Developing A Transition Program
Cheryl Ripp, RN, PNP
Rady Children’s Hospital, San Diego

The Research

Assessment of transi adolescents and you health conditions
Paul L. Janssen1, Gabrielle V. Paul2, Stephanie L. Brennan Boyle1, Masanori Kamble1, Chun1

Preparing Adolescents With Chronic Disease for Transition to Adult Care: A Technology Program
Jeannie S. Huang, Laura Terrones, Trevor Tompane, Lindsay Dillon, Mark Pian, Michael Gottschalk, Gregory J. Norman, L. Key Bartholomew

Transition of care for young adults with chronic diseases
Paula H B Bolton-Maggs

Arch Dis Child 2007;92:797–801. doi: 10.1136/adc.2006.103804
The Problems

- Can’t manage meds
- Can’t manage insurance
- Never establish care with adult provider
- Lost to follow up

POOR OUTCOMES

- Poor medication compliance
- Exacerbation of condition
- Increased ER utilization
- CKD progression
- Graft loss

Solutions?

Keep them until mid 20's?

- Insurance may dictate transfer of care
- Institutions may have policies against this
- Not where health care is today

Prepare them

- New concept and skill for providers
- Time consuming process
- Reimbursement is complicated
We’re All In This Together

Who We Are

- 300 bed children’s hospital
- Independent with university affiliation
- Non-profit
- Treat patients birth – 21 years old (typically)
Kidney Transplant Department

- 10 transplants per year
- 70 post-transplant patients
- 4 providers (nephrologists and NP)
- Pharmacist, social worker, dietitian and nurses at every clinic
- Patients seen every 1-3 months
- Most with public insurance

Our Transition Journey

- Driven by personal interest
- Literature review
- Selected Got Transition model
  - Good “how to” guide for transition based on specialty
  - Provides transition tools
  - Customizable questionnaire
  - Not validated
Implementation

- Transition statement
  - Brief statement to give families to explain transition process
- Annual questionnaire
  - Patient self-assessment of ability to manage health needs and goal setting
- Annual care plan
  - Track progress on attaining goals
- Formal transfer plan
  - Who/what/when of transfer
- Tried to implement whole program at once while getting the team’s buy-in

It didn’t work
Why???

- Team liked the idea of transition program BUT
- Got caught up in logistics of implementation
  - Who would see the patients?
  - Which rooms would we use?
  - When would the clinic be?
  - Why would they give up their patient?
  - They are already doing this
- Didn’t understand what it means to “transition”
- So nothing happened…for a while

A New Tactic

- Start slowly
  - Transition statement
  - Transition questionnaire
  - Transfer plan
- Allowed for some skill building and to really solidify our transfer plan with the adult side
- It went well, but what were the next steps?
What's Everyone Else Doing?

- Email sent to hospital NPs
  - Lots of interest
  - Only 1-2 clinics had any sort of formal transition program
- Found physician (GI) working on same idea with physician group
- We combined efforts and started a transition committee

Hospital Transition Committee

- 10 clinical staff at first meeting
- Around 6 consistently participated
  - GI (IBD): MD and RN
  - CF & hemophilia: NP
  - Kidney transplant: RN & NP
  - Nephrology: MD
Goals of Committee

**Philosophy**
- Age to start
- Model to use
- Standardizing age of transfer
- What is needed to successfully transition
- Which/how many specialties to involve

**Questionnaire**
- Wording
- Length
- Frequency of administration

**EMR build**
- Easier to track and maintain records
- More clinics likely to use if in EMR

---

Pilot Program

- Goal is to make universal for hospital, easier to sell completed project
- Fewer cooks in the kitchen
- Easier to establish hospital policies and “norms” of hospital
- 4 clinics
  - IBD
  - CF
  - Hemophilia
  - Kidney transplant
EPIC Build

- Took about 6 months to develop and 6 more months for revisions
- EPIC team could work on one specialty at a time

Transition Tab Contents

- Transition statement
- Annual knowledge assessment
- Skills practicum
- Summary of care
- Follow up call
Transition Tab Content

Transition Statement

- Important to establish a philosophy for transition process

Annual Knowledge Assessment

- Based on Got Transition model
- 28 questions divided up into 3 age appropriate sections
  - 12-14
  - 15-18
  - >18
- True/False style
- Generic for all specialties
- Able to select goals to help establish transition plan
Annual Knowledge Assessment

Kidney Transplant Assessment

- How confident do you feel about your ability to prepare for/switch to an adult doctor with 1 being not confident and 10 being extremely confident:
  - 12 - 14
- I can describe my medical condition(s):
- I can name my medications and know what they are for and the amount and time I need to take them:
- I know my allergies to medications and medicines I should not take:
- I know my doctor’s and nurses’ names and roles:
- I can use and read a thermometer:
- I can ask and answer at least 1 question during my health care visit:
- I can manage my medical issues at school:
- I know my doctor’s phone number and can call my doctor’s office to make or change an appointment:
- Before my doctor’s visit, I think about questions to ask:
- I have access to my own MyChart account and have checked MyChart:

Skills Practicum

Skills practicum
- Specialty-specific
- Optional (to specialty, not patient)
- Opportunity for fill in the blank format
- Helps eliminate simple “box checking”
Skills Practicum

Medical Summary

- Editable, add to it and review with patient annually

Content is the property of the presenter. It may not be used or distributed without the presenter's permission.
Follow Up Call

- So important!
- Make sure they went to their appointment and have another one scheduled
- Last chance for a reminder about self-care and education
What About the Transfer?

- It’s harder than you’d think
- Patients (and parents) do NOT want to go
- Need to find a way to make this easier for them
  - Introduce the concept early and remind them often
  - Find a way for them to build some sort of rapport with adult side
  - Entire team needs to agree on transfer age/date

Early Findings

- Lower literacy rate than expected
- No PCPs
- 50% no-show rate for first visit with adult providers
- Many don’t know/understand own diagnosis
- Honest answers on questionnaires
- Parents don’t know how to transition either
- Most were not registered for online medical information
- It takes time!
  - Especially connecting with other specialists
  - Difficult for provider to do both visit and transition
Lessons Learned

Patient needs
- Many patients lose insurance at 21. Financial counseling is important.
- Help establish care with PCP 1-2 years prior to transfer.
- Patients need rapport with adult team, or they won’t go.

Healthcare team needs
- Good relationship with adult provider.
- Adult team may need education on transition and/or what these patients are used to.
- Using the same language as the adult team.
- Follow-up phone call.
- Get signed consent for ongoing parental involvement.

Current Program - Kidney Transplant

RN/NP run
Post-kidney transplant patients ages 12 and up.
Consists of:
- Transition statement
- Readiness assessment/skills practicum - annually or more frequent if needed.
- Goal selection.
- Education.
- Financial counselor meeting for insurance management.
- Transfer.
- Follow-up after transfer.
- Transfer does not = abandonment. We are still available to help.
Transfer Care

- Well-established relationship with adult nephrologist group. Four nephrologists enthusiastic about taking young adults
- Meet approx. every 6 months with nephrologists, MA and office manager to review both upcoming and post-transfer patients as well as what's working and what's not
- Send records, especially medical summary, ahead of visit
- Offer to go to first visit with patient

No Really, How Do I Start?
How To Start

- Start somewhere
  - Something is better than nothing
- Start small and build as you go
  - Introduce the concept of transition
  - Find transition model that works for you and your patients
  - Administer a questionnaire, understand what education they need
  - Establish a relationship with adult provider
- Always follow up with patients after transfer
- If you are piloting for an institution keep it 3-4 participants to start

Do a lit review. See what other centers are doing

Identify transition model

Skills assessment

Goal setting

Establish relationship with adult provider
Validated Transition Tools

- UNC STARx
- ADAPT
- Am I ON TRAC
- JaxHATS
- UNC TR(x)ANSITION

Next Steps

- Transition the pediatric care team
  - Encourage adult behaviors before transfer
  - Stop enabling
- Transition parents
  - Provide social support and education on how to provide support while still allowing for independence and skill development
- Transitioning the cognitively delayed
Thank You!!!
cripp@rchsd.org