

*Transitioning Children with Chronic
Disease. How do we get there?
Perspectives and Challenges*

Jayanthi Chandar, M.D.

Associate Professor of Clinical Pediatrics,

University of Miami, Miller School of Medicine

Medical Director, Pediatric Kidney Transplantation

Kidney transplant recipient Chronic Kidney Disease

- Patients deal with health issues throughout their life
- Medication adherence and monitoring health status is key to well-being and to transitioning from pediatric to adult health care providers

Association Between Age and Graft Failure Rates in Young Kidney Transplant Recipients.

Foster, Bethany; Dahhou, Mourad; Zhang, Xun; Platt, Robert; Samuel, Susan; Hanley, James

Transplantation. 92(11):1237-1243, December 15, 2011. DOI: 10.1097/TP.0b013e31823411d7

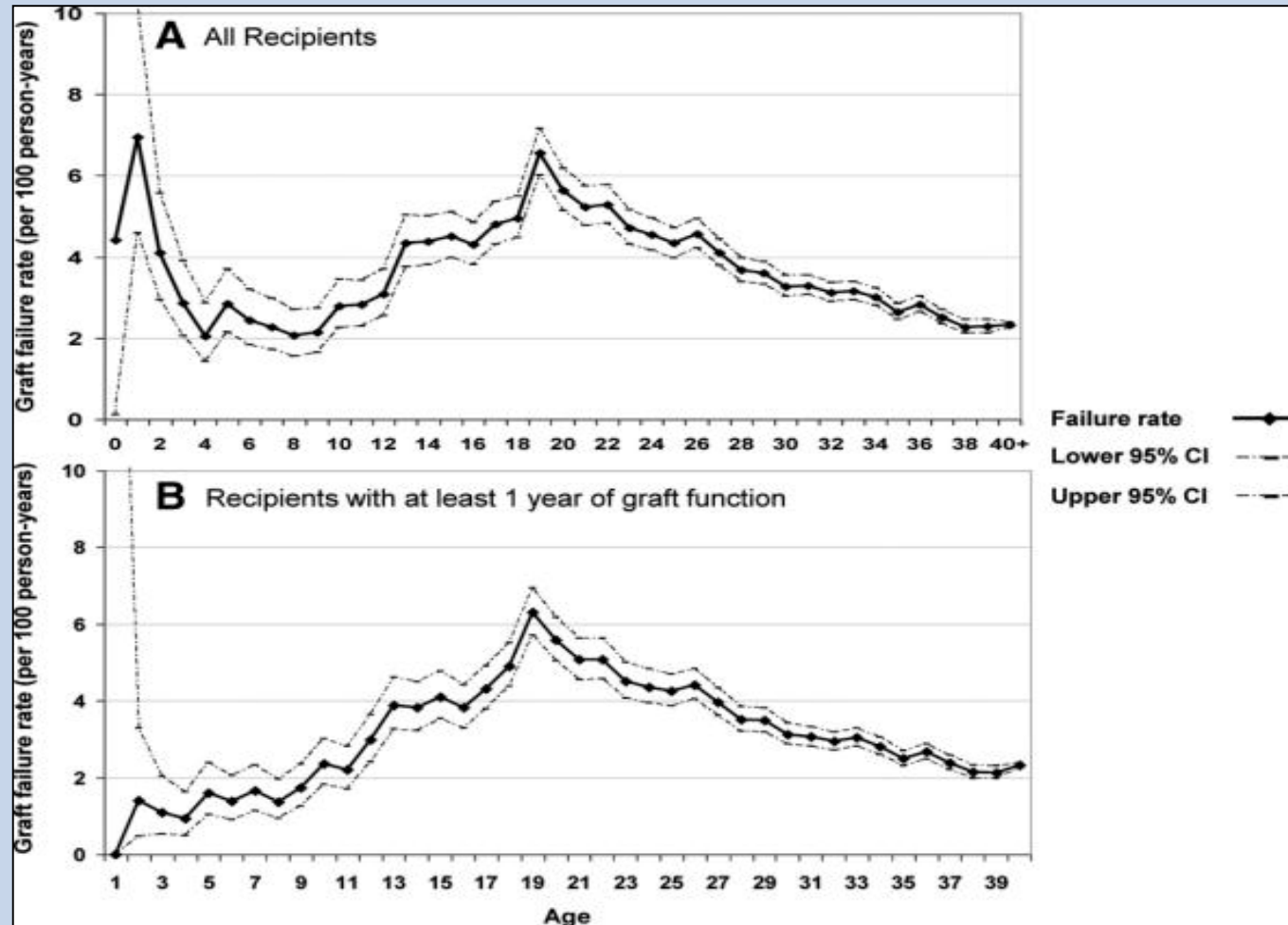
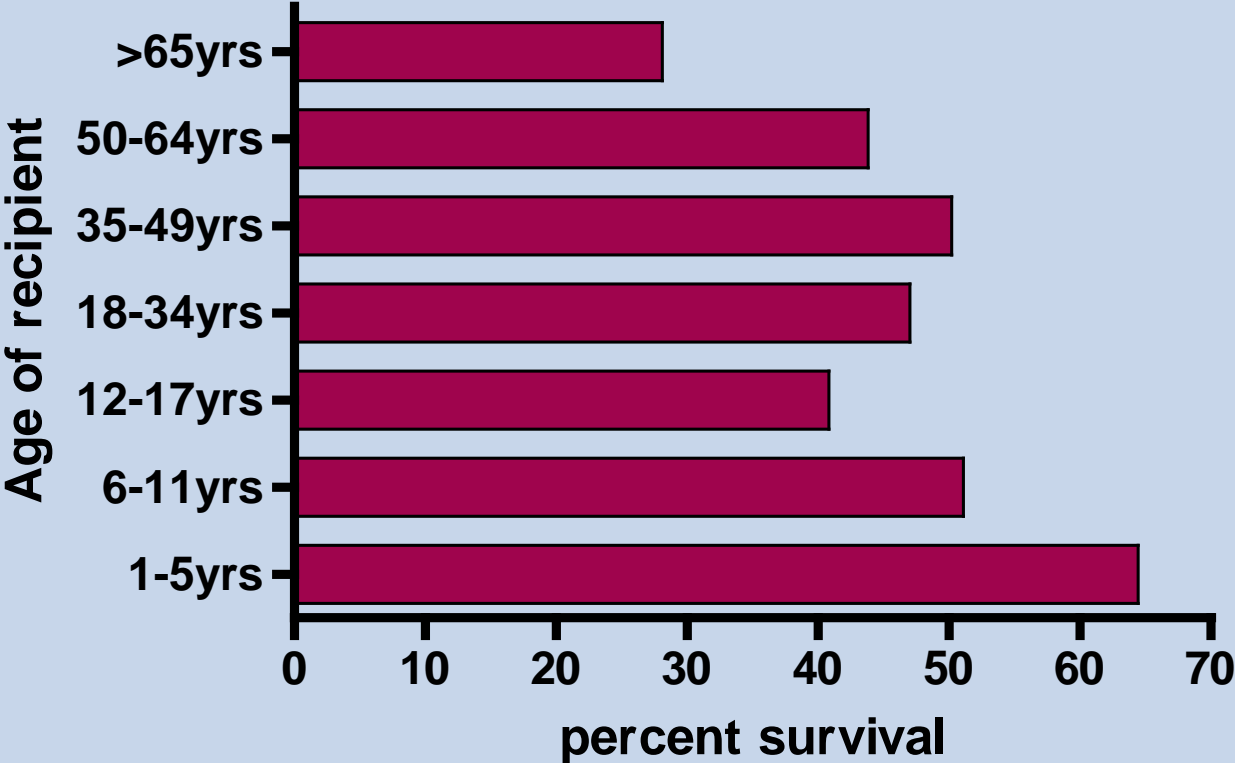


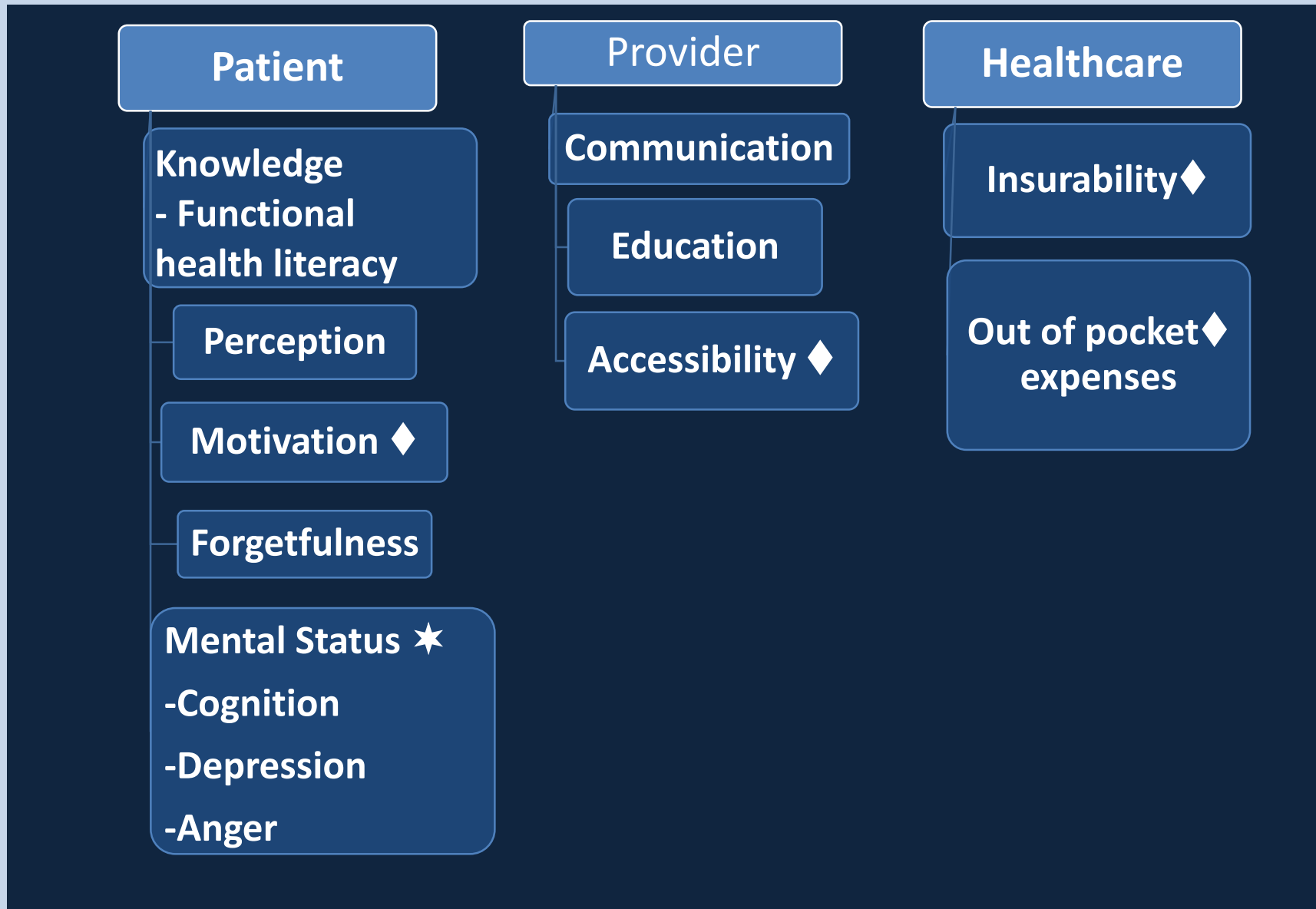
FIGURE 1. Crude age-specific death-censored graft failure rates (failures per 100 person-years) in each 1-year age interval are shown with 95% confidence intervals for (A) all recipients and (B) recipients with at least 1 year of graft function. These rates are not adjusted for time since transplant.

OPTN data

10 year adjusted graft survival 1997-2007



Barriers to adherence are barriers to transition



Transitioning –am I ready?

- I understand my condition and can describe it to others
- I know my medications and what they are for
- I can make decisions for myself about my treatment
- I know what the adult clinic arrangements are and who will be reviewing me in clinic
- I know how to make my appointments
- I can make my own transport arrangements to get to the hospital for appointments



Ferris ME, Harward DH, Bickford K, et al. A Clinical Tool to Measure the Components of Health-Care Transition from Pediatric Care to Adult Care: The UNC TR(x)ANSITION Scale. Ren Fail. 2012;34(6):744-753.

Transitioning –am I ready?

- I know details about my health insurance and know what to do when it changes
- I know who to call in a medical emergency
- I am able to talk about my worries concerning blood tests
- and other treatments
- I know the dietary advice that I have to follow and the
- importance of activity
- I have appropriate knowledge about sexual health matters
- I have discussed alcohol, smoking, and drug issues



Culture of Pediatric Health Care

- Multidisciplinary
- Psychosocial support
- Developmental
- Family-focused
- Flexible
- Warm, optimistic
- Informal and relaxed
- Partnerships with parents

Carolina Health and Transition (CHAT) The North Carolina Division of Public Health Women and Children's Health Section Children and Youth Branch 2010State



Culture of Adult Health Care



- Few psychosocial supports
- Business-like, formal
- Patient-centered
- Strong focus on disease process
- Insistence on compliance
- Procedure and lab-based
- Requires patient to be autonomous
- and to function independently

Literacy Scale in Adults

- Below basic
 - –nonliterate to finding simple information in text and numeracy skills such as simple mathematical skills
 - –score: 0-low 200s
- Basic
 - - read, understand, and use information in short, simple, everyday prose text, documents, and quantitative material (one-step problem with simple arithmetic operation).
 - Score 2: low 200s-high 200s
- Intermediate
 - -read and understand moderately dense prose text leading to summarization and inferences -can also find information in complex documents. individual can deal with less common quantitative information
 - High 200s-mid-300s
- Proficient
 - - most proficient in using written information in prose, document, or quantitative format
 - Score mid 300-500

Definitions-Literacy

- **Simple:** Literacy is the ability to read and write
- **Complex:** Ability to identify, understand, interpret, create, communicate and compute using printed and written materials associated with varying contexts

Functional Health literacy

- **Definition-the degree to which individuals have the capacity to obtain, process and understand basic health information and services to make appropriate health decisions**
- **Management of a child with CKD becomes difficult if caregivers and children do not understand the information given to them**

Literacy in the US

- 14% of the adult population and 19% of high school graduates cannot read
- 21% of adults read at 5th grade level
- Lower health literacy is associated with less education

Health Literacy in adults

12% adults have proficient health literacy

53% -intermediate health literacy

22%- basic health literacy

14% - below basic health literacy

16% of men below basic

12% women below basic

Hispanics- lower health literacy than other groups

Why is it important?

- Strong relationship between literacy and health literacy
- One in 3 adolescents and young adults have low health literacy
- Most child health information is written above 10th grade level
- Adults with low literacy skills 1.4-4 times more likely to exhibit behavior that negatively affects child health
- Adolescents with low literacy skills are more likely to exhibit anti-social behavior
- *7 million adults in the US are non-literate in English

-Sanders et al. Arch Pediatr Adolesc Med. 2009 Feb;163(2):131-40

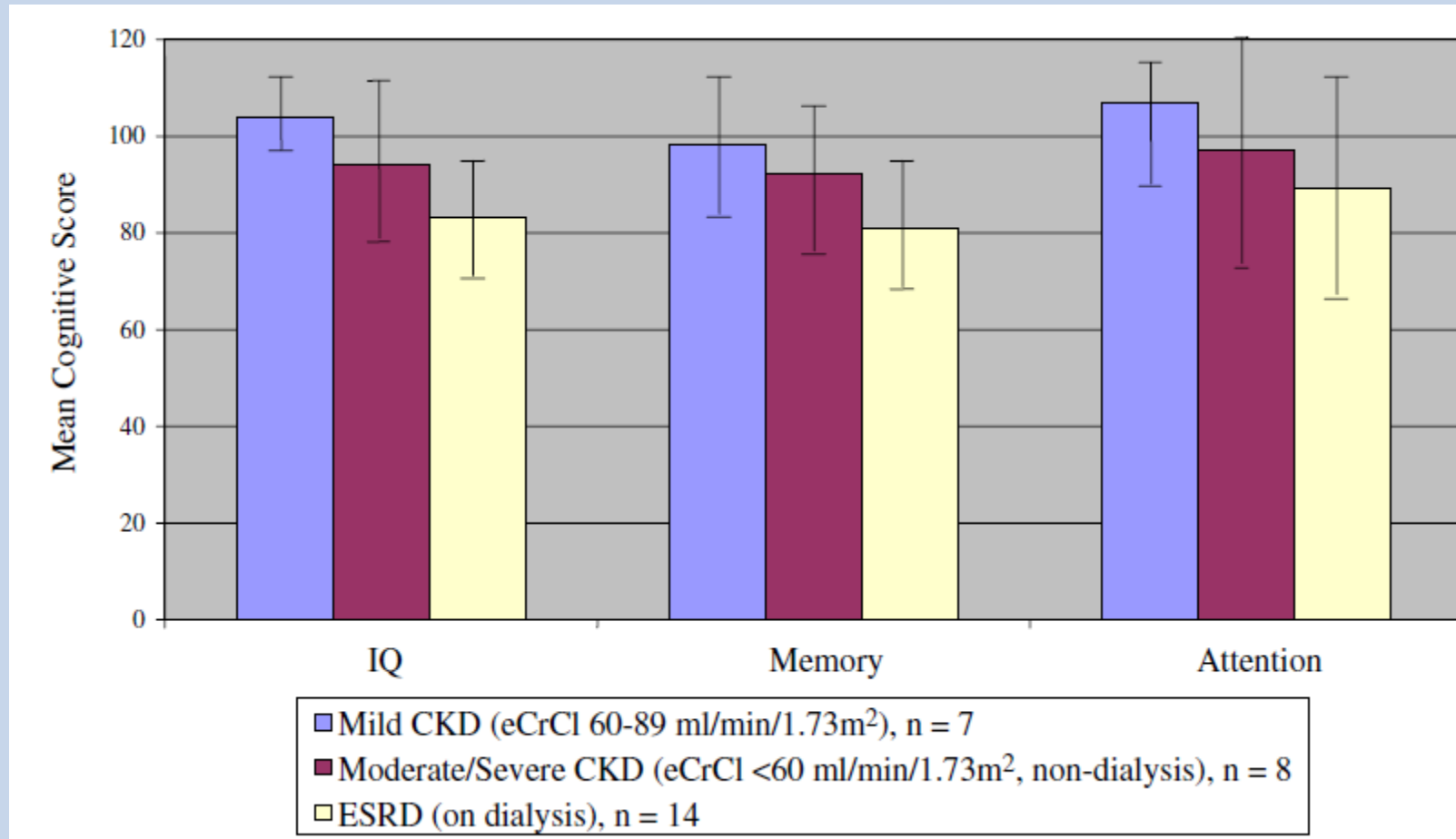
*National Center for Education Statistics

Children with chronic kidney disease

- There is a relationship between low literacy and poor health outcomes
- Children with CKD-higher risk of having poor literacy skills
- Deficits in memory, attention and intelligence
- Younger age of onset and duration of disease are associated with increased risk of neurocognitive deficits

•Lawry KW¹Cognitive functioning and school performance in children with renal failure. [Pediatr Nephrol](#). 1994 Jun;8(3):326-9.
•Brouhard BH. Cognitive functioning in children on dialysis and post-transplantation. [Pediatr Transplant](#). 2000 4(4):261-7.

Mean Cognitive Scores by Level of Renal Function



Clinical Predictors of Neurocognitive Deficits in Children with Chronic Kidney Disease
Slickers J et al; *Pediatr Nephrol* (2007) 22:565

Children with chronic kidney disease

- The optimal treatment of advanced chronic kidney failure is kidney transplantation
- Associated with a better quality of life
- Strict adherence to medical regimen is imperative
- Literacy is important to achieve functional health literacy in the adolescent years
- Functional health literacy is important to achieve transition to the adult world

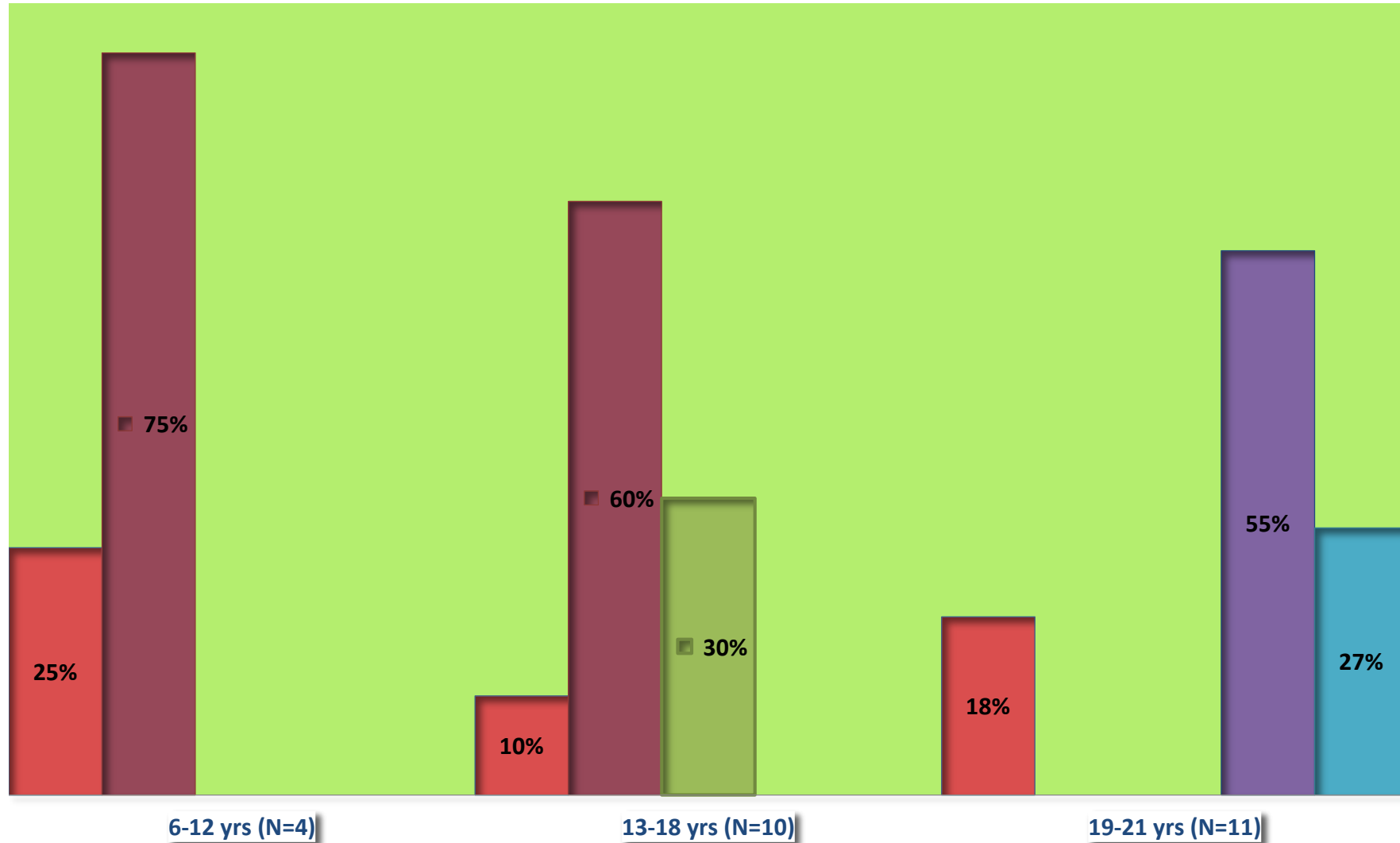
Pediatric Dialysis Literacy Project

OBJECTIVE

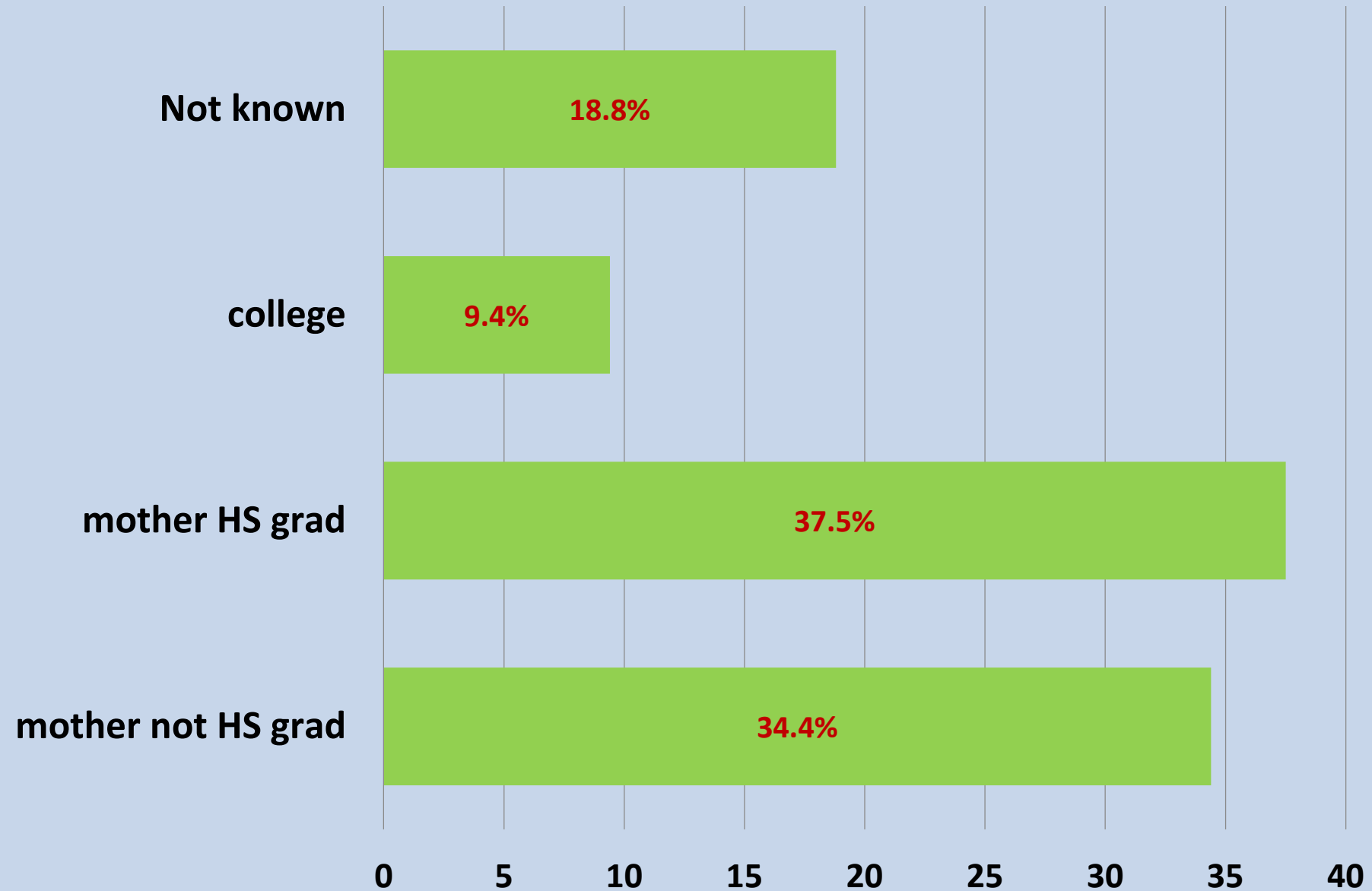
Promoting literacy in children with chronic kidney disease through education, advocacy, research and service

Educational Status of Children on Hemodialysis Holtz Children's Hospital

■ Special Ed ■ Regular School ■ Below grade level ■ Finished high School ■ School dropouts



Mother's Level of Education





TASK FORCE

Jayanthi Chandar, MD

Ashira Klein

Mariselis Rosa Sanchez, MD

Evel Michel, RN

Kathy Parks

COLLABORATORS

**Florida Alliance for Assistive Services and
Technology (FAAST)**

LIFESPAN

First year UM Medical Students

Learning methods

- Different mediums to engage the children in learning including but not limited to:
 - Art work
 - Poetry and story telling
 - Using ipads and computers for improving core curriculum
 - Each individual will have a folder depicting their own learning plan
 -

TEAM APPROACH

- Teacher –to provide guidance on age appropriate teaching
- Psychologist –to determine the developmental level of the child and provide appropriate teaching methods
- Child life specialist – teach through play therapy
- Parent – to provide insight into each child
- Social worker – input on psychosocial and economic circumstances
- Volunteers – help teach and play
- Peer –to provide guidance and support

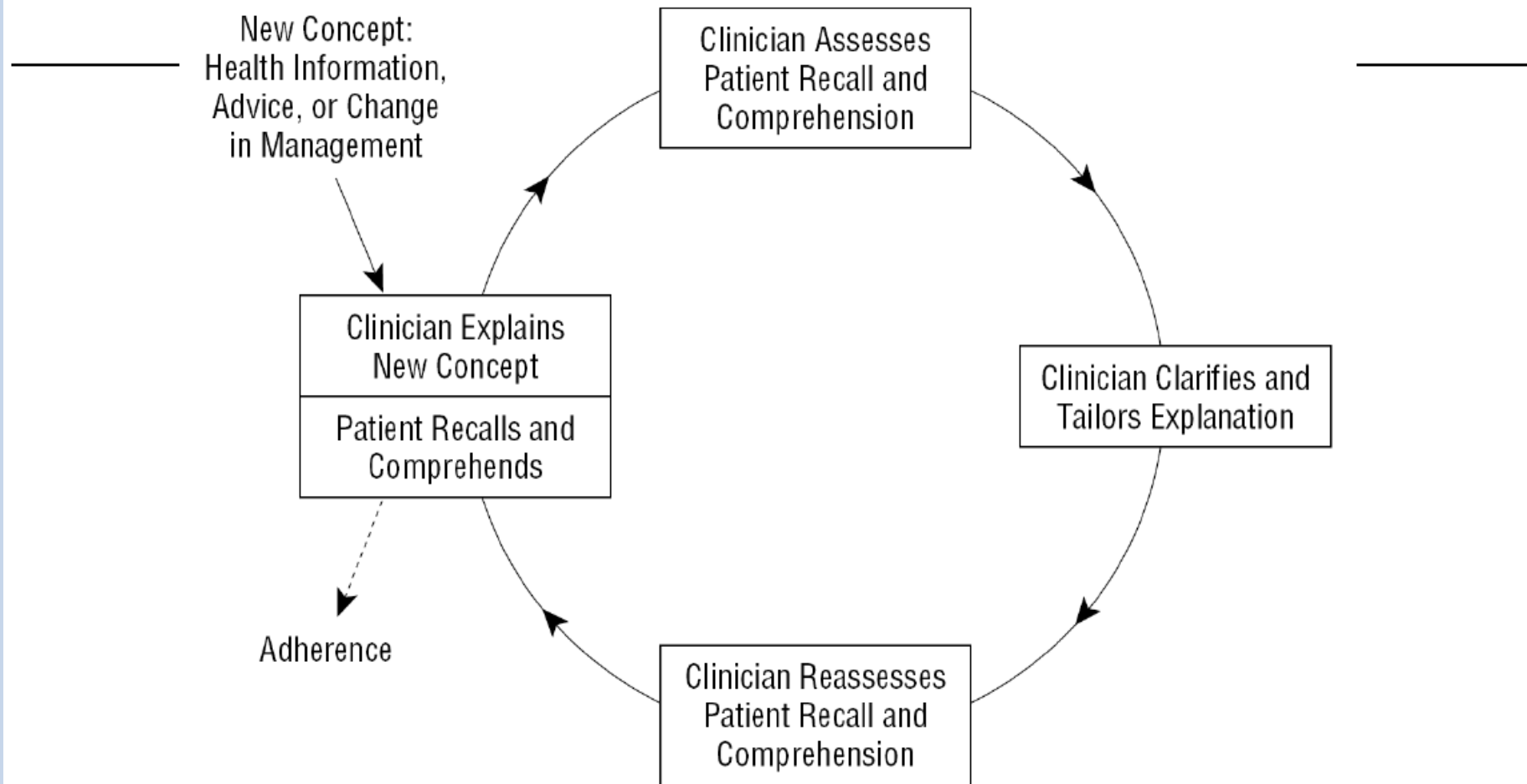
Mismatched Communication



Provider Process: Giving information

Patient Process: Understanding, remembering, and acting on information

Teach-Back: Closing the Loop



Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, Leong-Grotz K, Castro C, Bindman A. Closing the Loop Physician Communication With Diabetic Patients Who Have Low Health Literacy. Arch Intern Med/Vol 163, Jan 13, 2003

A Modified 'Teach Back' Method in Adolescents with Kidney Transplants

- ▶ *Jayanthi Chandar, M.D.*
- ▶ *Associate Professor of Clinical Pediatrics*
- ▶ *University of Miami, Miller School of Medicine, Miami, Florida*
- ▶ *Mariselis Rosa Sanchez, M.D.*
- ▶ *Pediatric nephrology fellow*
- ▶ *Holtz Children's Hospital, Miami, Florida*
- ▶ *Alan Delamater, PhD*
- ▶ *Professor of Pediatrics and Psychology*
- ▶ *University of Miami, Miller School of Medicine, Miami, Florida*

Methods

- ▶ Teach Back' method involves asking the patient to recall information that has been given to them by the health care provider
- ▶ At the University of Miami, we used a modified version of 'Teach Back' in kidney transplant recipients 15-22 years and caregivers of patients <15 years
- ▶ Retrospective analysis of data derived from these questionnaires which were filled by 22 patients and 31 caregivers was performed
- ▶ Questionnaires were administered at the time of the clinic visit before being seen by the physician

Format of Questionnaire

Name:

Date:

Date of transplant:

Problems:

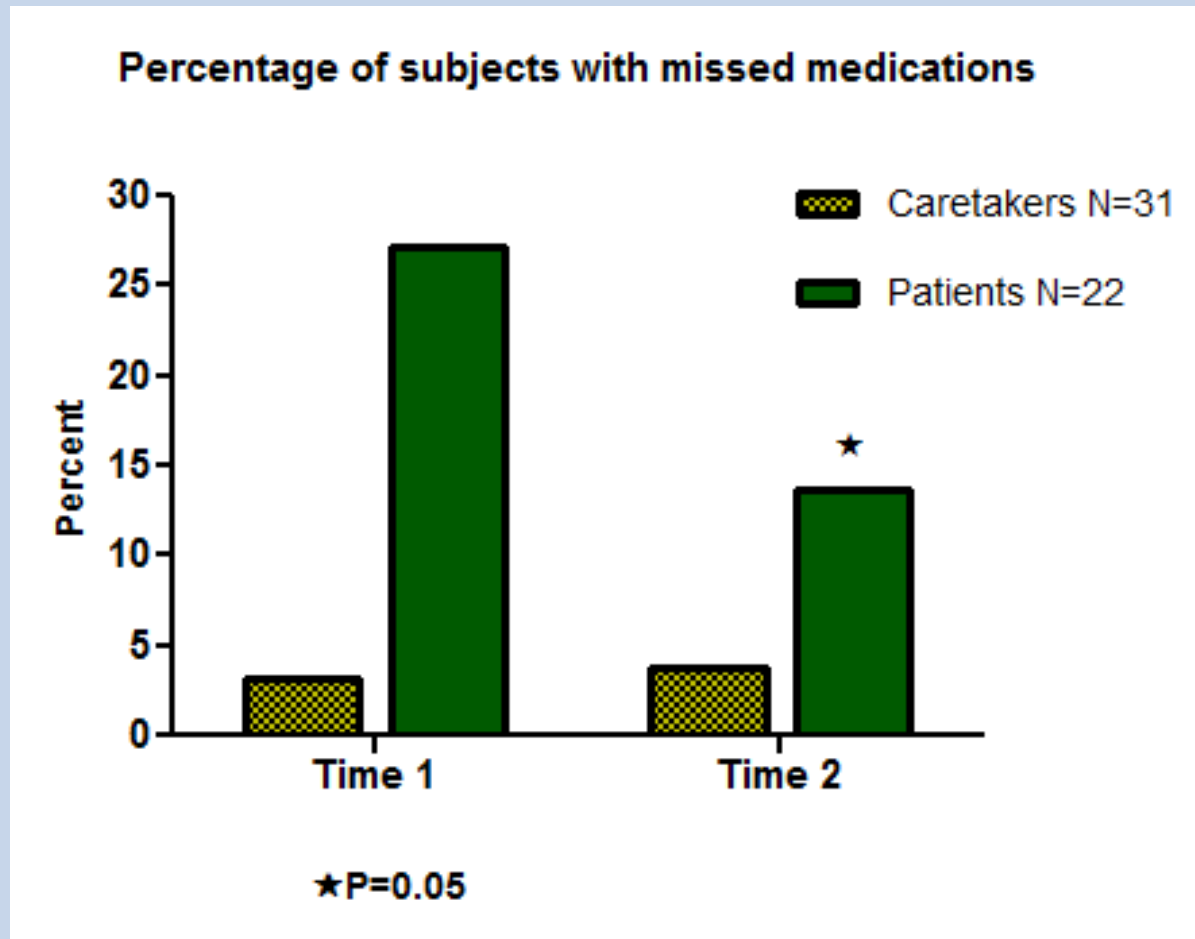
Hospitalizations or surgeries:

Allergies:

Medication	Dose	Time of Day

Questions for health care provider

Medication Recall Improves with Repetition of Task



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