Transition: The Pediatric Provider Perspective

COZUMEL PRUETTE, MD, MHS
ASSOCIATE PROFESSOR OF PEDIATRICS
JOHNS HOPKINS UNIVERSITY
DIVISION OF PEDIATRIC NEPHROLOGY

Disclosures

- None

Objectives

- Define transition and transfer of care
- Review consensus guidelines on transition
- Understand the challenges of transition from the provider perspective
- Discuss key elements of a transition program for pediatric dialysis
- Discuss challenges to implementing and assessing a transition program for pediatric dialysis
**Transition of Care: Definition**

- The purposeful, planned movement of adolescents with chronic physical and medical conditions from a child-centered to an adult-oriented healthcare system.
- Transition is a process, not an event.
- The transition process plays a critical role in how adolescents and young adults will engage with health services during their lifetime.
  - Promote engagement
  - Teach self-management skills


**Why is Transition Care Important?**

- In 2015, USRDS reported 1,373 children, ages 0-21 years, began renal replacement therapy:
  - 55% HD, 27% PD, 18% transplanted
- Prevalent ESRD in 2015: 9,672 children ages 0-21 years:
  - 18% HD, 10% PD, 72% transplanted

USRDS ESRD Database, 2015

**Consensus Statements on Transition in ESRD**

- Adolescent transition to adult care in solid organ transplantation: a consensus conference report (2008)^2

- Building consensus on transition of transplant patients from paediatric to adult healthcare (2010)^3

- 2011 International Pediatric Nephrology Association/International Society of Nephrology (IPNA/ISN) consensus statement^4

Provider Adherence to Transition Guidelines

  - 13 pediatric nephrology centers in 13 European countries
  - Quantitative survey of transition practices and cross-sectional questionnaire to assess perceived barriers to effective transition (100% response)
  - 33% incorporated guidance from the 2011 IPNA/ISN consensus statement
  - Highest clinician-rated barriers:
    - Patient and parent attachment to the pediatric unit and clinician
    - Difficulty getting parents to “let go” and allow young person to self-care
  

Provider Perspectives on Transition

  - 21 pediatric nephrology centers (14 nurses, 16 psychosocial team members) from Germany and Austria
  - Qualitative in-person interviews
  - Issues identified:
    - Timing the transfer: participants challenged the transfer age of 18yo
    - Medical factors: centers aimed for stable kidney function 6-12 months prior to transfer
    - Social factors: concern for too many changes at the same time
    - Individual aspects: readiness for transfer
    - Structural aspects: concern for transfer occurring irrespective of the patient’s situation
  

Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

- Expert opinion and consensus on practice-based implementation of transition for all youth beginning at 12 years old
- Roadmap for transition and decision-making algorithms

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Barriers to Transition of Care

According to the 2018 AAP Clinical Report “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home”, all of the following were clinician-identified barriers to transition, except:

A. Communication gaps
B. Training limitations
C. Lack of validated tools to assess medication adherence and transition readiness
D. Care delivery and care coordination gaps
E. Lack of patient knowledge and engagement

Barriers to Transition of Care - Response

https://api.cvent.com/polling/v1/api/polls/app/84d8

Transition and Adherence Assessment Tools

- Many tools exist, but none are specific to dialysis
- Adherence tools:
  - Pruette et al (2019). Does a multimethod approach improve medication nonadherence in adolescents with chronic kidney disease?
- Multimethod approach is ideal
- Transition tools/checklists:
  - Cat Transition™
  - AFT Transition Portal
  - UNC STARx Program

American Society of Transplantation: Pediatric Transition Portal

- Comprehensive patient-centered and developmentally appropriate program
- Goals: Achieve self-efficacy, optimize independence, provide self-care to the best of their ability
- Age-appropriate transition tool for providers to assist AYAs and their parents/guardians in transition beginning at 11 years old
  - Readiness Assessment Tool
  - Readiness Checklist
  - Transition Action Plan
  - Parent Action Form

Readiness Assessment Tool
Readiness Checklist
Transition Action Plan
Parent Action Form

9. https://www.myast.org/education/specialty-resources/peds-transition#

Transition of Care for Pediatric Dialysis

- How do we define transition for patients receiving dialysis?
- How do we create a transition program specific to dialysis?
- How do we implement a dialysis-specific transition program?
- How do we assess transition and measure outcomes?
Task 1: How do we define transition of care?

- What does the word transition mean in pediatric dialysis?
  - Transition from a pediatric dialysis unit to an adult dialysis unit
- Transition from dependence on parents/caregivers to independent self-care
- Common thread is promotion of self-management skills
- When do we start transition of care?
  - 11-12yo, however may differ from patient to patient

Task 2: How do we create a transition program specific for dialysis?

- Involve patients/families and adult providers in the development and implementation of the program
- Identify key concepts critical to self-management
- Tailor materials to dialysis when appropriate
- Incorporate flexibility to allow individualization of the program

Key Concepts of a Transition Program

- Knowledge
- Self-management
- Medications & Adherence
- School & Work
- Nutrition
- Risk-taking behaviors
- Guardianship, Insurance, Finances
- Support system
Task 3: How do we implement a dialysis-specific transition program?

- Education and training of medical team
  - Identify a "Transition Champion"
- Institutional and systems support
  - Recognize that transition planning is a necessary and important aspect of quality health care
  - Funding for transition planning/resources
  - Adequate private and/or public health insurance to pay for transition services
- In-center logistics
  - Utilize existing dialysis structure to implement transition programs
    - During dialysis sessions or 30 min pre/post session for programming

Task 4: How do we assess transition and measure outcomes?

- Patient-reported outcomes
  - Quality of life
  - Patient satisfaction
  - Self-report of self-management skills
- Provider-reported measures
  - Transition checklists
  - Content-specific assessments
  - Measures utilized by pediatric and adult providers

Transition Assessment

- Transition readiness checklists to be used along the continuum
  - Can we adapt existing tools?
  - Do we need dialysis-specific tools?
Tracking Transition Outcomes

- Identify best practices and cost-effectiveness of transition programs
  - Impact on infection rates, ED visits and hospitalizations
  - Impact on missed dialysis treatments, medication adherence

Transition: The Pediatric Provider Perspective

- Goal: Collaborate with patients, families, and pediatric and adult providers to develop, implement and measure the impact of a dialysis-specific transition program on patient self-care and health outcomes.

"Optimal health care is achieved when each person at every age receives health care that is medically and developmentally appropriate."

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. Pediatrics 2002; 110:1304