

# Adolescent Health Related Quality of Life: Mind the Gap!

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## BACKGROUND & AIMS

It is widely recognised that the health care and emotional needs in adolescence is distinctly different from younger children and adults. Clinical care during this transition period has transformed to ensure that adolescents needs are met. Decision making bodies around the world, such as the National Institute for Health Care Excellence (NICE), rely on Health Related Quality of Life (HRQoL) for funding decisions. They endorse the generic EuroQoL HRQoL questionnaires which have both an adult (EQ-5D-3L) and youth version (EQ-5D-Y-3L). Similar appraisal decisions are currently being considered for national health insurance (NHI) in South Africa. This study aims to:

- investigate whether adolescents living with HIV (ALHIV) and Diabetes Mellitus (ALDM) answer the adult and youth questionnaires differently and
- whether they can detect known-group validity with comparison to a general population sample.

## METHODS

Adolescents aged 13-18 years were recruited between June 2021 and May 2022 from the Infectious Diseases and Endocrine transition care clinics at Groote Schuur and Red Cross War Memorial Children's Hospitals. The general population sample was recruited from schools in the same geographical catchment area as clinics. The EQ-5D-3L and EQ-5D-Y-3L were presented to consenting adolescents in random order and separated by a cognitive task (word problem). Both questionnaires include five questions on health with slightly different wording e.g Mobility, Self-care (example of washing and dressing for youth), Usual Activities (with adult or youth appropriate examples), Pain/Discomfort and Anxiety/Depression (adult) or Worried, Sad or Unhappy (youth). The questionnaires include a rating of general health on a visual analogue scale (VAS) from 0 (worst imaginable health) – 100 (best imaginable health). Clinical information was extracted from the medical folder. Kruskal-Wallis H test was used to assess the known group-validity of HRQoL scores by health condition and clinical characteristics.

## RESULTS

### Adolescents living with HIV (ALHIV) (n=85)

ALHIV		n (%)	Adult EQ-5D-3L p-value	Youth EQ-5D-Y-3L p-value	EQ VAS p-value
WHO stage	1 or 2	11 (13%)	0.365	0.298	0.553
	3	45 (53%)			
	4	29 (34%)			
Viral Load	<50	18 (21%)	0.352	0.463	0.346
	51-1000	57 (67%)			
	>1000	10 (12%)			
Anti-retroviral Therapy (ART)	NNRTI	3 (3%)	0.913	0.799	0.251
	INSTI	42 (50%)			
	PI	40 (47%)			
Duration on ART (yrs)	Median	14	0.338	0.959	0.568
	(IQR)	(12,16)			
Complications	Yes	47 (55%)	0.338	0.959	0.568
	No	38 (45%)			

*NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitor, INSTI: Integrase Strand Transfer Inhibitors and PI: Protease Inhibitor*

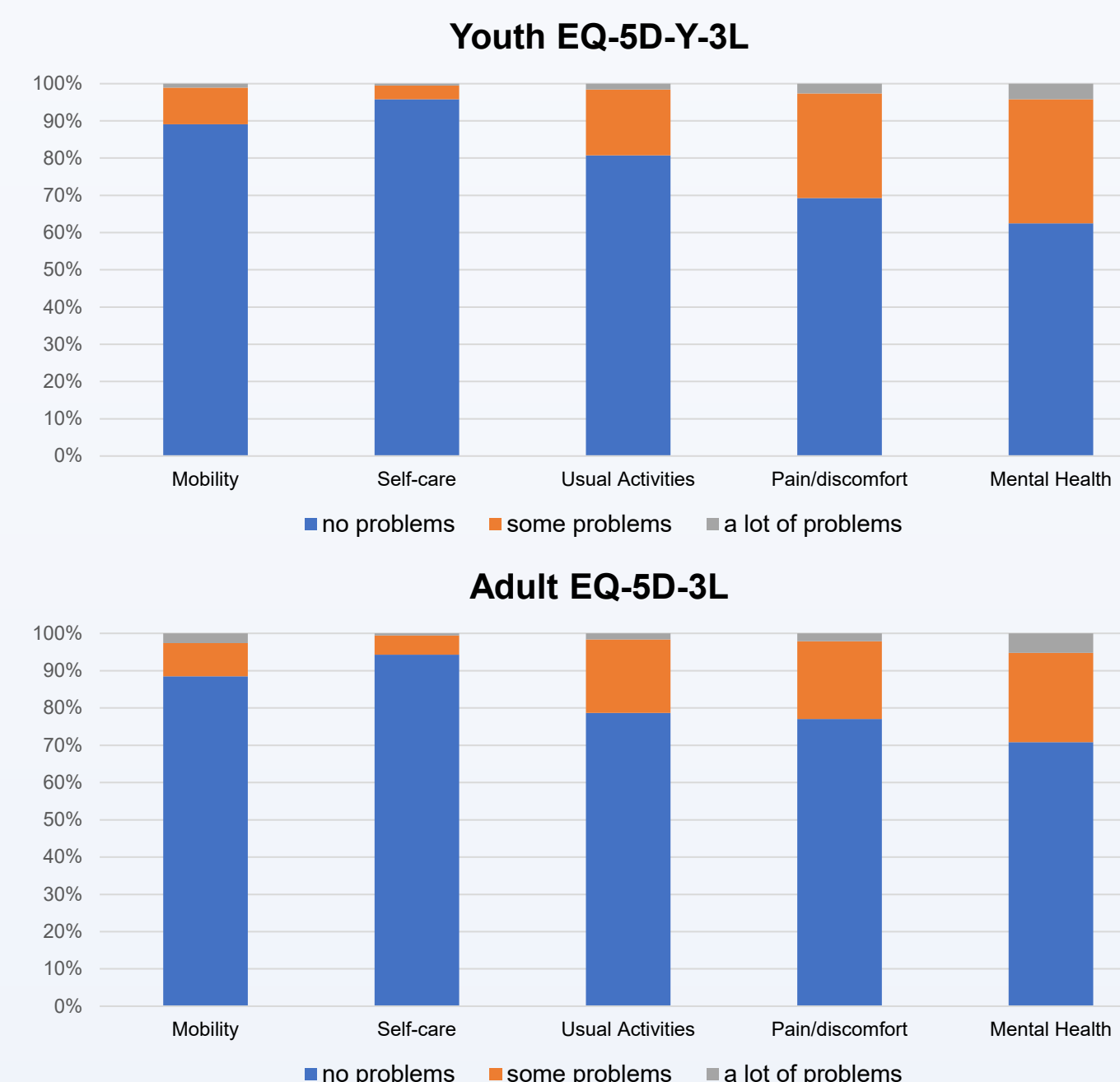
HIV related complications include HIV encephalopathy (n=9, 11%), HIV associated neurocognitive disorder (n=3, 4%) and chronic lung disease (n=3, 4%)

### Adolescents living with Diabetes Mellitus (ALDM) (n=107)

ALDM		n (%)	Adult EQ-5D-3L p-value	Youth EQ-5D-Y-3L p-value	EQ VAS p-value
HbA1C	<7.0	8 (7%)	0.539	0.447	0.314
	7.1-8.5	22 (21%)			
	8.6 -11	33 (31%)			
	>11	44 (41%)			
Duration living with DM (yrs)	0-1 yrs	19 (18%)	0.538	0.5	0.963
	2-4 yrs	24 (22%)			
	5-9 yrs	41 (38%)			
	≥10 yrs	23 (22%)			
Complications	Yes	19 (18%)	0.489	0.234	0.681
	No	88 (82%)			

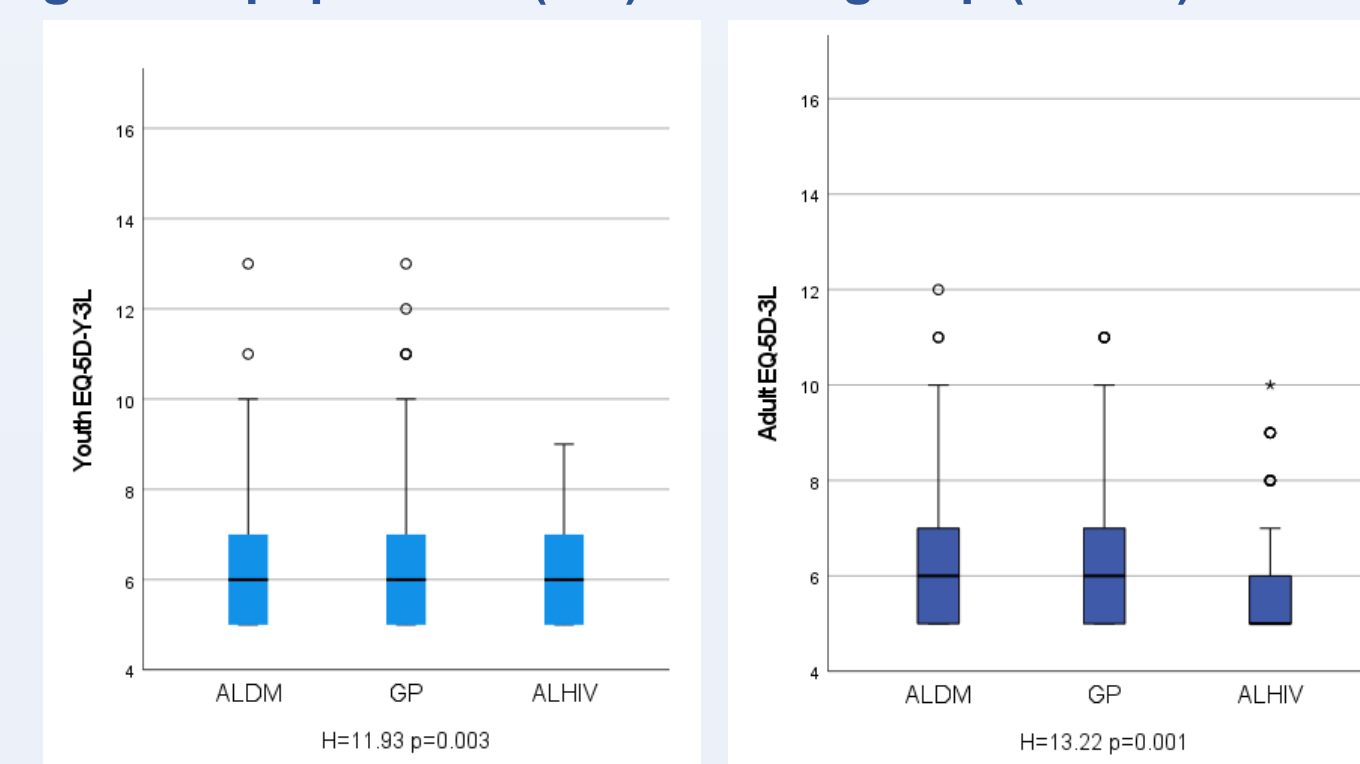
Co-morbidities in ALDM included leg pain, rash or acanthosis, diabetic ketoacidosis and headache (all <3%).

### ALHIV and ALDM (n=192) Dimension responses on youth and adult versions



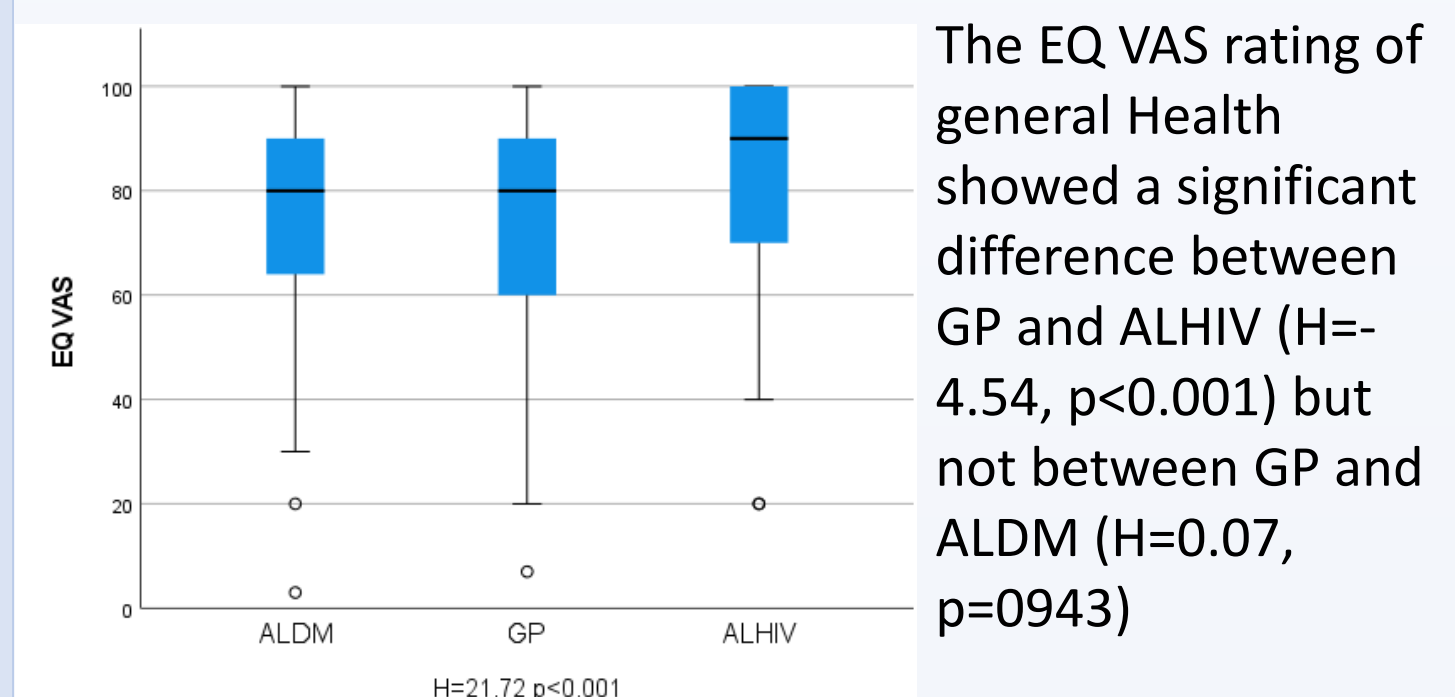
There was 9% discrepancy in responses for usual activities (n=10) and pain/discomfort (n=11) and 34% for mental health (n=36) between the youth and adult questionnaires with the youth version detecting more problems.

### Known group validity ALHIV (n=85) and ALDM (107) vs general population (GP) school group (n=294)



## RESULTS continued

ALHIV had significantly lower youth EQ-5D-Y-3L (H=3.280, p=0.003) and adult EQ-5D-3L (H=3.439, p<0.001) scores than children from the general population (GP) school sample. There were no significant differences on either measures for ALDM and the GP sample.



The EQ VAS rating of general Health showed a significant difference between GP and ALHIV (H=-4.54, p<0.001) but not between GP and ALDM (H=0.07, p=0.943)

## DISCUSSION & CONCLUSION

The EQ-5D-Y-3L describes mental health as worried, sad or unhappy whereas the adult EQ-5D-3L describes it as anxiety or depression. This results in the youth version detecting more problems with mental health compared to the adult version. However, the youth version did not detect any mental health concerns in 10% of ALDM who reported some problems with anxiety or depression, which may arguably be more clinically relevant. Despite the pain/discomfort question being identical in the two questionnaires there was a discrepancy noted for both ALHIV and ALDM. These discrepancy in responses needs to be investigated in responsiveness analysis in clinical trials as the choice of questionnaire could influence health resource allocation. Although the questionnaire showed validity in its ability to differentiate health between ALHIV, ALDM and the general population consideration needs to be given to the development of adolescent specific HRQoL measures.

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