistical investigator used the conditional large sample binomial test (z statistic) or the exact binomial test after a χ^2 analysis was performed to determine if the global distribution of primary diagnoses in the study cohort versus the convenience sample of the general adult ED population differed significantly. To meet the assumptions of the overall test for association, diagnostic categories with less than 25 cases were collapsed [23]. The null hypothesis for the conditional large sample and exact binomial tests was that within each disease category, the prevalence rate of the study cohort would equal the prevalence rate of the general adult ED population during the study period. The assumptions of the conditional large sample binomial test and the exact binomial test allowed appropriate consideration that a study subject or other general adult in the comparison convenience

Table 1 Characteristics of study cohort of intellectually disabled adults

	Total cohort (n = 433)	No ED presentation (n = 211)	ED presentation (n = 222)
Age (y)			
Mean (min, max)	45.5 (18, 88)	45.0 (19, 88)	46.0 (18, 86)
SD	13.9	13.0	15.0
Sex (%)			
Male	49.4	48.3	50.5
Female	50.6	51.7	49.5
Race (%)			
White	92.1	91.5	92.8
African American	7.4	8.1	6.8
Other	0.5	0.4	0.4
Degree of intellectual disability (%)			
Mild or borderline	9.5	10.9	8.1
Moderate	11.1	11.4	10.8
Severe	22.4	27.5	17.6
Profound	57.0	50.2	63.5
Diagnosis related to intellectual disability (%)			
Down syndrome	11.8	13.7	9.9
Other specified diagnosis	12.2	10.0	14.4
None specified	76.0	76.3	75.7
Autism presence (%)			
No	92.6	89.1	95.9
Yes	7.4	10.9	4.1
Cerebral palsy presence (%)			
No	60.3	68.7	52.3
Yes	39.7	31.3	47.7
No. of medications (prescribed and PRN)			
Mean (min, max)	15.2 (2, 34)	14.0 (2, 32)	16.0 (4, 34)
SD	5.3	5.0	5.0
Tracheostomy presence (%)			
No	94.7	98.1	91.4
Yes	5.3	1.9	8.6
Weight level based on BMI (%)			
Underweight	5.3	4.3	6.3
Normal	62.1	63.5	60.8
Overweight	26.3	26.0	26.6
Obese	6.3	6.2	6.3
Visual impairment presence (%)			
No	40.9	43.1	38.7
Yes	59.1	56.9	61.3
Auditory impairment presence (%)			
No	80.4	76.3	84.2
Yes	19.6	23.7	15.8
Bladder control (%)			
Continent	38.6	47.4	30.2
Occasionally continent	14.8	15.2	14.4
Incontinent	46.6	37.4	55.4
Bowel control (%)			
Continent	44.6	55.9	33.8
Occasionally continent	10.6	10.0	11.2

Table 1 (continued)

	Total cohort (n = 433)	No ED presentation (n = 211)	ED presentation (n = 222)
Incontinent	44.8	34.1	55.0
Feeding status (%)			
Self	55.2	68.2	42.8
Partial help	13.2	12.8	13.5
Requires feeding	15.9	13.3	18.5
Gastrostomy/ jejunostomy	15.7	5.7	25.2
Mobility status (%)			
Ambulatory	37.0	49.8	24.8
Ambulatory with assistance	9.4	10.4	8.6
Wheelchair/ completely dependent	53.6	39.8	66.6

PRN indicates as needed.

sample might have 1 or more visits to the ED during the study period [22]. Significance was defined as a *P* value of less than .05 for all analyses.

All statistical analyses were performed using SPSS 16.0 for Windows (SPSS Inc, Chicago, Ill) and Microsoft Excel 2007 (Microsoft Corporation, Seattle, Wash). Data are presented in tabular format using percentages and means along with the adjusted OR, 95% CIs, *z* statistics, and *P* values where appropriate.

3. Results

3.1. Characteristics of study subjects

Table 1 shows the characteristics of the study cohort of intellectually disabled adults. A total of 433 subjects met the inclusion criteria, with a mean age of 45 years and a range from 18 to 88 years. Of the study population, 49.4% was male and 92.1% were white. Of the overall study population, 57% was profoundly intellectually disabled; 76% had no specified diagnosis that explained their intellectual disability, whereas 11.8% had Down syndrome and 12.2% had some other diagnosis as the etiology of intellectual disability.

Two hundred twenty-two subjects (51.3%) presented to an ED during the study period with a total of 741 ED visits. One hundred thirty-two subjects (30.5%) required hospitalization during the study period via an ED visit—323 of the 741 visits—resulting in an admission rate through the ED of 43.6%. As determined by the investigators from the visit report forms described above, 90.6% of all ED visits in the cohort and 92.9% of all ED visits resulting in hospitalization during the study period were to this tertiary center.

At this tertiary center during the study period, there were 60 448 ED visits by 41 332 adults (excluding the study cohort), with 27.1% of all general adult ED visits resulting in

admission. Forty general adult ED visits did not have primary diagnoses assigned in the information services database of this center at the time of data abstraction. The general adult ED population to this facility during the study period, excluding the study cohort, was 48.8% male, 51.2% female, 66.8% white, 29.5% African American, 3.7% other minority race, and had a mean age of 46.5 years.

3.2. Main results

Table 2 shows the association between the abstracted variables and ED utilization within the study cohort. The

Table 2 Odds ratios (OR) for ED utilization among intellectually disabled adults based on abstracted variables^a

Abstracted variable	Reference value	OR	95% CI	P
Age	NA	1.01	0.99 1.02	.44
Sex	Male	0.83	0.54 1.26	.38
Race				
African American	White	0.74	0.33 1.68	.47
Other		0.57	0.03 10.16	.70
Degree of intellectual disability				
Mild or Borderline	Profound	1.00	0.44 2.25	.99
Moderate		1.81	0.85 3.86	.13
Severe		1.08	0.58 2.01	.80
Diagnosis related to intellectual disability				
Down syndrome	No diagnosis specified	1.42	0.69 2.95	.34
Other specified diagnosis		1.80	0.91 3.54	.09
Autism presence	No	0.50	0.20 1.25	.14
Cerebral palsy presence	NO	1.25	0.70 2.23	.45
No. of medications	NA	1.04	0.99 1.08	.12
Tracheostomy presence	No	1.91	0.56 6.46	.30
Weight level based on BMI				
Normal	Underweight	1.17	0.43 3.21	.76
Overweight		1.52	0.51 4.52	.45
Obese		1.35	0.36 5.06	.66
Visual impairment presence	No	0.78	0.50 1.22	.27
Auditory impairment presence	No	0.63	0.37 1.09	.10
Bowel control				
Occasionally continent	Continent	1.59	0.77 3.29	.21
Incontinent		1.05	0.52 2.13	.89
Feeding status				
Partial help	Self	1.34	0.65 2.80	.43
Requires feeding		1.43	0.62 3.27	.40
Gastrostomy/ jejunostomy		4.16	1.64 10.58	.00
Mobility status				
Ambulatory with assistance	Ambulatory	1.40	0.64 3.07	.39
Wheelchair/completely dependent		1.94	0.97 3.85	.06

The Hosmer-Lemeshow test of this model showed a χ^2 of 3.73 (significance level = .88, *df* = 8). NA indicates not applicable.

^a Model χ^2 statistic of 70.8 (significance level <.001, *df* = 25).

presence of a gastrostomy or jejunostomy tube was associated with increased odds of ED presentation among this cohort of intellectually disabled adults. Wheelchair mobility/complete dependence approached, but did not reach, significance for increased odds of ED presentation.

Table 3 shows the association between the abstracted variables and hospitalization within the study cohort. Rising number of medications and impaired feeding ability increased the odds of hospitalization. The presence of auditory impairment, unexpectedly, showed a decreased odds of hospitalization.

Table 3 Odds ratios (OR) of hospitalization among intellectually disabled adults based on abstracted variables^a

Abstracted variable	Reference value	OR	95% CI	P
Age	NA	1.01	1.00 1.03	.13
Sex	Male	0.92	0.57 1.48	.74
Race				
African American	White	1.23	0.51 2.96	.65
Other		1.90	0.11 32.82	.66
Degree of intellectual disability				
Mild or borderline	Profound	1.16	0.44 3.11	.76
Moderate		1.51	0.60 3.83	.38
Severe		1.05	0.49 2.24	.90
Diagnosis related to intellectual disability				
Down syndrome	No diagnosis specified	1.29	0.51 3.25	.59
Other specified diagnosis		1.98	0.95 4.12	.07
Autism Presence	No	0.79	0.26 2.38	.68
Cerebral palsy presence	No	1.07	0.57 2.00	.83
No. of medications	NA	1.08	1.03 1.14	.00
Tracheostomy presence	No	2.20	0.77 6.34	.14
Weight level based on BMI				
Normal	Underweight	1.04	0.38 2.86	.93
Overweight		1.44	0.47 4.37	.52
Obese		0.95	0.22 4.04	.95
Visual impairment presence	No	1.02	0.61 1.69	.94
Auditory impairment presence	No	0.45	0.23 0.88	.02
Bowel control				
Occasionally continent	Continent	1.90	0.82 4.40	.14
Incontinent		1.12	0.49 2.55	.79
Feeding status				
Partial help	Self	2.59	1.14 5.88	.02
Requires feeding		2.05	0.83 5.06	.12
Gastrostomy/ jejunostomy		3.26	1.30 8.18	.01
Mobility status				
Ambulatory with assistance	Ambulatory	0.85	0.31 2.35	.76
Wheelchair/completely dependent		2.02	0.90 4.57	.09

The Hosmer-Lemeshow test showed a χ^2 of 5.96 (significance level = .65, *df* = 8). NA indicates not applicable.

^a Model χ^2 statistic for this model was 90.4 (significance level <.001, *df* = 25).

Table 4 Comparison of prevalence of primary ED discharge diagnoses between the intellectually disabled adult and the general adult ED population (number and percentage of total diagnoses)

ICD-9 disease and injury category (code range)	Intellectually disabled adult population	General adult ED population	z statistic	P
Infectious/parasitic (001-139)	1 (0.3%)	763 (1.7%)	-2.12	.03
Neoplasms (140-239)	1 (0.3%)	84 (0.2%)	^a	1.00
Endocrine/nutritional/metabolic (240-279)	10 (2.7%)	722 (1.6%)	1.02	.31
Blood (280-289)	2 (0.5%)	68 (0.2%)	^a	1.00
Mental disorders (290-319)	5 (1.4%)	2159 (4.9%)	-3.29	<.001
Nervous system/sense organs (320-389)	8 (2.2%)	1579 (3.6%)	-1.65	.10
Circulatory (390-459)	7 (1.9%)	899 (2.0%)	-0.34	.74
Respiratory (460-519)	32 (8.6%)	2542 (5.8%)	1.52	.13
Digestive (520-579)	38 (10.2%)	2721 (6.2%)	2.31	.02
Genitourinary (580-629)	19 (5.1%)	2006 (4.6%)	-0.10	.92
Pregnancy (630-677)	0 (0.0%)	564 (1.3%)	-2.09	.04
Skin (680-709)	24 (6.5%)	1686 (3.8%)	1.89	.06
Musculoskeletal (710-739)	17 (4.6%)	4123 (9.4%)	-3.43	<.001
Congenital (740-759)	0 (0.0%)	15 (0.0%)	^a	1.00
Perinatal (760-779)	0 (0.0%)	5 (0.0%)	^a	1.00
Ill-defined symptoms/signs (780-799)	124 (33.4%)	10 018 (22.8%)	2.96	<.001
Injury/poisonings (800-999)	68 (18.3%)	11 512 (26.1%)	-3.84	<.001
Health status/contact with health services (V01-V85)	15 (4.0%)	2550 (5.8%)	-1.74	.08
External causes of injury and poisoning (E800-E999)	0 (0.0%)	1 (0.0%)	^a	1.00
Total assigned ED discharge diagnoses	371 (100%)	44 017 (100%)		

^a Indicates use of exact binomial test for category due to variance of diagnostic prevalence being less than 5.

Tables 4 and 5 show the compared prevalence of primary ED and hospital discharge diagnoses between the study cohort and the convenience sample of the general adult ED

population at this center. For both the ED and hospital discharge diagnoses, the χ^2 test for global distribution of diagnoses between the study cohort and the general adult ED

Table 5 Comparison of prevalence of primary hospital discharge diagnoses between the intellectually disabled adult and the general adult ED population (number and percentage of total diagnoses)

ICD-9 disease and injury category (code range)	Intellectually disabled adult population	General adult ED population	z statistic	P
Infectious/parasitic (001-139)	40 (13.3%)	724 (4.4%)	7.02	<.001
Neoplasms (140-239)	1 (0.3%)	457 (2.8%)	-2.37	.02
Endocrine/nutritional/metabolic (240-279)	6 (2.00%)	517 (3.2%)	-0.95	.34
Blood (280-289)	1 (0.3%)	104 (0.6%)	^a	.87
Mental disorders (290-319)	0 (0.0%)	829 (5.1%)	-3.76	<.001
Nervous system/sense organs (320-389)	19 (6.4%)	492 (3.0%)	3.10	<.001
Circulatory (390-459)	5 (1.7%)	3228 (19.7%)	-6.96	<.001
Respiratory (460-519)	130 (43.4%)	1481 (9%)	18.86	<.001
Digestive (520-579)	40 (13.3%)	1588 (9.7%)	1.91	.06
Genitourinary (580-629)	15 (5.0%)	643 (3.9%)	0.78	.43
Pregnancy (630-677)	0 (0.0%)	96 (0.6%)	^a	.35
Skin (680-709)	4 (1.3%)	235 (1.4%)	^a	1.00
Musculoskeletal (710-739)	1 (0.3%)	406 (2.5%)	-2.17	.03
Congenital (740-759)	0 (0.0%)	15 (0.1%)	^a	1.00
Perinatal (760-779)	0 (0.0%)	0 (0.0%)	^b	
Ill-defined symptoms/signs (780-799)	17 (5.7%)	882 (5.4%)	0.09	.93
Injury/poisonings (800-999)	19 (6.3%)	4678 (28.5%)	-7.13	<.001
Health status/contact with health services (V01-V85)	2 (0.7%)	16 (0.1%)	^a	1.00
External causes of injury and poisoning (E800-E999)	0 (0.0%)	0 (0.0%)	^b	
Total assigned hospital discharge diagnoses	300 (100%)	16 391 (100%)		

^a Indicates use of exact binomial test for category due to variance of diagnostic prevalence being less than 5.

^b Indicates no test performed due to no assigned diagnoses within each population.

population indicated that they were significantly different ($P < .01$). For primary ED discharge diagnoses, intellectually disabled adults were more likely ($P < .05$) than the convenience sample of the general adult ED population to have ICD-9 diagnoses among digestive disorders and ill-defined symptoms/signs, less likely among infectious/parasitic, mental, pregnancy, musculoskeletal, and injury/poisoning disorders. There was no significant difference between the 2 groups in the distribution of neoplastic, endocrine/metabolic, blood, nervous system/sense organs, circulatory, respiratory, genitourinary, skin, congenital and perinatal disorders, or health status/contact with health services and external causes of injury/poisoning primary diagnoses.

For primary hospital discharge diagnoses, intellectually disabled adults were more likely ($P < .05$) than the convenience sample of the general adult ED population to have ICD-9 diagnoses among infectious/parasitic, nervous system/sense organs, and respiratory disorders, less likely among neoplastic, mental, circulatory, musculoskeletal, and injury/poisoning disorders. There was no significant difference between the 2 groups in the distribution of endocrine/metabolic, blood, digestive, genitourinary, pregnancy, skin, congenital and perinatal disorders or ill-defined signs/symptoms, health status/contact with health services, and external causes of injury/poisoning primary diagnoses.

4. Discussion

Our study shows that among candidate variables for association with increased odds of ED presentation or hospitalization among intellectually disabled adults, the most clearly significant contributors are feeding ability and rising number of prescribed medications. This suggests that future studies focused on identifying methods to reduce ED utilization and hospitalization among intellectually disabled adults should consider testing whether aggressive physical and occupational therapy as well as simplification of pharmacologic regimens may result in such reduction.

Previous studies have found that among intellectually disabled individuals, the ability to feed, toilet, or ambulate is the most important contributors to mortality [12]. This study adds to this literature by suggesting that the ability to feed oneself may be critical to acute morbidity that results in ED presentation or hospitalization among intellectually disabled adults. For outpatient and emergency providers of intellectually disabled individuals, this represents a target of therapy that warrants further investigation.

In addition, for emergency physicians, that gastrostomy/jejunostomy requirement is associated with increased odds of ED presentation, and hospitalization is not likely limited to difficulties with artificial devices for nutrition. When considering the range of disorders found to be more prevalent in comparison to the general adult ED population, it does suggest that gastrostomy/jejunostomy may also serve

as a surrogate marker of the inability to prevent aspiration that may explain the increased odds of respiratory ailments in the hospitalized intellectually disabled population and the decreased host response that occurs with decreased nutrition, even if provided enterally, resulting in increased likelihood of hospitalized infectious disorders as just 2 examples [16].

Polypharmacy has also been found to be a particular concern among intellectually disabled individuals. Beange et al [19] concluded in their study of intellectually disabled adults that polypharmacy contributed to the increased likelihood of iatrogenic disease in this population, specifically recommending regular medication reviews to reduce unnecessary prescriptions. Our finding that increasing number of medications was associated with increased odds of hospitalization among intellectually disabled adults suggests that simplification of medication regimens should be further investigated as a means of reducing hospitalization requirements among intellectually disabled adults.

Our finding that auditory impairment was associated with decreased odds of hospitalization was unexpected. Possible explanations of this finding include the fact that we did not differentiate between degrees of auditory impairment and that the presence of auditory impairment may result in adaptive characteristics that improve overall health status and prevent acute morbidity. This has been suggested in a previous study comparing perceived health status between elderly hearing impaired and nonhearing impaired individuals [24]. In retrospect, we might have differentiated the degree of auditory impairment that was present in the study cohort to see if such differentiation explained this most unusual finding.

Our study supports the previously cited literature that has found that morbidity and mortality among intellectually disabled adults are due to different causes than the general adult population [18,19]. To our knowledge, however, this study represents the first to compare directly the primary ED discharge and hospital discharge diagnoses of intellectually disabled adults and the general adult ED population. Our finding that inpatient circulatory diagnoses are less prevalent among intellectually disabled adults in comparison to the general adult ED population is of particular interest because previous studies that have attempted to differentiate the intellectually disabled outpatient population from the general population have come to opposite conclusions regarding the variability of circulatory disorder prevalence [18-20]. We have avoided some of the factors that may explain the differing findings in these studies by comparing the care of these 2 groups in the same treatment setting and time period [17].

In addition, by only considering the primary diagnosis assigned during each ED visit that resulted in either discharge or admission, we have provided data on the perceived most acute issue that required assessment during each care episode. This is of particular relevance to emergency physicians because that is the area in which we specialize. The data on prevalence of primary diagnoses presented here provide a gross pretest probability of disease

population indicated that they were significantly different ($P < .01$). For primary ED discharge diagnoses, intellectually disabled adults were more likely ($P < .05$) than the convenience sample of the general adult ED population to have ICD-9 diagnoses among digestive disorders and ill-defined symptoms/signs, less likely among infectious/parasitic, mental, pregnancy, musculoskeletal, and injury/poisoning disorders. There was no significant difference between the 2 groups in the distribution of neoplastic, endocrine/metabolic, blood, nervous system/sense organs, circulatory, respiratory, genitourinary, skin, congenital and perinatal disorders, or health status/contact with health services and external causes of injury/poisoning primary diagnoses.

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categorization in comparison to the general adult ED population. Such information is of interest to all emergency physicians given that lack of knowledge about intellectual disability, and its resultant morbidity has been shown to be a barrier to care of the intellectually disabled in the ED [5,9].

In examining Tables 4 and 5, we would conclude that in this comparison of intellectually disabled adults to the convenience sample of the general adult ED population, emergency physicians, when encountering intellectually disabled adults, should expect to see a higher prevalence of serious infectious, respiratory, and nervous system/sense organ disorders, which is perhaps expected given the higher prevalence of epilepsy in this population [12], as well as less serious digestive disorders. Even with the aging of the intellectually disabled population, in this study, there was a lesser prevalence of inpatient neoplastic and circulatory disorders, though these are leading causes of mortality in the general adult population [17]. For emergency physicians, our findings, therefore, suggest that a lowered preassessment probability for otherwise common general adult conditions may be appropriate when encountering intellectually disabled adults. Our finding that injury-related diagnoses were less prevalent among the studied intellectually disabled adults may be a result of our focus on individuals in a supervised setting, though one previous study that examined injury as relates to intellectually disabled individuals also found a lesser prevalence and severity of trauma in this population [7].

To date, prevalence data regarding ED diagnoses of intellectually disabled adults have been, to some degree, speculative, drawing on the pediatric literature for intellectually disabled individuals, small outpatient clinic studies, direct reporting of inpatient diagnoses alone [5,18-21]. For emergency physicians, our study gives guidance regarding prevalence of diagnoses in the intellectually disabled population in comparison to the general adult ED population, albeit at a single center, aiding in the generation of differential diagnosis and evaluation of intellectually disabled adults.

Our finding that the study cohort of intellectually disabled adults had a higher admission rate through the ED than the general adult population at this center supports previous reported data that the intellectually disabled adult population has a higher disease burden overall than the general adult population [20] and up to a 3 times greater likelihood of hospitalization in comparison to a general adult population followed in the same clinical region [22]. This higher prevalence of morbidity emphasizes the importance of this study in informing emergency physicians about this patient population that faces significant communication and other logistical barriers in obtaining effective emergency care [5,9].

5. Limitations

Though this study, for the first time to our knowledge, tests comprehensively what factors might be associated with

ED utilization and hospitalization among intellectually disabled adults and directly compares the prevalence of ED and hospital discharge diagnoses in this population with a convenience sample of the general adult ED population, there are a number of limitations that affect the generalizability of our findings. Having used retrospective methodology, we are limited by the available resources for data and the assigned diagnoses whose accuracy we cannot verify prospectively. This limitation largely affects the entire body of literature on intellectual disability due to inherent difficulties with informed consent and prospective experimentation in this vulnerable group.

We did not test whether residential location or type directly impacts on ED utilization or hospitalization. Though controversy exists as to whether the transfer to community care from institutional settings of intellectually disabled individuals may have increased mortality in this population [14,15], our study population was limited to those in supervised care, ranging from a community group home to a larger institutional setting. In assessing our ability to test for type of residence as a variable in this study, we discovered that a number of residents of this intermediate care facility were transferred between locations, making it difficult to standardize this consideration. We also did not test whether length of residence itself in the intermediate care facility was a factor related to ED presentation as some individuals, depending on medical circumstances, had been transferred over time out of and back into this intermediate care facility.

We did not test whether particular preexisting medical conditions or classes of medications were associated with increased odds of ED presentation or hospitalization in the study cohort. We did not have a specific method of categorizing such diseases (eg, hypertension, diabetes, epilepsy, etc) or types of medications (antihypertensives, antiarrhythmics, urologic agents, psychotropic agents) without adding a large number of variables that would have affected the ability to analyze the data involved in a methodologically sound manner and given that there is much overlap in how such medications are used (eg, valproic acid for seizure control, mood stabilization, or both). We instead selected number of prescribed medications as a variable that had been previously been found to be associated with morbidity among intellectually disabled adults [19] as an incomplete surrogate marker of these issues.

Our study does suffer from a degree of spectrum bias given the close relationship that exists between this intermediate care facility and the study hospital. Such a relationship does not exist for most hospitals or emergency physicians who see intellectually disabled patients sporadically [5,9]. However, such a relationship is likely necessary for the study of the intellectually disabled population given the difficulty in identifying the presence or degree of intellectual disability in patients who present to the ED using the standardized testing instruments required. Previous studies on the subject of ED utilization by intellectually disabled adults have also come

from facilities that have a close relationship with an institution that cares for such individuals [6] or have been limited in the variables that can be assessed that may contribute to their presentation to the ED [8].

Another area of spectrum bias in our study involves the fact that the cohort of intellectually disabled adults was resident at an intermediate care facility. Though such facilities exist across all 50 states and care for a significant number (more than 129 000) of intellectually disabled individuals, it is generally acknowledged that such facilities exist for more seriously intellectually disabled individuals who therefore require intermediate care [10]. However, such facilities may be the only feasible source to evaluate the intellectually disabled population in a comprehensive manner given the data maintained by such centers and their set referral patterns for medical care

Finally, the diagnoses in the less than 10% of ED visits in the study cohort to outside facilities could not be assessed. To the extent that those diagnoses affect the prevalence data within the cohort, our findings are limited, though the same limitation applies to the assessment of diagnoses from the general adult ED population. Categorization of the identified diagnoses within their ICD-9 categories allowed a reasonable ability to compare the prevalence of morbidity by organ system as has been done in previous literature on intellectually disabled adults [18]. However, classification in this regard does only provide gross as opposed to specific diagnostic prevalence, which would be ideal but difficult to present given the large number of diagnoses involved. Our use of a convenience, as opposed to an exact matched population, sample for comparison does limit the generalizability of our diagnosis prevalence data, though even such gross comparative prevalence data have been lacking for this patient population until this study.

6. Conclusions

In summary, we conclude that feeding ability and rising number of prescribed medications are most significantly associated with increased odds of ED utilization and hospitalization among intellectually disabled adults in this study cohort and that their ED and hospital discharge diagnoses significantly differ from this convenience sample of a general adult ED population in a pattern of relevance to emergency physicians. These conclusions are of interest to both outpatient providers as well as emergency physicians because they suggest targets of investigation that may potentially reduce ED utilization and hospitalization among intellectually disabled adults. In addition, our findings provide data regarding prevalence of acute diagnoses that cause morbidity resulting in both ED presentation and hospitalization that can be used to generate a gross pretest probability of diagnosis in the challenging population of intellectually disabled adults.

Acknowledgment

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