Service improvement project:
Analysis of routine clinical data in paediatric neuropsychological rehabilitation

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BACKGROUND:

The international collaboration of the Common Data Elements (CDE) group recommend measures for the paediatric ABI population (McCauley et al., 2012). These may or may not be the most appropriate for rehabilitation outcome measurement.

Recolo UK Ltd is a provider of privately funded community based neuropsychological rehabilitation for children, young people and young adults. Associates collect data from their assessments and reviews to describe impairments and monitor rehabilitation outcome. We have used measures recommended by the CDE (Gosling, 2015).

AIMS:

Exploration of clinical hypotheses in assessment data.

METHOD:

Ethics: Classed as a service evaluation, research ethics application is not required (University of Bristol Research Enterprise and Development: Ethics Application 61661).

Clients: Children with age range 0-18 yrs, age at injury 0-18 yrs, brain injury types traumatic and non-traumatic, severity mild to severe.

Through routine clinical practice, associates have collected data of 150 children with brain injury and their families.

Measures: PedsQL Core and Fatigue inventories (child and parent forms), PedsQL Family Impact Module, Family Assessment Device (FAD), Behaviour Rating Inventory of Executive Function (BRIEF), Strengths and Difficulties Questionnaire (SDQ) and Child and Adolescent Scale of Participation (CASP).

Procedure: Data was anonymized for analysis, tested for normality. Nonparametric tests used due to the data being abnormally distributed.

Hypotheses: Clinically relevant hypotheses were generated by Research Lead, Clinical Lead and Researcher, as below:

RESULTS:

SOCIAL

1. 'Social Functioning on the PedsQL Core (Self-report) and Peer Problems index on SDQ (Self-report) will correlate'. There was a strong negative correlation between the two variables. $\rho = -0.664$, n=18, p = 0.003. (See Fig. 1.)

2. A hypothesized Spearman's correlation between Cognitive Fatigue on PedsQL Fatigue (Self-report) and Social Functioning on PedsQL Core (self-report) was found to be statistically non-significant: $\rho = .386$, n=25, p = .057.

### Fig. 1. Relationship between self-report Social Functioning and Peer Problems
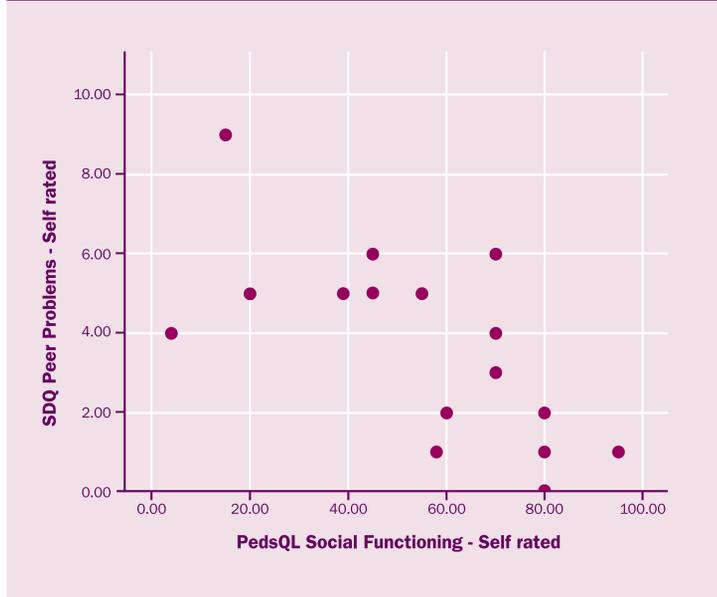
EMOTIONAL

3. 'Emotional Problems on SDQ (self-report) will negatively correlate with Emotional Functioning in the PedsQL Core (self-report)'. This was not statistically significant: $\rho = -.194$, n = 17, p = 0.456.

4. A negative correlation was hypothesised between Behaviour Regulation Index on BRIEF (parent report) and Emotional Functioning on the PedsQL Core (parent report). There was a weak but statistically significant negative correlation: $\rho = -0.374$, n=84, p < 0.01.

In addition to the hypothesised correlations, there were also significant associations between self-report Emotional Functioning PedsQL and Peer Problems from SDQ ($\rho = -610$, n = 17, p = 0.009) and Social Functioning from PedsQL ($\rho = .730$, n = 18, p = 0.001). (See Fig. 2.)

Fig. 2. Relationship between self-report Social and Emotional Functioning
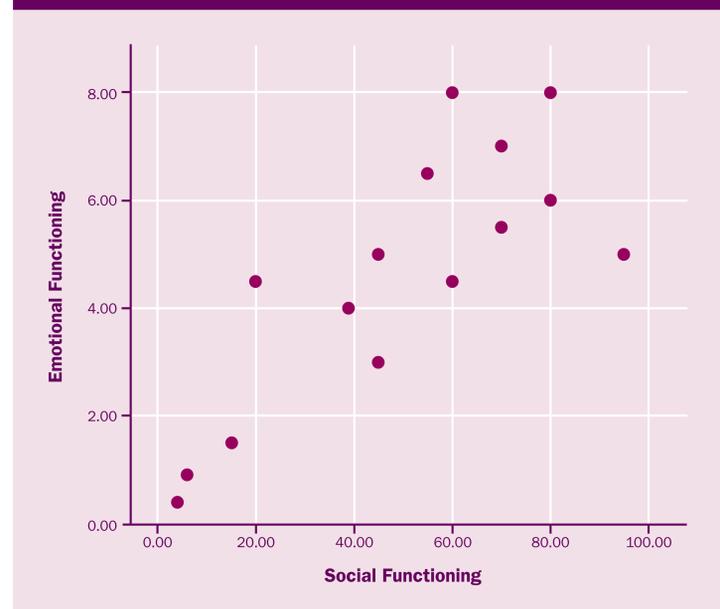
ACADEMIC

5. A moderate positive Spearman's correlation between Cognitive Fatigue on PedsQL Fatigue (self-report) and School Functioning on PedsQL Core (self-report) was observed, $\rho = 0.583$, n=25, p = 0.02.

6. A moderate negative correlation between Metacognitive Index in BRIEF (parent-report) and School Functioning in the PedsQL Core (parent-report) was statistically significant, $\rho = -0.445$, n = 81, p < 0.01.

CHILD/PARENT RATING CORRESPONDENCE

Mann Whitney U Tests were used to test the hypothesis that children will rate themselves differently on the PedsQL Core than parents. (See Table 1.) Children rated their quality of life higher than their parents in Physical, Social and School Function and Total Health Related Quality of Life. The difference between groups on the Emotional Function domain was not significant.

Table 1. Differences Between Ratings by Parents and Children on PedsQL Core

	Physical Function		Emotional Function		Social Function		School Function		Total HRQL	
	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child
Median	47	62	45	50	50	65	45	55	46.9	60.9
var	589	466	446	481	611	587	452	399	261	303
N	72	73	71	73	72	72	71	73	66	68
Sig (2-tailed)	0.002		0.065		0.005		0.020		0.000	

DISCUSSION:

All but one of the clinical hypotheses were supported.

A strong correlation between social and peer difficulties suggests good construct validity of children's self-rated social functioning. Strong associations between a child's report on the PedsQL of their emotional functioning, peer problems and social functioning.

The less children report cognitive fatigue, the higher they rate their social and school function. Would improving energy levels see better social and school quality of life?

Poorer metacognitive function associated with lower quality of school life. Would metacognitive strategy development and fatigue management improve school function?

Surprisingly, the association between children's rating of their emotional distress and emotional functioning was not significant. This is likely due to differing symptoms in subscales and/or a small *n*.

A relationship between parents' rating of their child's behavioural regulation and emotional function requires further exploration. Children rate their quality of life higher than parents in physical, social, school domains and overall ratings but interestingly not significantly differently in emotional domains.

RECOMMENDATIONS:

Further analysis will include:

• Relationships between child and family ratings
• Evidence for sensitivity of change of measures
• Comparison with CDE guidance standard
• Consistency of data collection

Future database improvement by collecting:

• Data relating to intervention (e.g. number of sessions, focus of work)
• Data at the item level allowing more targeted analysis
  (e.g. isolating activity and participation items that are targeted in the rehab)
• Idiographic data (e.g. individually tailored goals)
• Client views on their experiences
• Streamlined data by reducing overlap of measures
• Prospective consent from families for use of data in research

CONCLUSION:

Preliminary analysis of our outcome data regarding the a priori hypotheses provided evidence of cognitive, emotional, social and educational relationships in the brain injured children. Once further analysis is complete, recommendations from the project will feed in to an improved Recolo database that will allow for targeted case and item-specific analysis.

References:

McCauley, S. R., Wilde, E. A., Anderson, V. A., Bedell, G., Beers, S. R., Campbell, T. F., et al. (2012). Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. *Journal of Neurotrauma*, 2: 678-705.

Gosling, S. (2015). Measuring outcomes for children with brain injury: challenges and solutions. In J. Reed, K. Byard & H. Fine (eds.) *Neuropsychological Rehabilitation of childhood brain injury: a practical guide*. Palgrave Macmillan.