Self-reported health-related quality-of-life in adolescent patients with special healthcare needs from a longitudinal registry study in Los Angeles County

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BACKGROUND

Adolescent patients with special healthcare needs are at increased risk for chronic physical, developmental, behavioral, or emotional conditions.
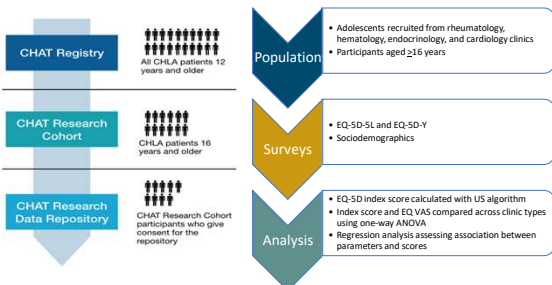
OBJECTIVE

To assess trends in health-related quality-of-life (HRQoL), measured using EQ-5D-5L index and visual analog scale (VAS) scores in adolescent patients with special healthcare needs by age and specialty clinic, specifically cardiology, endocrinology, hematology, and rheumatology.

METHODS

The CHAT registry is a longitudinal registry at Children's Hospital Los Angeles (CHLA) enrolling those aged 12+ to track their transition out of pediatric care over time. The Research Cohort is made up of individuals aged 16+ from the registry who have opted to participate in research (Figure 1).
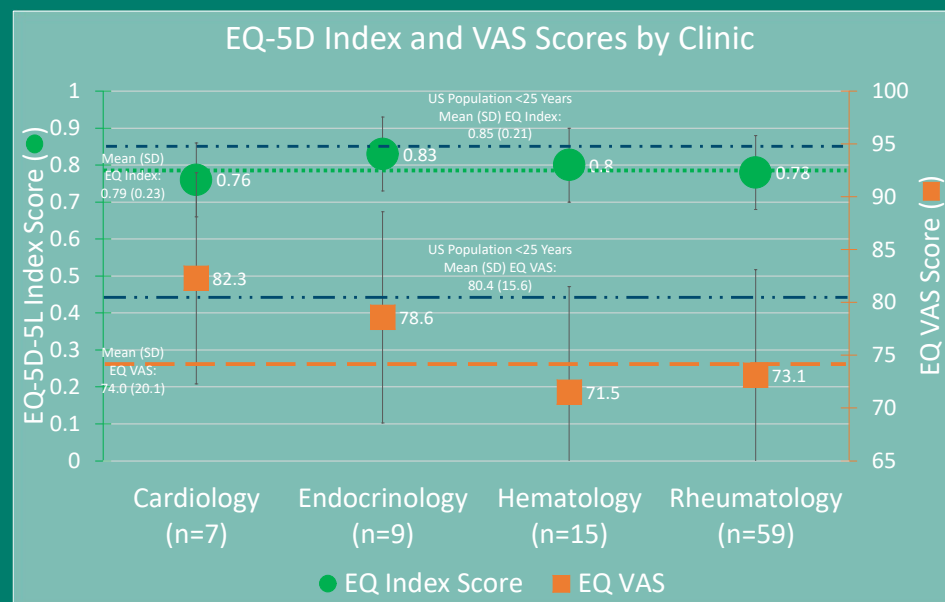
FIGURE 1. SAMPLE COHORT AND METHODS

Individuals complete a battery of surveys, including the EQ-5D-5L, annually until they no longer receive care at CHLA (age 26). In addition, specialty clinic from which the individual was recruited is noted as a proxy for primary chronic condition. Age at time of survey completion is also collected.

ANALYSIS

EQ-5D-5L index scores and VAS scores were calculated for the overall cohort, by specialty clinic, and by age group (17-18, 19-20, 21-22, and 23-25 years of age). ANOVA was used to test for statistically significant differences in index and VAS scores by age group and clinic type. Given the largest sample size was from rheumatology, t-test was used to test for significant differences between rheumatology and other specialty clinic types. A regression was also run to determine the impact of age on EQ-5D-5L index and EQ VAS scores.

EQ-5D-5L[1] index and VAS scores among adolescents with special healthcare needs are lower than those for the US population aged <25 years and at age 21-22.[2] The magnitude of the score differences between age groups and disease conditions may be considered clinically meaningful.

EQ-5D Index and VAS Scores by Clinic

RESULTS

A total of n=90 individuals completed the EQ-5D-5L from cardiology (n=7, 7.8%), endocrinology (n=9, 10%), hematology (n=15, 16.7%), and rheumatology (n=59, 65.5%). The median (range) age was 20 (17-24) years; mean (SD) 19.91 (1.78) years; most were aged 19-20 (n=37), the other age groups were 17-18 (n=21), 21-22 (n=24), and 34-25 (n=8) years of age. Overall, the EQ-5D-5L index and VAS scores were as follows:

- **EQ-5D-5L Index Score**
  - Median (range): 0.85 (-0.35-1.00)
  - Mean (SD): 0.79 (0.23)
- **EQ-VAS Score**
  - Median (range): 78.00 (16.00-100)
  - Mean (SD): 74.04 (20.57)

Scores were lowest for cardiology and hematology, while those aged 21-22 reported the lowest scores. These are shown by age and clinic in Table 1 below:

TABLE 1. EQ-5D-5L INDEX and VAS BY CATEGORY

Age		17-18 (n=21)	19-20 (n=37)	21-22 (n=24)	23-25 (n=8)	ANOVA
EQ-5D-5L	Mean (SD)	0.78 (0.20)	0.81 (0.17)	0.73 (0.33)	0.84 (0.15)	p=0.54
	Median (range)	0.88 (0.36-1.00)	0.85 (0.49-1.00)	0.83 (-0.35-1.00)	0.83 (0.60-1.00)	--
EQ-VAS	Mean (SD)	78.2 (16.5)	72.1 (21.8)	71.0 (22.8)	81.1 (17.6)	p=0.95
	Median (range)	80.0 (46.0-100.0)	78.0 (30.0-100.0)	75.0 (16.0-100.0)	78.0 (52.0-100.0)	--
Clinic		Cardiology (n=7)	Endocrinology (n=9)	Hematology (n=15)	Rheumatology (n=59)	ANOVA
EQ-5D-5L	Mean (SD)	0.76 (0.19)	0.83 (0.19)	0.80 (0.17)	0.78 (0.25)	p=0.61
	Median (range)	0.82 (0.51-1.00)	0.88 (0.50-1.00)	0.79 (0.50-1.00)	0.88 (-0.35-1.00)	--
EQ-VAS	Mean (SD)	82.3 (19.2)	78.6 (21.8)	71.5 (18.9)	73.1 (21.1)	p=0.88
	Median (range)	85.0 (50.0-100.0)	79.5 (46.0-100.0)	76.0 (41.0-100.0)	78.0 (16.0-100.0)	--

KEY: ANOVA – analysis of variance; EQ-VAS – EuroQol Visual Analog Scale

When comparing rheumatology to other clinics, there was no statistically significant difference in EQ-5D-5L index score (p=0.64). When examining the association of age and EQ-5D-5L index score, age was found not to be statistically significant; similar results were found for the EQ-VAS.

CONCLUSION

Pediatric patients with special healthcare needs showed lowest HRQoL at age 21-22, though age was not significantly associated with HRQoL changes in this patient cohort. Continued data collection and analysis is warranted.

LIMITATIONS

- Sample size is limited given difficulties in recruiting and retaining participants for research.
- High degree of attrition throughout the study limits the number of surveys able to be collected.
- Recruitment location (clinic) was used as a proxy for primary medical concern, though this may not necessarily be the primary diagnosis affecting the patient. Given difficulties in obtaining accurate ICD diagnoses in this cohort, clinic was used to simplify analyses.

REFERENCES

1. EQ-5D-5L. EuroQol. January 21, 2025. Accessed April 30, 2025. https://euroqol.org/information-and-support/euroqol-instruments/eq-5d-5l/
2. Jiang R, Janssen MFB, Pickard AS. US population norms for the EQ-5D-5L and comparison of norms from face-to-face and online samples. Qual Life Res. 2021;30(3):803-816.

DISCLOSURES