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No-Show Clinic Appointments and the Social Determinants of Health in Pediatric Patients with 22q

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No-Show Clinic Appointments and the Social Determinants of Health in Pediatric Patients with 22q11.2 Deletion Syndrome

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Abstract

Introduction: 22q11.2 deletion syndrome (22q11DS) and 22q duplication syndrome present a wide range of medical challenges. The health and well-being of pediatric patients with 22q11DS may be influenced by socioeconomic factors, which can significantly shape their healthcare experiences, access to services, and overall quality of life. The objective of this study is to identify what factors are correlated with no-show clinic visits for children with 22q11DS.

Methods: A retrospective chart review was performed on pediatric patients in a 22q patient registry of a tertiary care facility that includes patients with 22q11DS and 22q duplication syndrome. Demographic data, sex assigned at birth, appointment attendance, comorbid conditions, and patient specific outcomes were collected for analysis. The patient's home address was cross-referenced with the GeoMarker database to define corresponding specific socioeconomic contextual variables.

Results: 236 patients were included in the study including 198 patients (83.9%) with 22q11DS and 38 patients (16.1%) with 22q duplication syndrome. Collectively, these patients were scheduled for a total of 9,734 clinic visits and 2,347 visits with the 22q multidisciplinary clinic (22q MDC). The overall mean rate of no-show clinic visits for the 22q MDC was 7.7% ± 10.9 and the median was 0% (IQR = 8.4%). Factors associated with clinic no-show included lower median household income (OR (95% CI) 1.43 (1.25-1.64), p < .001), lower fraction of population with high school diploma (OR (95% CI) 2.33 (2.04-2.67), p < .001) higher fraction of population below the poverty line (OR (95% CI) 1.52 (1.32-1.73), p < .001) and higher fraction of population that required assisted income (OR (95% CI) 1.38 (1.21-1.58), p < .001). Interestingly, farther distance from the tertiary care facility was associated with lower no-show rate (OR (95% CI) 0.71 (0.60-0.85), p < .001).

Conclusion: These findings highlight the potential influence of socioeconomic factors on no-show clinic appointments in pediatric patients with 22q11DS. These factors can be used to help identify patients at risk of no-show clinic appointments and be used to develop targeted interventions aimed at improving clinic attendance and ultimately elevating patient outcomes.

Introduction

➢ 22q11.2 deletion syndrome (22q11DS) and 22q duplication syndrome cause a range of health issues in children, which include congenital heart defects, unique facial characteristics, airway problems, learning challenges, and immune disorders.[1–3]

➢ This study aims to determine what factors are linked to children with 22q11DS not attending their clinic appointments. Specifically, we aim to identify if non-medical factors such as household income, education level, and how far patients live from the clinic contribute to missed appointments. Our goal is to understand better how these social and economic factors affect the care of this vulnerable group.

Methods and Materials

➢ **Study Design:** A retrospective chart review was performed on pediatric patients in a 22q patient registry of a tertiary care facility that includes patients with 22q11DS and 22q duplication syndrome. These patients were referred to 22q multidisciplinary clinic (22q MDC) and had genetic confirmation of 22q11DS or 22q duplication syndrome.
- ➢ Inclusion Criteria:
  - ➢ Patients had at least two scheduled 22q Multidisciplinary clinic appointments
  - ➢ Appointment attendance data was available
- ➢ Exclusion Criteria:
  - ➢ Socioeconomic data not available

➢ **Data collected:** Demographic data, sex assigned at birth, appointment attendance, comorbid conditions, and patient specific outcomes were collected for analysis. The patient's home address was cross-referenced with the GeoMarker database to define corresponding specific socioeconomic contextual variables.[4]
- ➢ Socioeconomic contextual variables from the GeoMarker database are derived from the 2018 ACS 5-year (2014-2018) dataset in National Historical Geographic Information System. The deprivation index was derived from the 2018 American Community Survey.[5]
- ➢ No-show status was defined as a scheduled clinic appointment that the patient did not attend and was not cancelled or rescheduled prior to the appointment time.

➢ **Statistical analysis:**
- ➢ Kendall tau correlation coefficient was used to identify relationships between numerical data
- ➢ Linear and logistic regression models were used to further characterize the relationship between the socioeconomic variables and clinic no-show status.
  - ➢ The upper or lower quartiles of each socioeconomic variable was used as a cut off value for these models.

Results

➢ 290 total patients were identified in the 22q registry. 54 patients were excluded for incomplete socioeconomic data or less than two scheduled 22q Multidisciplinary clinic appointments.

➢ 236 patients were included in the study for a total of 9,734 clinic visits and 2,347 visits with the 22q multidisciplinary clinic

Patient characteristics	Included patients
Gender (n, %)	
Male	140 (59.3%)
Female	96 (40.7%)
Race (n, %)	
American Indian and Alaska Native	2 (0.8%)
Asian alone	8 (3.4%)
Black or African-American	20 (8.5%)
Multiracial	8 (3.4%)
Not Reported	15 (6.4%)
Some Other Race	1 (0.4%)
White	182 (77.1%)
Ethnicity (n, %)	
Hispanic or Latino	19 (8.1%)
Not Hispanic or Latino	215 (91.1%)
Not Reported	2 (0.8%)
Spoken language (n, %)	
Burmese	1 (0.4%)
English	228 (96.6%)
Mandarin	1 (0.4%)
Spanish	6 (2.5%)
22q Genetic diagnosis (n, %)	
22q11.2 Deletion Syndrome	198 (83.9%)
22q Duplication Syndrome	38 (16.1%)
Percent of no-show for all clinic appointments (Median (IQR))	4.2% (15.0%)
Percent of no-show for 22qMDC appointments (Median (IQR))	0% (8.4%)

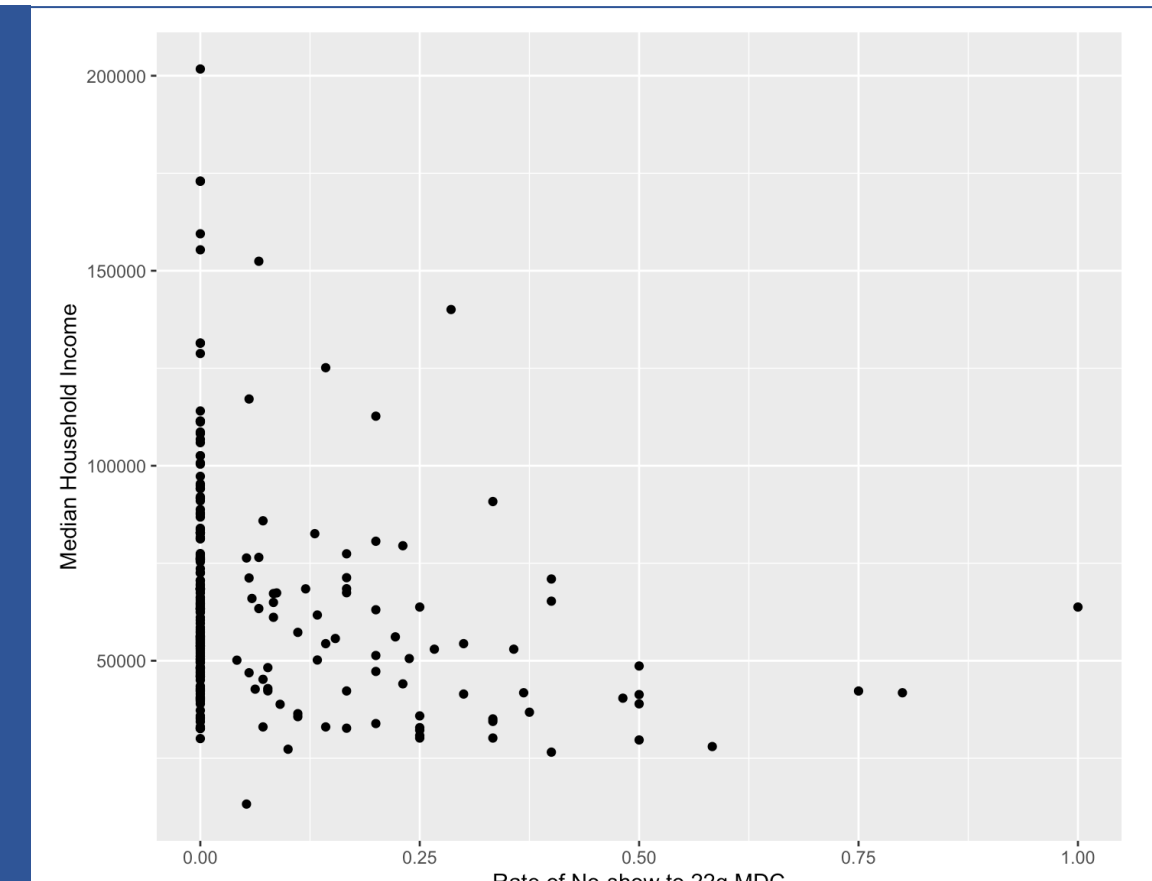**Table 1.** Patient characteristics and demographics.

Figure 1. Median household income vs. Rate of no-show to the 22q multidisciplinary clinic (22q MDC).
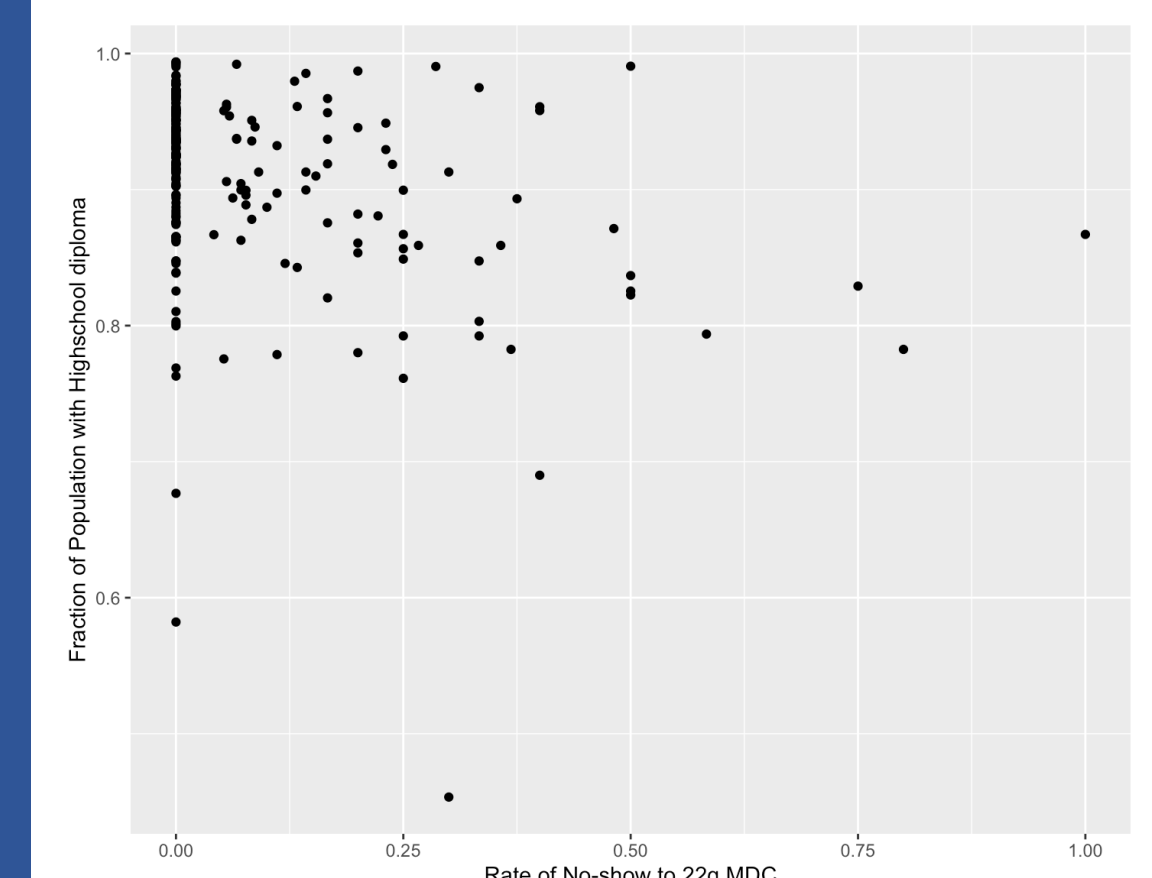

Figure 2. Fraction of population with high school degree vs. Rate of no-show to the 22q multidisciplinary clinic (22q MDC).

Socioeconomic factors	Median (IQR)	Kendall tau correlation coefficient	p-value
Median household income ($)	57772 (30598.25)	-0.223	< .001
Fraction of population on assisted income	0.079 (0.960)	0.226	< .001
Fraction of population with high school diploma	0.926 (0.076)	-0.241	< .001
Fraction of population with no health insurance	0.081 (0.079)	0.195	< .001
Fraction of population below the poverty line	0.107 (0.110)	0.206	< .001
Deprivation index	0.313 (0.135)	0.240	< .001
Distance from Children's Mercy (km)	52.54 (174.27)	-0.105	0.032

Table 2. Socioeconomic factors for included patients. Median and interquartile range (IQR) are reported for all values. Correlation with rate of no-show clinic visits represented by Kendall tau correlation coefficient and corresponding p-value.

Discussion

➢ The complex healthcare requirements for children with 22q11DS and 22q duplication syndrome will often require care from many healthcare providers, making it difficult for patients and their caregivers to get treatment and attend follow-up care.[6] This complexity can also lead to missed appointments due to the strain it puts on caregivers.

➢ Patients living in areas with lower median household income, lower fraction of population with high school diploma, higher fraction of population below the poverty line and higher fraction of population that required assisted income had a higher observed rate of missed clinic appointments.

➢ Multidisciplinary clinics aim address these issues by providing a coordinated approach to care. This approach can lead to more effective management of the conditions, better patient outcomes, and improved overall quality of care. However, our study has revealed that socioeconomic differences exist in this population and lead to differences in missed clinic appointments.

Conclusions

➢ These results underscore how socioeconomic factors can affect the likelihood of pediatric patients with 22q11DS missing clinic appointments.

➢ Identifying these factors can help pinpoint patients at risk of missing appointments and may help guide the development of interventions to improve attendance, leading to better patient outcomes.

References

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