Characteristics of Emergency Department Visits by Adults with Down Syndrome: A Single-Institution Retrospective Study

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BACKGROUND

- People with Down syndrome (DS) are living longer due to advances in medical care, increasing the need for adult healthcare services.[1-5]
- Studies have shown that patients with DS who do not transition to adult services may receive suboptimal care due to limited training of pediatricians and pediatric specialists in managing co-morbidities for these older patients.[2]
- However, patients with DS often struggle when moving to adult care due to barriers in coordinating these transitions.[6]
- Patterns of use of these patients in adult EDs is unknown.

OBJECTIVE

The objective of this study was to describe visits by adult patients with DS to an academic medical center.

METHODS

- **Study Design:** Retrospective chart review of adults with DS aged ≥18 years presenting to either of two EDs within The Ohio State University Wexner Medical Center from January 1, 2019 – December 31, 2023.
- **Patient identification:** Patients were identified using ICD-9 and ICD-10 diagnostic codes for DS.
- **Data source:** All data were abstracted from the EMR by chart review and securely stored in REDCap.
- **Analysis:** This was a descriptive study, with results reported as counts (n) and percentage (%). Age-based trends in testing patterns and comorbidities were compared to the general population.

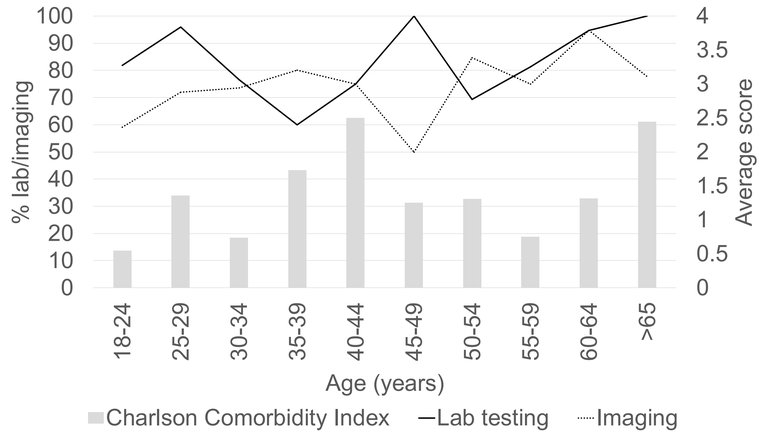
RESULTS

- There were 177 ED visits by 106 patients during the study period.
- Most patients were male (64.3%), lived in a private residence with family, friends, or other non-medical hired assistance (67.9%).
- Most had a primary care physician listed (95.3%).
- The top 3 chief complaints were abdominal pain (10.2%), seizure (7.9%), extremity or back pain (7.3%).

Table. Post-ED visit healthcare needs. (n=177)

Next healthcare visit	
Emergency department	29 (16.4)
Primary care	55 (31.1)
Specialist	84 (47.5)
No visit in our electronic health record	9 (5.1)
Next healthcare visit related to ED visit? (n=168)	
Yes	84 (50.0)
No	84 (50.0)
Return to ED within 72 hours	
Yes – related to index	5 (2.8)
Yes – unrelated to index	1 (0.6)
No	171 (96.6)

Figure. Frequency of any lab test, any imaging test and the average Charlson Comorbidity Index at emergency department visits by adults with DS across the age span. (n=177)



CONCLUSIONS

- Adults with DS demonstrated higher rates of ED testing and hospital admission compared to national ED trends reported by the 2022 National Hospital Ambulatory Medical Care Survey (NHAMCS).
- ED presentations differed from the general population, with seizure and neurologic complaints occurring more frequently (2022 NHAMCS).
- Patterns of comorbidity and imaging use suggest earlier aging-related changes in DS individuals.
- These findings highlight the need for greater awareness of the emergency care needs of adults with DS as this population continues to age.

FUTURE DIRECTIONS

- Determine if this pattern is consistent in other EDs including children's EDs that see many complex patients into adulthood.
- Explore type of primary care provider and potential affects on these patterns.
- Compare utilization to matched patients without DS.

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