National Academies Of
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The State of the Science of Solid Organ Transplantation and Disability

Assessing Physical & Cognitive Functioning in Children

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Introduction

- Solid Organ Transplantation recipients may have significant morbidity which affects their overall health

- Physical and Cognitive functioning may be assessed by
  - Exam: Strength measurements, problem solving
  - Instrument: Self reported ability and disability

Differences in Children

- Children are transplanted early in life
- They may have other congenital diseases that cause impairment
- Tend to be resilient

Defining Function

- Physical: The ability to perform everyday tasks.
- Cognitive: The processes involved in the acquisition of knowledge, manipulation of information, and reasoning.
- Age and Pre transplant health are important determinants of function

Interpreting Functional Assessments

- Tools must be age appropriate
- Depends on type of illness: (e.g dialysis or not)
- Type of assessment: Subjective vs objective
- Rater: Self or Proxy (parent, healthcare professional)

Physical Functioning

- Observation of physical ability
  - Attaining milestones
  - Lansky Scale
  - 6 min walk

LANSKY PERFORMANCE STATUS FOR CHILDREN*	
100	Fully active, normal
90	Minor restrictions in strenuous physical activity
80	Active, but tired more quickly
70	Greater restriction of play and less time spent in play activity
60	Up and around, but active play minimal; keeps busy by being involved in quieter activities
50	Lying around much of the day, but gets dressed; no active playing; participates in all quiet play and activities
40	Mainly in bed; participates in quiet activities
30	Bedbound; needing assistance even for quiet play
20	Sleeping often; play entirely limited to very passive activities
10	Doesn't play; does not get out of bed
0	Unresponsive

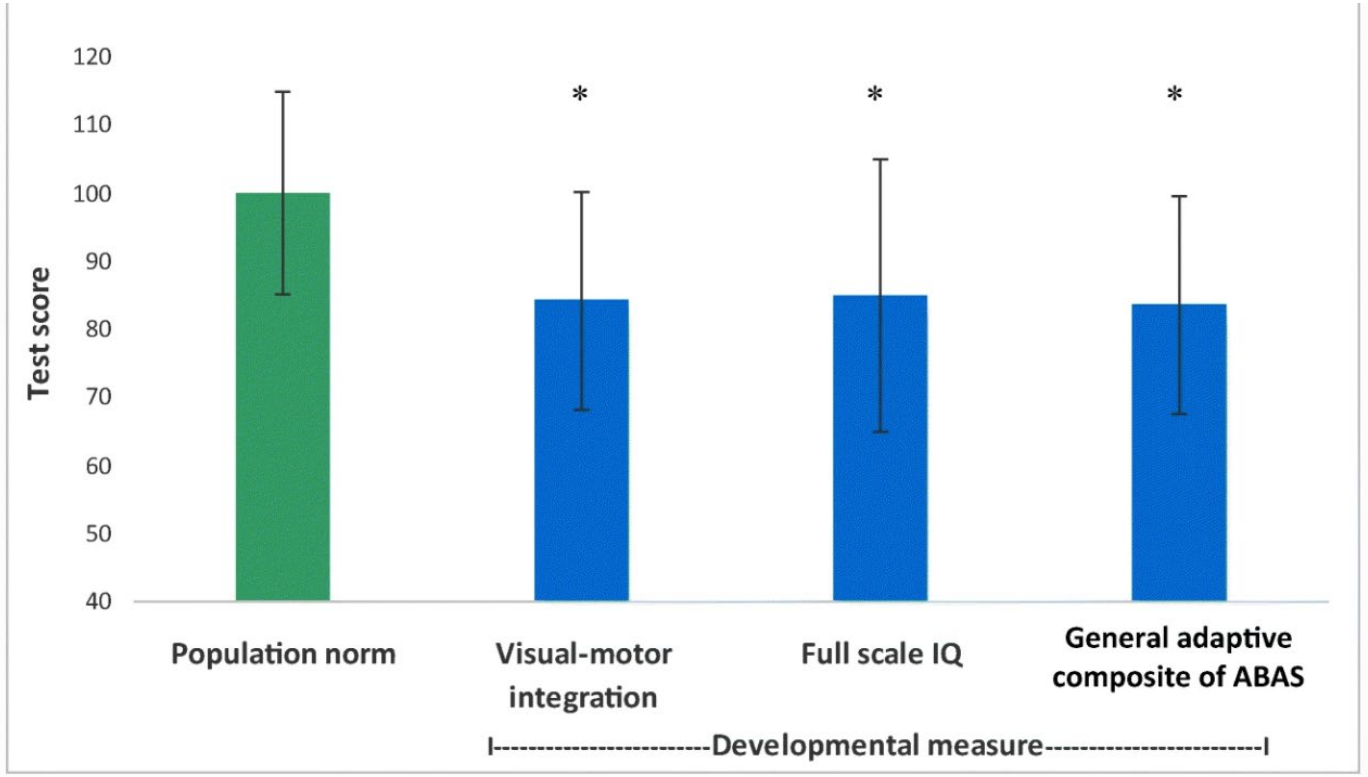
Physical Functioning

- Survey instruments: PedsQL™, PROMIS
- Ask about difficulty of daily activities such as walking etc
- May be completed by child or parent

Cognitive Functioning

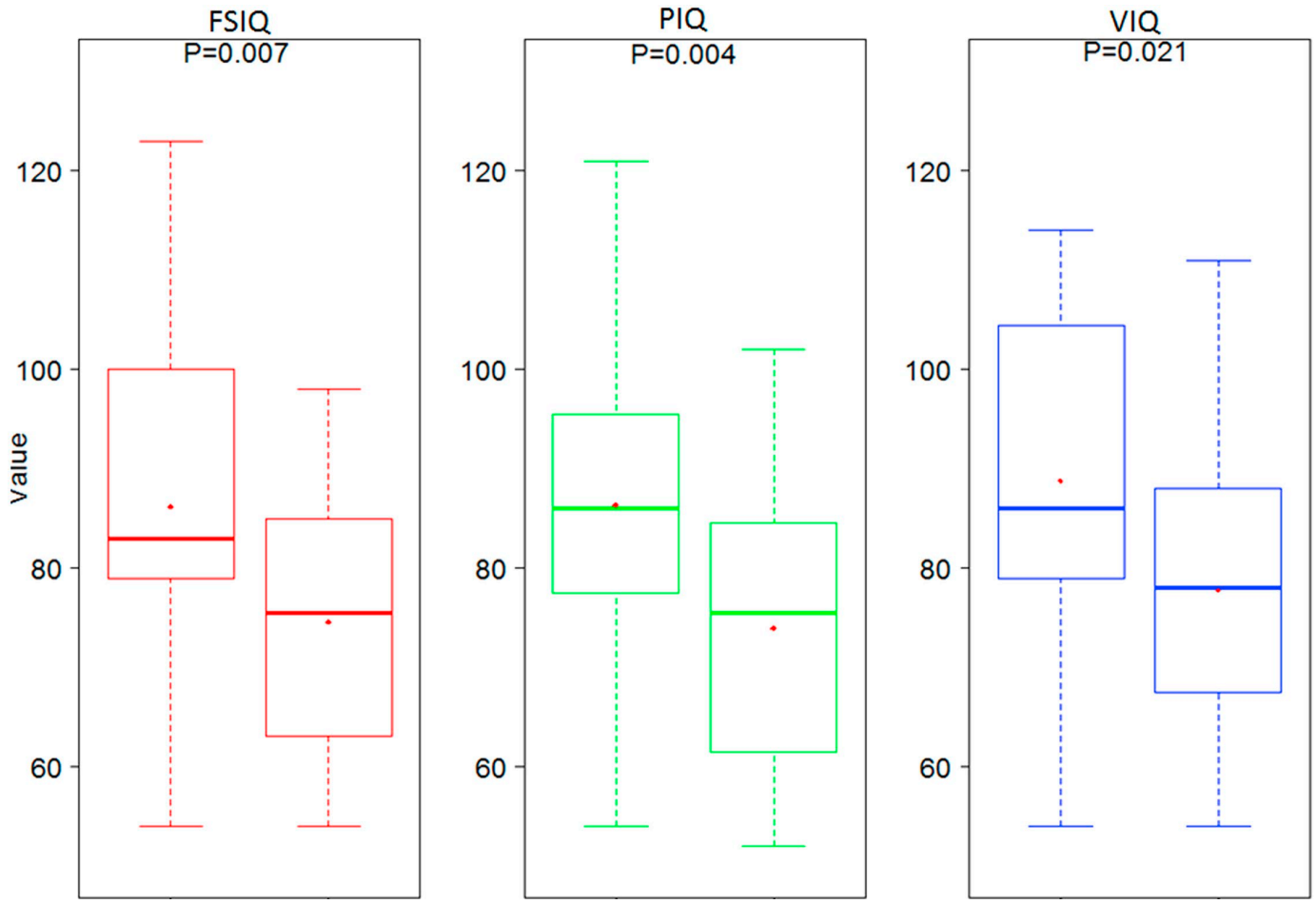
- Variable depending on child's development
- May use IQ tests
- Tests for Executive functioning, visuospatial abilities
- Survey instruments: PedsQL™, PROMIS

- Fifteen kidney transplant recipients transplanted before age 5.
- Developmental outcome was worse if dialysis was longer term.
- Hemodialysis associated with worse outcomes



Neurocognitive and functional outcomes at 5 years of age after renal transplant in early childhood. Pediatric Nephrology 2019

- Children with congenital heart disease (n=32) fare worse than those with a failing heart (n=23)
- CHD had more surgeries, more kidney injury and greater days in the ICU



Neurocognitive outcomes after heart transplantation in early childhood, published in The Journal of Heart and Lung Transplantation 2018

- Multicenter trial of liver transplant recipients at three time points
- Cognitive functioning did not improve over time
- Over half of adolescents may be at risk for poor school functioning

	n	T1	T2	T3	*P* Value
Parent-reported PedsQL					
Total score	49	78.7 ± 14.0	76.7 ± 14.7	78.5 ± 16.1	NS
Physical health	49	83.4 ± 16.8	80.9 ± 21.1	86.2 ± 15.8	NS
Psychosocial functioning	49	76.3 ± 14.7	74.4 ± 15.0	74.3 ± 19.0	NS
Emotional functioning	49	73.1 ± 15.4	73.8 ± 15.7	71.3 ± 23.0	NS
Social functioning	49	83.7 ± 17.8	79.6 ± 17.5	84.2 ± 18.5	NS
School functioning	39	70.7 ± 20.1	67.3 ± 19.4	67.1 ± 23.8	NS
Cognitive functioning	35	70.8 ± 20.6	68.1 ± 23.1	66.3 ± 27.5	NS
Self-reported PedsQL†					
Total score	24		79.2 ± 13.3	77.3 ± 15.3	NS
Physical health	24		81.8 ± 15.0	84.4 ± 15.7	NS
Psychosocial functioning	24		77.7 ± 15.0	73.5 ± 17.7	NS
Emotional functioning	24		71.9 ± 22.8	72.7 ± 25.4	NS
Social functioning	24		83.3 ± 16.7	83.0 ± 15.2	NS
School functioning	18		77.8 ± 14.0	64.4 ± 18.0	NS
Cognitive functioning	23		69.6 ± 20.0	67.2 ± 22.5	NS

Health-Related Quality of Life and Cognitive Functioning in Pediatric Liver Transplant Recipients published in *Liver transplantation 2020*

Ideal Measure

- Age appropriate
- Objective & Reliable
- Easy to administer
- Disease specific
- Self and proxy report correlate well

Assessed 34 patients who survived over two decades

Majority were in school or employed

69% lives with parents

20% were on some disability

	LONG TERM SURVIVORS N=34	HEALTHY CONTROLS N=1171		CHRONIC ILLNESS N=102	
PedsQL 4.0 Generic Core	MEAN ± SD	MEAN ± SD	EFFECT SIZE	MEAN ± SD	EFFECT SIZE
Age in Years	23.15±4.5	19.7±1.65		19.7±1.65	
Total Score	76.25 ± 16.89	78.18 ± 9.20	0.20	70.25± 9.20	0.52
Physical	81.62 ± 20.5	86.25 ± 10.6	0.42	74.49± 16.07	0.42
Psychosocial	74.47 ± 17.98	73.87 ± 10.5	0.06	67.99± 11.85	0.48
Emotional	69.41± 22.01	66.68± 15.0	0.18	60.02± 17.30	0.51
Social	82.65± 21.40	85.48± 11.9	0.23	82.21± 13.10	0.03
School	71.32± 23.14	69.47± 13.9	0.13	61.27± 16.72	0.55
Cognitive	67.7 ± 30.62	70.88+18.15	0.17	62.89+20.26	0.22

Health status in young adults two decades after pediatric liver transplantation. AJT 2012

Areas for Improvement

- Physical functioning is close to normal in liver and kidney recipients
- Heart transplant recipients are the most at risk
- Cognitive functioning may worsen with age due to increased need for executive functioning
- Real time assessment measures may help identify modifiable factors