Assessment of Health-Related Quality of Life in Pediatric Acquired Demyelination Using Two Instruments

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INTRODUCTION

- Health-related quality of life (HRQOL) in children is a broad and multidimensional construct that includes aspects of life quality affected by health status such as physical health, as well as social, emotional, and school functioning[1].
- A first episode of acquired demyelination in childhood may negatively affect HRQOL.
- Assessment of HRQOL in children with acquired demyelination is important for understanding the particular burden of the illness and treatment, as well as for informing efforts aimed at improving HRQOL[2].
- Despite the importance of assessing HRQOL, the utility of different HRQOL measures in children with pediatric demyelinating disease is unknown.

AIM & HYPOTHESIS

AIM:

- To investigate the utility of two well-known HRQOL measures, the **PedsQL 4.0** and the **KIDSCREEN-27**, in evaluating HRQOL in pediatric patients with a first-time episode of demyelination.

HYPOTHESIS:

- Patients with acquired demyelination and their parents will report lower scores on the specific and overall HRQOL scales of the **PedsQL 4.0** and **KIDSCREEN-27** in comparison to controls.

METHODS

SAMPLE:

- 18 consecutive patients with newly diagnosed acquired demyelinating syndrome (ADS) attending a Pediatric MS clinic and their parents and 29 healthy controls and their parents

Table 1. Sample demographics.

Demographics	ADS Patients (n=18)	Controls (n=29)
Sex (M:F)	10 : 8	9 : 20
Age at assessment, M (SD)	12.5 years (2.4) range = 8.06-16.04	14.5 years (1.8) range = 11-18.02
Age at demyelination, M (SD)	11.7 years (2.7)	–

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METHODS

Assessment of Health-Related Quality of Life (HRQOL)

- Participants completed the **Pediatric Quality of Life Inventory Version 4.0 (PedsQL 4.0)** and **KIDSCREEN-27** six months after experiencing a demyelinating event (mean = 6.3 ± 1.0 months).
- Each questionnaire is comprised of parallel child and adolescent self-report and parent-proxy report formats and is rated on a 5 point response scale
- Groups were compared on specific and overall HRQOL scales using an analysis of variance

Table 2. Generic Health-Related Quality of Life Instruments

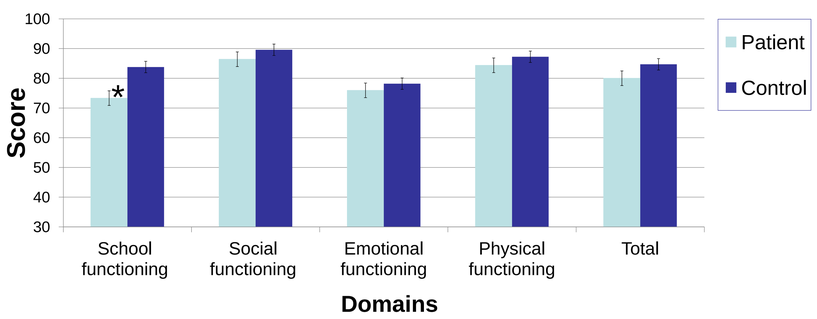
Pediatric Quality of Life Inventory Version 4.0 (PedsQL™ 4.0)		KIDSCREEN-27 (Short-version)	
Physical Functioning	**8 items**	***Physical Well-Being***	**7 items**
Emotional Functioning	**5 items**	***Parent Relations & Autonomy***	**7 items**
Social Functioning	**5 items**	***Social Support & Peers***	**4 items**
School Functioning	**5 items**	***School Environment***	**4 items**
Instructions: How much of a problem has each item been during the past 1 month?		*Instructions*: Rate the frequency of a behaviour, feeling or the intensity of an attitude within a one week period.	

RESULTS

PedsQL™ 4.0

- Scores on the Physical, Emotional, and Social scales were within normal limits and did not differ between groups on the self- and parent-report.
- Lower School Functioning was reported by the patient group relative to controls on the self-report (73.3 vs. 83.8, *p*= .02) and parent report (68.2 vs. 85.4, *p*= .01).

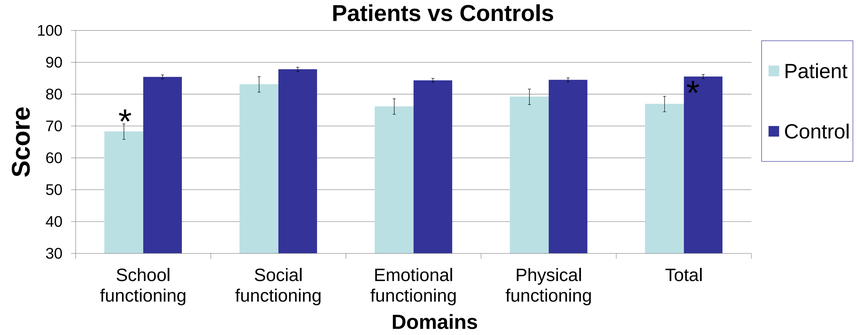
Figure 1. Self Report generic core scales of the PedsQL™ 4.0 – Patients vs Controls



RESULTS – Cont'd

- Total score on the PedsQL 4.0 was lower in the patient group on the parent version (76.9 vs. 85.5, *p*=.05), but not the self-report version (80.0 vs. 84.7, *p* = .19).

Figure 2. Parent Report PedsQL™ 4.0 generic core scales – Patients vs Controls



Kidscreen-27

- Scores on the Physical, Psychological Well-Being, Parents, Peers and School scales were all within the normal range and did not differ between groups (all *p* values >.50).

Figure 3a. Self Report KIDSCREEN-27 generic core scales – Patients vs Controls

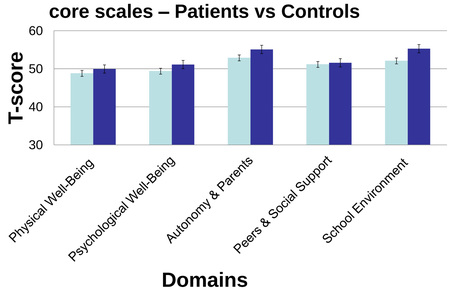
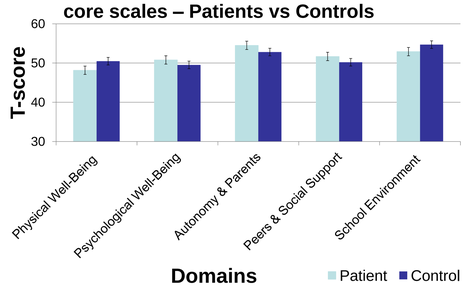


Figure 3b. Parent Report KIDSCREEN-27 generic core scales – Patients vs Controls



CONCLUSIONS & FUTURE DIRECTIONS

- HRQOL, as assessed by both instruments, and reported by patients and their parents six months after experiencing acquired demyelination was comparable to controls with the exception of the School Functioning scale on the PedsQL 4.0.
- Lower School Functioning reflects the need to miss school and make visits to the doctor within the first six month after a demyelinating event. Both parents and patients endorsed lower School Functioning scores on the PedsQL 4.0.
- Based on these findings and the strong psychometric properties and broad age range of the PedsQL 4.0, we recommend its use for assessing HRQOL in youth with ADS.
- Whether responses of patients with ADS and their parents on these two HRQOL instruments remain stable over time is being investigated by our group.

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