Transition: The Pediatric Provider Perspective

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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

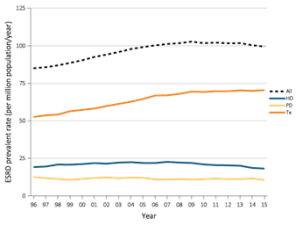
Transition of Care: Definition

- The purposeful, planned movement of adolescents with chronic physical and medical conditions from a child-centered to an adult-oriented healthcare system[1]
- 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

1. Blum RW, Garell D, Hodgman CH, et al. (1993) J Adolesc Health 14:570-576.

Why is Transition Care Important?

- In 2015, USRDS reported 1,373 children, ages 0-21 years, began renal replacement therapy
  - 52% HD, 27% PD, 21% 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]

2. Bell LE, Bartosh SM, Davis CL, et al. (2008) Am J Transplant 8:2230-2242; 3. Webb N, Harden P, Lewis C, et al. (2010) Arch Dis Child 95:606-611; 4. Watson AR, Harden P, Ferris M, et al. (2011) Pediatr Nephrol 26:1753-1757.

Provider Adherence to Transition Guidelines

- Forbes TA, et al (2014). Adherence to transition guidelines in European paediatric nephrology units[5]
  - 15 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

5. Forbes TA, Watson A, Zurowska A, et al. (2014) Pediatr Nephrol 29:1617-1624.

Provider Perspectives on Transition

- Prufe J, et al (2017). Transition structures and timing of transfer from paediatric to adult-based care after kidney transplantation in Germany: a qualitative study[6]
  - 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

6. Prufe J, Dierks M-L, Bethe D, et al. (2017) BMJ Open 7(6):e015593.

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

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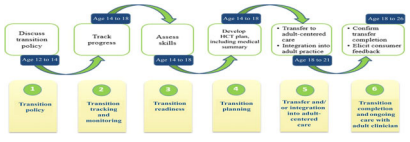
- Expert opinion and consensus on practice-based implementation of transition for all youth beginning at 12 years old
- Roadmap for transition and decision-making algorithms



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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/spp7b4h8

Transition and Adherence Assessment Tools

- Many tools exist, but none are specific to dialysis
- Adherence tools
  - Lam et al (2015). Medication Adherence Measures: An Overview[7]
  - Pruette et al (2019). Does a multimethod approach improve medication nonadherence in adolescents with chronic kidney disease?[8]
  - Multimethod approach is ideal
- Transition tools/checklists
  - Got Transition™
  - AST Transition Portal
  - UNC STARx Program

PEDIATRIC Transition PORTAL

NATIONAL HEALTH CARE TRANSITION CENTER got transition?

7. Lam WY, Fresco P. (2015) Biomed Res Int (2015) 217047; 8. Pruette CS, Coburn SS, Eaton CK, et al. (2019) 34(1):97-105.

- American Society of Transplantation- Pediatric Transition Portal[9]
  - 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 tools 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

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

Transition of Care for Pediatric Dialysis

Simpler Transition	More Complex Transition
Single health condition	Multiple health conditions
Low risk of future health problems	High risk of future health problems
No dependence on medical equipment	Reliance on life-sustaining medical equipment
Rare acute illness, medically stable	Frequent acute episodes, medically unstable
Few medications	Multiple medications, medication problems
No cognitive impairments	Profound mental retardation
No physical impairments	Serious physical impairments
Mentally healthy	Mentally ill
No behavioral concerns	Serious behavioral concerns

Kelly AM, Kratz B, Bielski M, et al. (2002) Pediatrics 110(6 Pt2):1322-1327.

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?

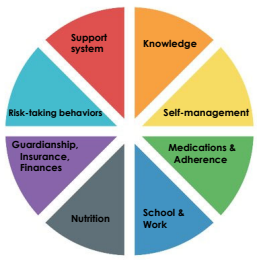
Task 1: How do we define transition of care?

- 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



Task 3: How do we implement a dialysis-specific transition program?

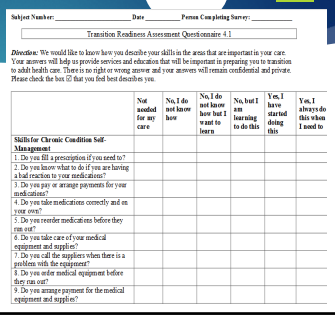
- Education and training of medical team
  - Identify a "Transition Champion"
- Institutional and systems support
  - Recognize that transition planning is a necessary and important aspect of quality health care
  - Funding for transition planning/resources
  - Adequate private and/or public health insurance 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?



Subject Number: _____ Date _____ Person Completing Survey: _____

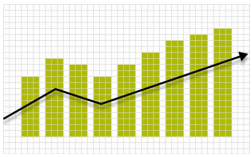
Transition Readiness Assessment Questionnaire 4.1

Direction: We would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private. Please check the box ☑ that you feel best describes you.

	Not needed for my care	No, I do not know how	No, I do not know how but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Skills for Chronic Condition Self-Management						
1. Do you fill a prescription if you need to?						
2. Do you know what to do if you are having a bad reaction to your medications?						
3. Do you pay or arrange payments for your medications?						
4. Do you take medications correctly and on your own?						
5. Do you reorder medications before they run out?						
6. Do you take care of your medical equipment and supplies?						
7. Do you call the suppliers when there is a problem with the equipment?						
8. Do you order medical equipment before they run out?						
9. Do you arrange payment for the medical equipment and supplies?						

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 wh person at every age receives health c is medically and developmentally appropriate. "

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