Kidney Transplant: Beyond Healthcare

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STARx Program Mission: To teach, enhance and promote self-management and transition readiness among 12-29 y.o. patients

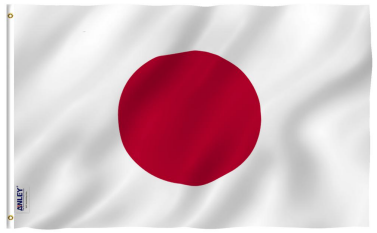
THANKS TO:

- Patients, families and volunteers (we have produced > 70 publications)
- USA: UTSA, University of Michigan, Columbia University, The Ohio State University, Carolinas Medical Center and Victory Junction Camp
- Intl: Mexico, Colombia, Philippines, S. Korea, Turkey, Japan and China
- Past/Present Funding: The Renal Research Institute, CDC, HRSA, UNC STARx interdisciplinary research team









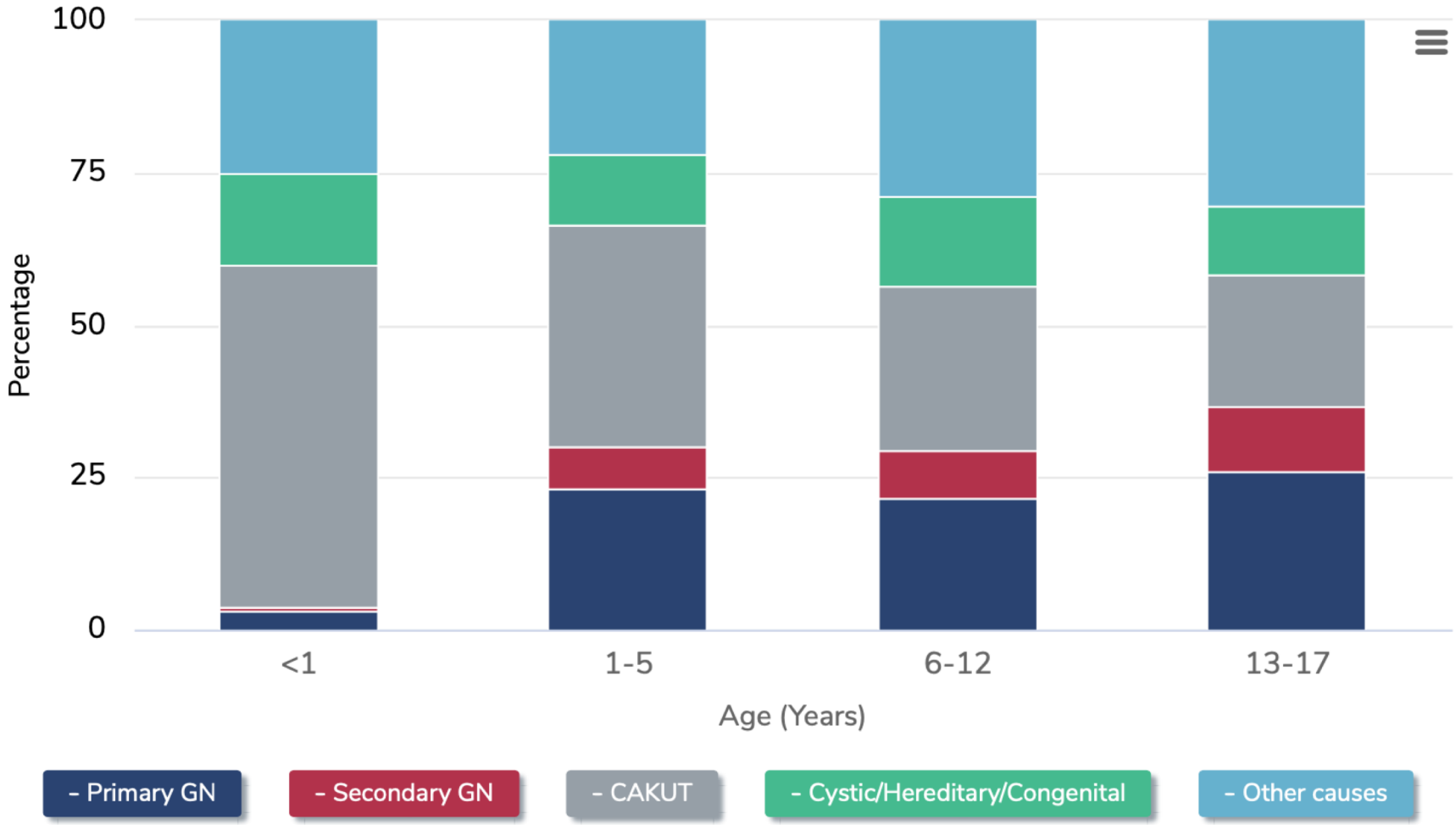

***Self-management and Transition to Adulthood with Rx=treatment**

Points I will discuss

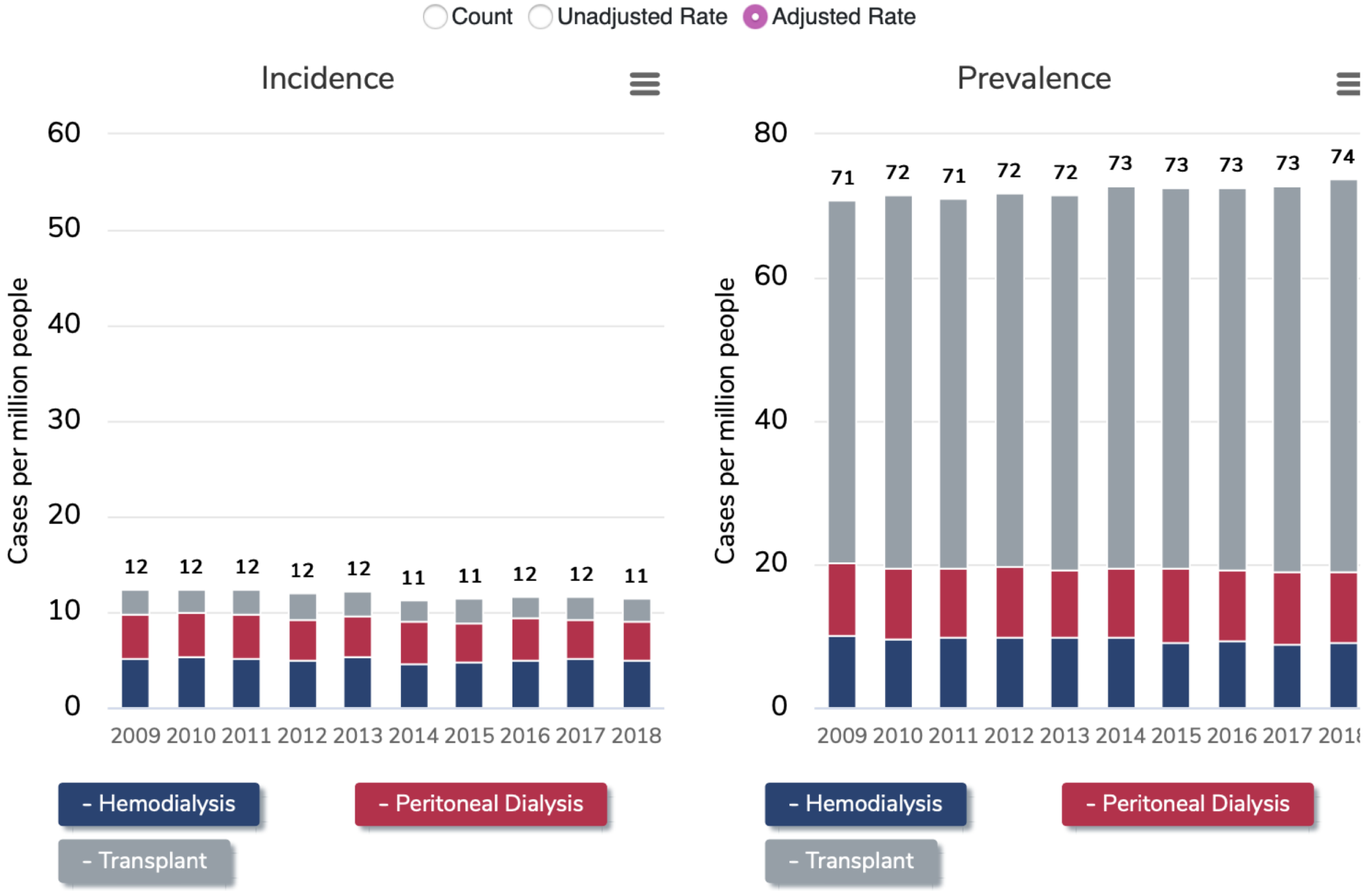
- How many children have end-stage kidney disease, kidney transplants and what is their 10-year survival
- Their medical/cognitive issues
- Their longitudinal psychosocial needs
- Their healthcare transition to adult-focused providers issues
- Their educational/employment/insurance/quality of life issues

Causes of Pediatric End-stage Kidney Disease

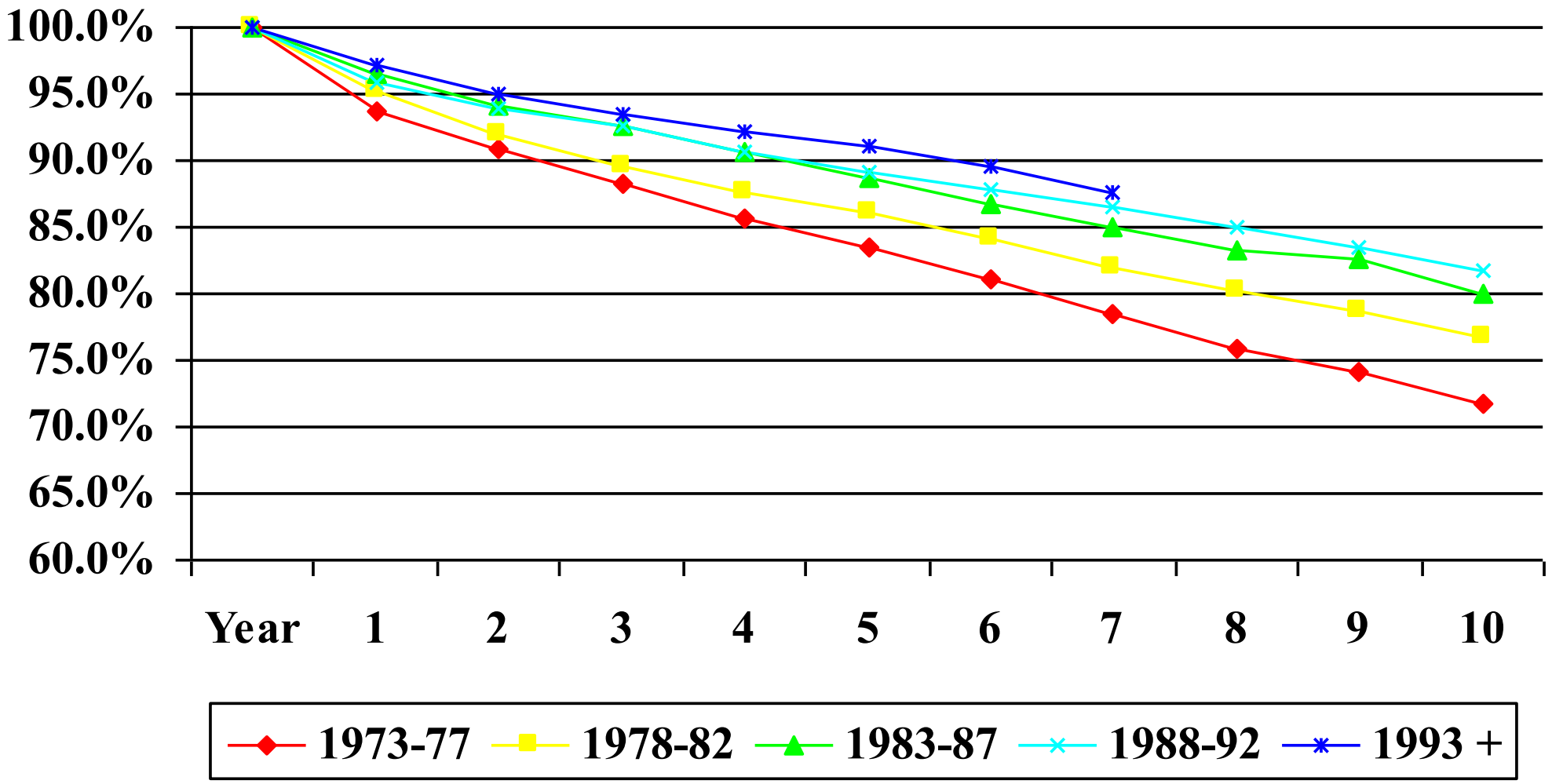
Figure 7.4 Distribution of primary cause of ESRD in children with incident ESRD, by age, 2015-2018



ESRD 2015-2018 in 0-17 year old patients per the USRDS



10-year survival of adolescent-onset ESKD - USRDS



Ferris M et al Pediatric Nephrology 21, 1020-1026 (2006)

Cognitive impairment/poor executive function ADHD/learning abnormalities, mood disorders (> anxiety than depression) and risk behaviors

Dental abnormalities

Cardiovascular disease

Gastrointestinal disturbances

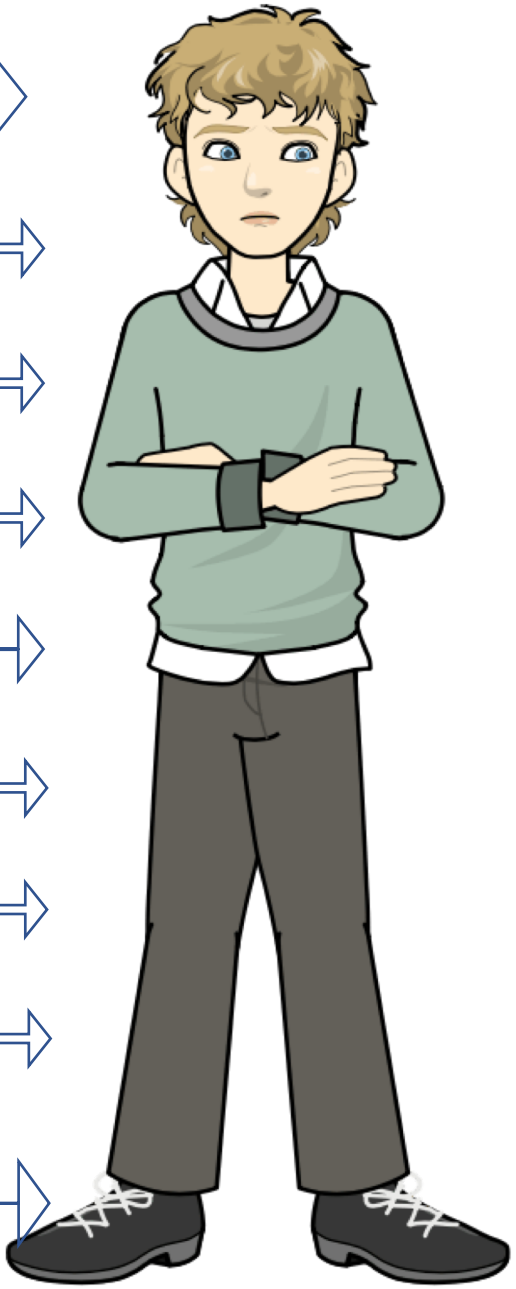
Fertility issues (> in males with congenital anomalies). Menstrual irregularities and endometriosis in females

Metabolic bone disease, metabolic acidosis

Surgical issues: dialysis access, urological procedures and orthopedic issues

Anemia

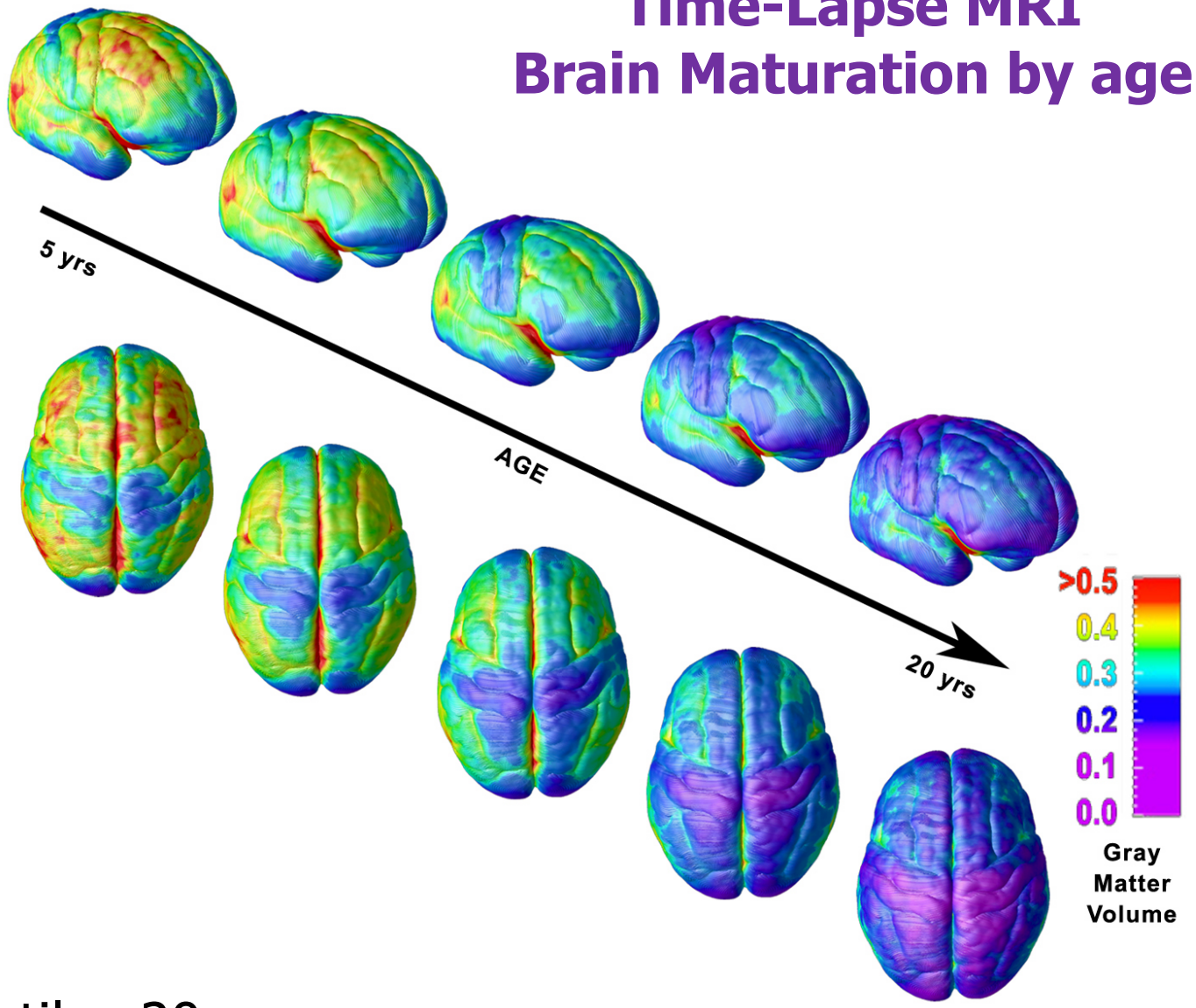
Low employment/self-esteem/health-related quality of life, non-adherence, poor self-management & decreased lifespan



Comorbidities of Pediatric-onset Chronic or End-stage Renal Disease

Cognitive Issues: Typical Brain Maturation

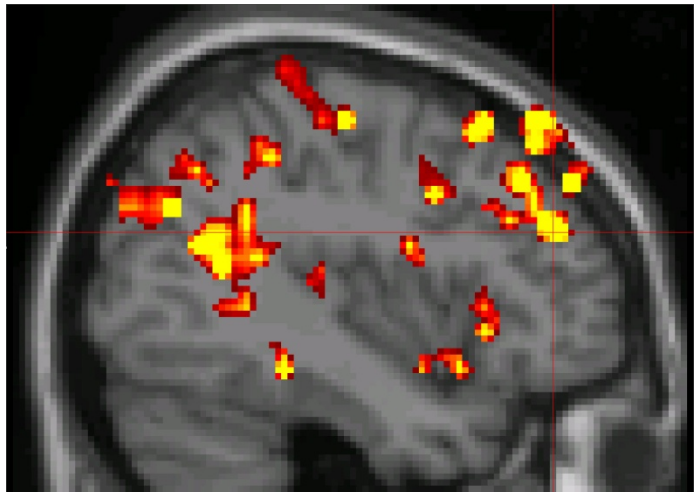
Time-Lapse MRI Brain Maturation by age



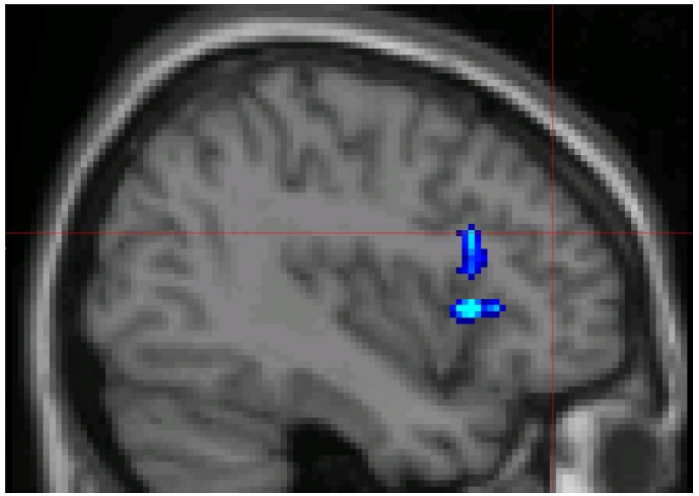
- 10-year NIH MRI study
- Starting at age 4
- Brain continues to change until ~ 20s

Visual Working Memory in fMRI for Pediatric Patients with CKD

Controls (n=20)



CKD (n=18)

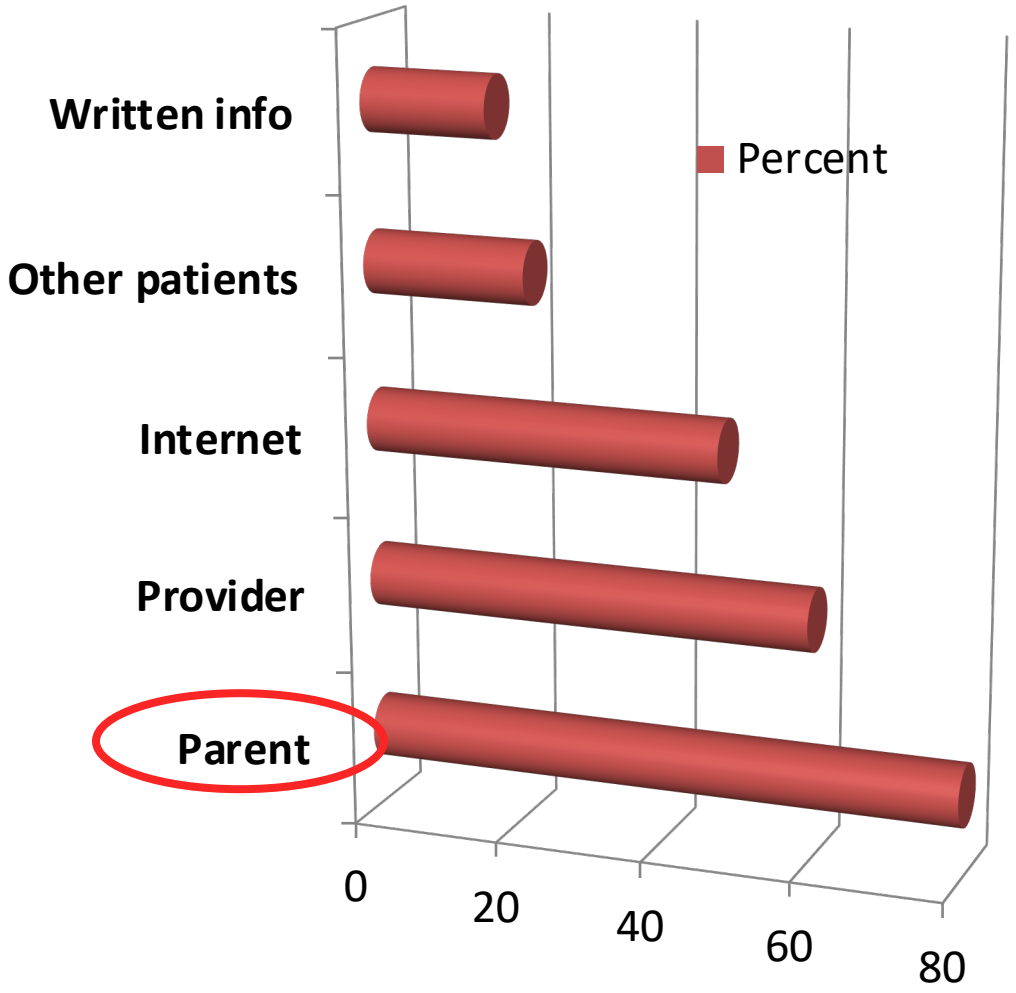


Decreased activation in the parietal lobe and prefrontal regions with CKD

This "multi-level" view of brain activity can include "executive" functions and high level cognitive tasks simultaneously with primary & secondary input (vision and audition) as well as cerebellar contributions

Harrell and Gipson, 2008

Adolescent preference to learn about health condition from…



(n=160)

- If parents = greater adherence
- If providers = greater self-efficacy and HCT readiness in all diagnoses

Johnson M et al J Pediatr Nurs. 2015 Sep 30 (5):e83

Short Stature in Pediatric-onset Chronic or End-stage Renal Disease

Related to:

- Metabolic acidosis
- Metabolic bone disease
- Growth hormone resistance
- Chronic anemia
- Lack of health care/medication access
- Low treatment adherence

Affects life-long:

- Social life
- Health-related quality of life

Treatment:

- Regulate treatment of MBD, Acid-base disorders and anemia
- Growth hormone – which does not seem to accelerate progression to ESRD

Pediatric Graduates in Adult Settings

- <2% of patient population
- Less knowledge about Dx and Rx
- 45% considered non-adherent
- “Healthiest”
- Come with parents

25th GDCN Conference n = 35 practices

Unprepared Transferred Adults

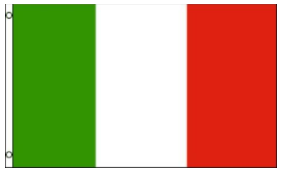
Transplant rejection

Watson 2005, Annunziato ‘07

Death or graft loss

Prestidge C Ped Neph (2012)

Higher Hgb A1C



Cadario ‘09

↑ Arthritis activity

Hersh ‘09

10-year Longitudinal Total TR$_x$ANSITION Score n = 862

Age 12-14

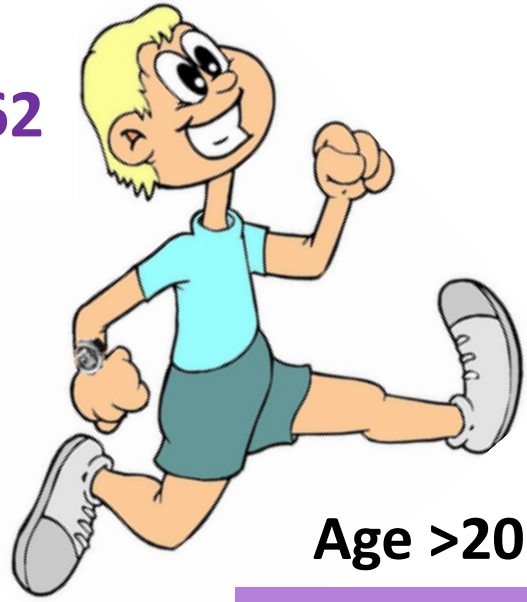
Adherence (0.785)
Ongoing Support (0.878)

Age 15-16

Type of Dx (0.784)
Medications (0.783)
Nutrition (0.758)

Age 17-18

Trade or School (0.770)



Age 19-20

Issues of Reproduction (0.768)

Age >20

Self-Management Skills (0.815)

Zhong et al, J of Pediatrics J Pediatr. 2018 Dec;203:361-370
Stollon et al, World J Gastroenterol. 2017 23:18 pp3349

Transplant International

INVITED COMMENTARY

We have to do more for former paediatric renal transplant recipients!

Guido Filler[1] & Maria Diaz-Gonzalez de Ferris[2]

Social Rehabilitation

- Disability pension: 19%
- Marriage in males: 27%
- Live with their parents 15 years post-transplant: 46%

Broyer M et al. Transplantation 2004; 77: 1033.

Quality of Life

- Lower quality of life

Filler and Ferris Transplant International 2018; 31: 152-4

QoL (Median post-transplant of 18.7 years)

- Significantly lower QoL in kidney transplant patients compared to Leukemia survivors or healthy controls
- Worse in older patients or those with longer time on dialysis or lower transplant function
- Unemployment: 24%
- No permanent relationship: 40%
- Biological children 10%

Enden et. Al. Transplant International 2018; 31: 157

Utility and Cost of a Renal Transplant Transition Clinic in British Columbia, Canada

- No deaths in HCT program patients
- Pre-program costs: (CAD) $17,000-38,000
  - **Cost on dialysis: (CAD) $41,000-61,000**
- Post-program costs: (CAD) $11,380-34,312

Prestidge C et al Pediatric Nephrol 2012 Feb;27(2):295

Summary

- Former pediatric transplant recipients have special unmet needs which are not well addressed in adult transplant clinics
- Graft loss may occur just due to transition at high cost
- Transition clinics are needed for young adults with CKD/ESKD
- Former pediatric transplant recipients have a high morbidity and mortality due to cardiorenal syndrome, hypertension, infectious complications and cancer
- Quality of life is poor with short stature, low social integration, low independent living, and high unemployment rates