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

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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


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

- >65yrs
- 50-64yrs
- 35-49yrs
- 18-34yrs
- 12-17yrs
- 6-11yrs
- 1-5yrs

percent survival
Barriers to adherence are barriers to transition

**Patient**
- Knowledge - Functional health literacy
  - Perception
  - Motivation ♦
  - Forgetfulness
- Mental Status ★
  - Cognition
  - Depression
  - Anger

**Provider**
- Communication
- Education
- Accessibility ♦

**Healthcare**
- Insurability ♦
- Out of pocket expenses
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

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
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 antisocial behavior
• *7 million adults in the US are non-literate in English

*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

Mean Cognitive Scores by Level of Renal Function

Clinical Predictors of Neurocognitive Deficits in Children with Chronic Kidney Disease
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**: 75% in 6-12 yrs (N=4), 10% in 13-18 yrs (N=10), 30% in 19-21 yrs (N=11)
- **Regular School**: 25% in 6-12 yrs (N=4), 60% in 13-18 yrs (N=10)
- **Below grade level**: 6% in 6-12 yrs (N=4), 18% in 13-18 yrs (N=10)
- **Finished high School**: 18% in 13-18 yrs (N=10), 55% in 19-21 yrs (N=11)
- **School dropouts**: 27% in 19-21 yrs (N=11)
TASK FORCE
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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

New Concept: Health Information, Advice, or Change in Management

Clinician Explains New Concept
Patient Recalls and Comprehends

Adherence

Clinician Clarifies and Tailors Explanation

Clinician Assesses Patient Recall and Comprehension

Clinician Reassesses Patient Recall and Comprehension

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

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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:

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Questions for health care provider
Medication Recall Improves with Repetition of Task

![Graph showing percentage of subjects with missed medications](image-url)

- Caretakers N=31
- Patients N=22

**P=0.05**
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