Developing A Transition Program

Cheryl Ripp, RN, PNP
Rady Children's Hospital, San Diego

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The Research

RESEARCH ARTICLE

Assessment of transi
adolescents and you
health conditions

Paul T. Jensen[1,2], Gabrielle V. Paul[2], Stephanie L
Brendan Boyle[1,2], Manmohan Kamboj[1,2], Christ

Pediatrics
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Article

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. Kay Bartholomew

REVIEW

Transition of care from haematology

Paula H B Bolton-Maggs

Transition of care for young adults with chronic diseases

The transition from paediatric to adult care is a crucial phase, defined by the US Society for Adolescent Medicine as "the purposeful, planned movement of mostly initiated by paediatric specialists for one disease or a group of diseases, and frequently with no special reimbursement for these efforts. These

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

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The Problems

- Can't manage meds
- Can't manage insurance
- Never established care with adult provider
- Lost to follow up

POOR OUTCOMES

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

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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

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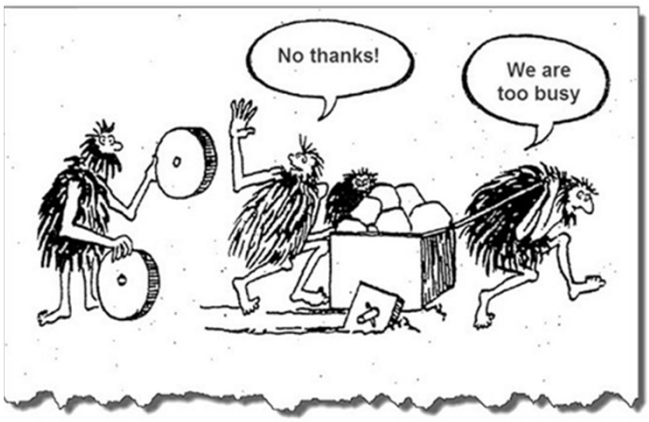
We're All In This Together



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Who We Are

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

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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

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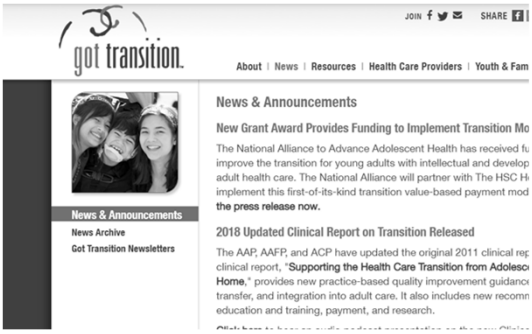
Our Transition Journey

- 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



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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

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It didn't work

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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

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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?

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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

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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

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Goals of Committee

Philosophy	Questionnaire	EMR build
• Age to start • Model to use • Standardizing age of transfer • What is needed to successfully transition • Which/how many specialties to involve	• Wording • Length • Frequency of administration	• Easier to track and maintain records • More clinics likely to use if in EMR

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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

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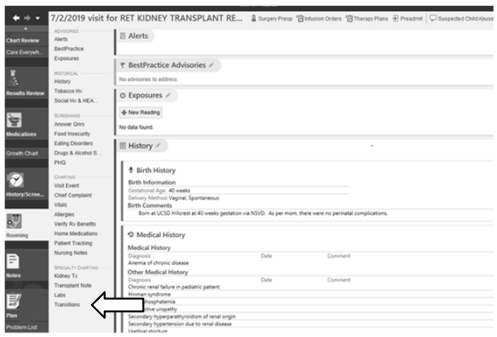
EPIC Build

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



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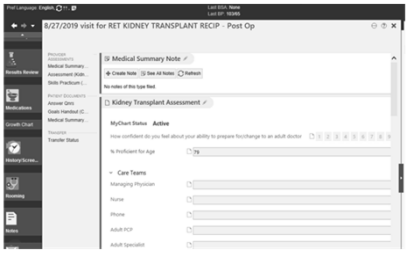
Transition Tab Contents

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



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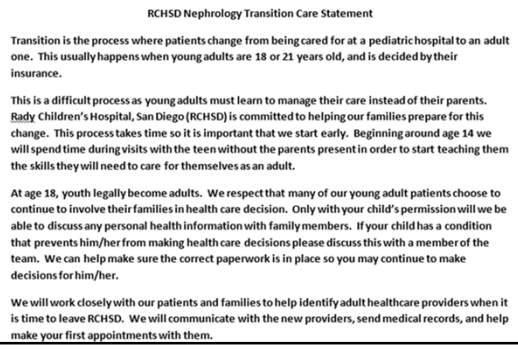
Transition Tab Content

Transition Statement

- Important to establish a philosophy for transition process



RCHSD Nephrology Transition Care Statement

Transition is the process where patients change from being cared for at a pediatric hospital to an adult one. This usually happens when young adults are 18 or 21 years old, and is decided by their insurance.

This is a difficult process as young adults must learn to manage their care instead of their parents. Rady Children's Hospital, San Diego (RCHSD) is committed to helping our families prepare for this change. This process takes time so it is important that we start early. Beginning around age 14 we will spend time during visits with the teen without the parents present in order to start teaching them the skills they will need to care for themselves as an adult.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decision. Only with your child's permission will we be able to discuss any personal health information with family members. If your child has a condition that prevents him/her from making health care decisions please discuss this with a member of the team. We can help make sure the correct paperwork is in place so you may continue to make decisions for him/her.

We will work closely with our patients and families to help identify adult healthcare providers when it is time to leave RCHSD. We will communicate with the new providers, send medical records, and help make your first appointments with them.

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Annual Knowledge Assessment

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

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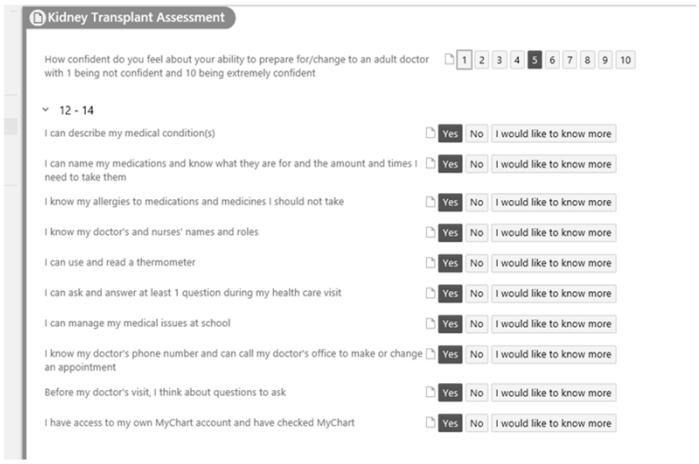
Annual Knowledge Assessment



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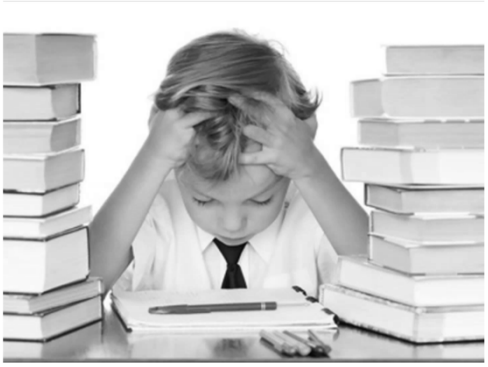
Skills Practicum

Skills practicum

- Specialty-specific
- Optional (to specialty, not patient)
- Opportunity for fill in the blank format
- Helps eliminate simple "box checking"



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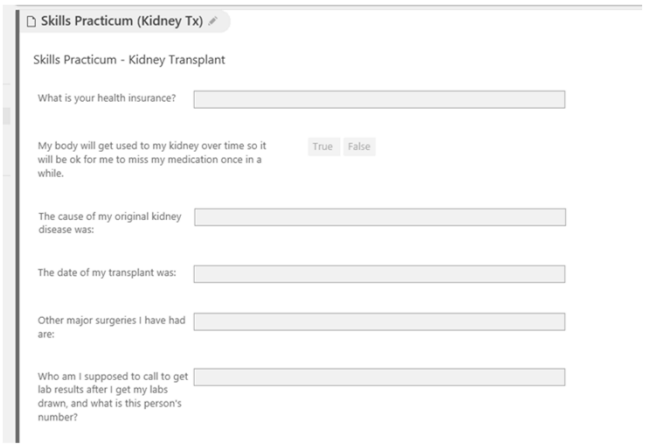
Skills Practicum



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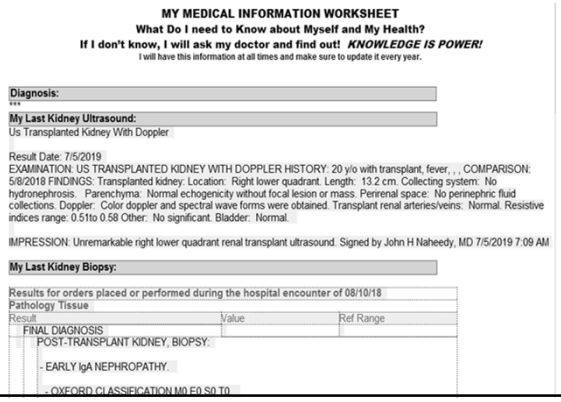
Medical Summary

- Editable, add to it and review with patient annually



MY MEDICAL INFORMATION WORKSHEET
What Do I need to Know about Myself and My Health?
If I don't know, I will ask my doctor and find out! *KNOWLEDGE IS POWER!*
I will have this information at all times and make sure to update it every year.

Diagnosis:

My Last Kidney Ultrasound:
Us Transplanted Kidney With Doppler

Result Date: 7/5/2019
EXAMINATION: US TRANSPLANTED KIDNEY WITH DOPPLER HISTORY: 20 y/o with transplant, fever, , , COMPARISON: 5/8/2018 FINDINGS: Transplanted kidney: Location: Right lower quadrant. Length: 13.2 cm. Collecting system: No hydronephrosis. Parenchyma: Normal echogenicity without focal lesion or mass. Perirenal space: No perinephric fluid collections. Doppler: Color doppler and spectral wave forms were obtained. Transplant renal arteries/veins: Normal. Resistive indices range: 0.51to 0.58 Other: No significant. Bladder: Normal.

IMPRESSION: Unremarkable right lower quadrant renal transplant ultrasound. Signed by John H Naheedy, MD 7/5/2019 7:09 AM

My Last Kidney Biopsy:

Results for orders placed or performed during the hospital encounter of 08/10/18
Pathology Tissue

Result	Value	Ref Range
FINAL DIAGNOSIS		
POST-TRANSPLANT KIDNEY, BIOPSY:		
- EARLY IgA NEPHROPATHY.		
- OXFORD CLASSIFICATION M0 E0 S0 T0		

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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

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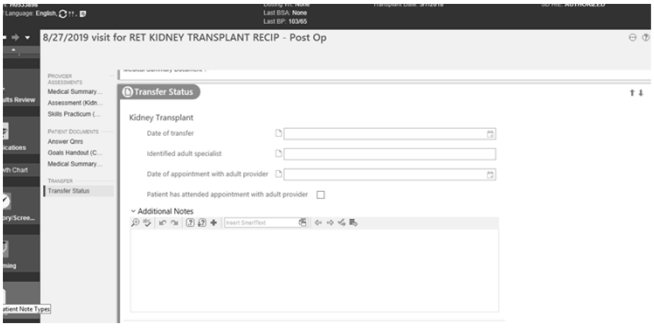
Follow Up Call



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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

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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

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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
  - Good to observe visits to see what the norm is
- Follow-up phone call
- Get signed consent for ongoing parental involvement

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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

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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

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No Really, How Do I Start?

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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

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How To Start

Do a lit review. See what other centers are doing

↓

Identify transition model

↓

Skills assessment

↓

Goal setting

↓

Establish relationship with adult provider

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Validated Transition Tools

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

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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

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Thank You!!!

cripp@rchsd.org

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