Transition, Transplantation & Teenager’s

Pediatric to Adult Transition (PAT)

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What is Transitional Care?

- Process -- not an event
- Journey from pediatric to adult care
- Starts early
- Collaboration
  - Adult and pediatric providers
  - Patient
  - Family
  - Third party payers
Organizational Commitment

- **American Academy of Pediatrics (2002)**
  - “To maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood”

- **American Society of Transplantation Joint Adult and Pediatric Transition Workgroup (2/27/2012)**
  - “All Pediatric transplant recipients in North America will have access to an effective coordinated process of transition to adult care that optimizes their potential for health and well-being within the constraints of their underlying medical condition”

- **National Health Care Transition Center 2012**
  - 6 Core Elements: Pediatric & Adult
    - Transition Policy
    - Youth Registry
    - Transition Preparation
    - Transition Planning
    - Transition/Transfer of Care
    - Transition Completion
Background

- UNOS 2011:
  - LTx N=504 <17 years
  - KTx N=757 <17 years
- ~7,000 solid organ transplant recipients between ages 15-24 with a functioning graft
- Identified need for formalized PAT transition programs

Bell et al, 2010; ANZDATA, 2009, UNET, 2008
Transitional Programs Vary Nationally

- Checklist model
- Workbook model
- Care Plan model
- Quick card reference
- Audio visual
- Utilization of a comprehensive transition clinic
  - Staffing funding dependent
  - Pediatric – adult provider availability
  - Billing issues
  - CCS provider
  - Credentialing concerns
Paucity of Research
PAT in Organ Transplantation

- **Watson (2000)** 36 months of transfer
  - 8 of 20 kidney allografts failed

- **Remorino & Taylor (2006)** 1 year of transfer
  - 16 of 28 KTx recipients had higher rate of non attendance to clinic
  - Level of satisfaction with transfer
    - 9 of 11 “OK”
    - 2 “gone badly” and “really badly”

- **McCurdy et al (2006)** conclusions from 17 Tx recipients (9 renal, 5 liver, 4 heart)
  - Confirmation from recipients that pediatric care is “different” than adult care
  - General feeling of being poorly prepared to face the adult health care system
  - Need for greater recipient investment in transition planning

- **Annunziato et al (2007)**
  - LTx recipients showed an increased variability in TAC levels following transfer to adult care

- **Chaturvede et al (2009)** 1 year of transfer
  - 10 of 11 KTx pts were receiving regular medical
  - None had an unexpected clinical course
  - Clinic attendance decreased from 73% the first year to 57%
  - 9 of 10 did not feel involved in the transition planning

- **Koshy et al (2009)**
  - N=115 13.9 +/- 3.7 years no increase in allograft loss observed during the transition period (aged 19-19.9 year)

  - N= 162 risk of acute rejection decreases after transition
Observation

- Children grow up!

- Identified need to:
  - Improve the post Tx educational process across the pediatric developmental stages
  - Develop a formalized program to transition transplant patients to the adult service
Conceptual Framework

- Family Centered Care
- Adolescent Development & Emerging Adulthood
Adolescence Development and Emerging Young Adulthood

- Adolescence time between childhood and adulthood
- Changes in physical psychological and social development
- Time of significant change and a time of vulnerability
- Early 20\textsuperscript{th} century defined as continuing into mid 20’s
- WHO (2002) definition age between 10-19 starting with the onset of puberty, spanning from 13-19
- 18 years is the age of legal majority of most high income countries (Patton et al 2009)
- Arnett (1999) used the term “emerging adulthood”
- Time between 18-25 years
- Recognition of ongoing maturation and social development

Bell & Sawyer, 2010
Review of Normal Adolescent Concerns
Understanding & Supporting Chronically Ill Adolescents

- **Appearance**
  - Disruption of body image

- **Independence**
  - Altered sense of self identity
  - Prolonged dependence

- **Peer involvement**
  - “do I fit in”
  - Missing important social activities can be devastating
  - Increased feelings of isolation

- **Sexuality**
  - Altered sexual maturation can impact self esteem, self image and emerging sexuality

- **Management of Medical Regime**
  - Need to have a sense of control and independence

- **Family/siblings**
  - Need for support
  - Balance between ill adolescent and other siblings

- **School/Work**
  - Maintain future goals
  - Provide a social structure
  - Assist in completing developmental tasks
Goal of Transition at UCSF

“Moving transplant care from pediatrics to the adult care team in a manner that feels safe, simple, smooth and cooperative for the patient, their families and staff.”
Purpose

- Prepare the child (family) for adulthood
  - Support achievement of normal developmental milestones

- Provide patient (family) consistent ongoing education and support over time
  - general health care
  - transplant care
  - developmentally appropriate

- Ensure a smooth transition between services
- Optimize communication between providers
- Identify any potential areas of concern
All patients <18 years will be cared for by the pediatric team.

The majority of patients will be transferred to the adult service between ages 18-21.

Patients will be transferred by age 26.

Readiness to transfer to the adult team will be assessed individually, variables include:

- An expressed readiness
- Understanding of their illness
- Demonstration of their ability to provide self care
- Developmental status
- Social support
- Insurance
Implementation Considerations

- Develop a transplant transition patient education program for recipients and families
  - Based on developmental age/stage
  - Clear outline of expectations for each stage
    - What you need to learn and achieve.
  - Questions indicating “How do you know when it is time to transition?”
  - List of frequently asked questions
- Patient Checklist “Expectations Prior to Transition”
- Provider Transfer Checklist
- Program approval from the Transplant Professional Practice Committee
- Formulation of a Multidisciplinary Transplant Transition Committee
Transitional Process

- Education
  - Staff
  - Patient/families
- Create Transition Booklet
- Input recommendations
  - Adult team
  - Patient/families
- Approval Tx Ed. Co. and PPC
- Identify PAT committee members
  - Establish meeting times
UCSF Multidisciplinary Transplant Transition Committee Members

- Robert Blackmond FC
- Maria Bracamonte MSW
- Jennifer Cadematori NP
- Chris Freise MD
- Chris Mudge PNP
- Lisa Omar FC
- Claudia Praglin NP
- Pauline Rogers MSW
- Susan Stritzel PNP
Transplant Transition Program Development

- Based on well established pediatric stages of development
- Utilized a Rocketship motif as a model for transition
  - Rocketship model to be removed with next draft of the booklet
- 5 stages “Countdown to Transition”
- Focus on the last stage of transition

Blast Off
Stages of Transition

- Stage 5 *Building the Rocketship* ages 8-10
- Stage 4 *Bring the Rocketship to the Launch Pad* ages 10-12
- Stage 3 *Fueling the Rocketship* ages 13-15
- Stage 2 *Equipment Check* ages 16-17
- Stage 1 *Starting the Engines* ages 18-21
- *Blastoff*
University of California San Francisco
Transplant Services

Transition from Pediatrics to Adult Care Program

November 2009
Transition Stages

- Brief explanation of what is expected of the provider and the patient
- List of what the patient needs to learn and achieve at each stage
- Examples of what parents and adult family members can do to help prepare the child for transition
- Provider responsibilities
Transplant Transition
Pediatric Provider Expectations

- Educate & support
  - Recipient
  - Family
- Encourage achievement of developmental milestones
- Assess Readiness (checklist)
- Coordination of Care
- Assist with insurance issues
- Present to PAT committee
- “LET GO”!
Key Concepts When Working With Chronically Ill Adolescents

- Spend time, listen
- Establish trust and mutual respect
- Be honest
- Enlist cooperation
- Promote normal growth and development
- Support completion of developmental tasks
- Provide continuity of care
- Avoid power struggles
- Encourage independence
- Provide ongoing supportive education
- Promote peer and family involvement
Critical Points: Patient Expectations Prior to Transition

- Explain the cause of their organ failure and the need for transplant
- Understands their medical history
- Describes the short and long term impact of Tx e.g. cancer surveillance, reproductive health/pregnancy/sexual activity, infection prevention
- Discusses potential problems/complications
- Consistently completes routine blood work
Critical Points: Patient Expectations Prior to Transition

- Independently schedules and attends clinic
- Demonstrates adherence to post Tx routines
- Knows when/how to seek urgent/emergent medical attention
- Know all medications: name, dosing, administration times, side effects, why they are taken
- Demonstrate ability to refill medications
- Able to change medication doses over the phone
Critical Points: Patient Expectations
Prior to Transition

- Identified PCP
- Discusses and participates in routine health care activities
- Capable of providing self care independently or there is a plan for resource assistance
- Understands their medical insurance coverage and eligibility requirements
- Expresses a readiness to transfer to the adult service
Transition: Related Topics

- Self management
  - Developmental delay
  - Cognitive and or physical impairment
- Guardianship
- Self advocacy
- Transition planning
- Employment, education, recreation
- Housing and independent living
- Social support: family and community resources
- Transportation
- Insurance
Examples: What Parents/Adult Family Members Can Do To Prepare for Transition

Start Young
Examples: What Parents/Adult Family Members Can Do To Prepare for Transition

- Talk to your child about the transplant
- Discuss routine blood work and medications
- Start working with your child to become an active participant in their own care
- Encourage independence and preparation for the future
- Investigate and secure financial coverage
Examples: What Adolescents Can Do To Prepare For Transition

- Keep a copy of standing lab order
- Keep a list of medications
- Keep pharmacy number and learn how to refill prescription
- Call and make own appointments
- Find out about health insurance
Examples:

Frequently Asked Questions

- How do I meet the people on the adult Tx team?
- What can I expect from the adult Tx team?
- Who do I call if I have a question?
- Will I transition to the adult Tx team if I haven’t had my Tx yet?
- How do you know when it is time to transition?
- How does my health care information get transferred to the adult team?
Pediatric Provider Transfer Checklist

- Demographics
- Tx date and organ
- H&P summary
- Last clinic note and lab work
- Medication list
- Problem list
- Pharmacy and lab numbers
- PCP
- Insurance status
- Present to the Transition Committee
- Date anticipated for transfer

Computer Update
Transplant Transition
Process Operationalized

- Review the process with patient/family
  - Verbally
  - Letter
- Confirm the patient is able to make the transition successfully
- Present to Transition Committee
  - Specific template
  - Adult and pediatric participants
  - Multidisciplinary group: surgeon/doctor, nurses (NPs), social work, financial counselor
  - Discussion and recommendations
- Schedule a combined adult – pediatric clinic
Barriers to Successful Transition

- Lack of patient readiness
- Adherence
- Timing, avoid transition in the mist of a crisis
  - Key Point: Transplant recipients typically transfer to adult health care at a time in life that coincides with increased “risk taking behaviors”.
- Parental anxiety
- Attitudes of staff
  - Pediatric team not letting go
  - Adult team concerns
- Insurance issues

UCSF, 2009; Bell, et al 2010
Challenges for the Adult Transplant Team

- Adherence
- Patient has not been prepared adequately for transfer
- Assume autonomous adult
- Adult providers often have 10xs the number of patients to care for may result in:
  - Shorter clinic visits
  - Difficulty building pt/provider relationships
  - Adolescence/young adults may feel less likely to share sensitive issues or concerns
- Transition in time of crisis
- Insurance issues
Non-Adherence a Related Risk

- Estimated adolescent transplant recipients non-adherence rates 17-53%
- UCSF
- Medical non-adherence rates 4x higher than adult Tx recipients

Fredericks, 2009
Strategies to Optimize Adherence in Adolescents and Young Adults

- Trusting, collaborative and open relationship that encourages dialog

- Stepwise approach to education and treatment regimen
  - Medications (purpose, name, dose, schedule, side effects)
  - Enhance with booklets, DVD, labels
  - Assess comprehension

- Behavioral Strategies
  - Simplify the regimen
  - Individualize & tailor the medication schedule
  - Recording of medications, use of labels, alarms, text
  - Link medications to ADL e.g. brushing teeth, meals

Bell & Sawyer, 2010
Strategies to Optimize Adherence in Adolescents and Young Adults

- Structured clinical and social network support
  - More frequent clinic/nursing visits
  - More contact phone, text, email
  - Health care provider continuity
  - Peer group support and mentoring

- Provide a clinic environment that is welcoming to young adults and adolescents

- Family & friends support

Bell & Sawyer, 2010
Family Support is Important to Transitional Success
UCSF Liver Transplant Patients
Transitioned Between 18-25 years

- Transitioned N=83
- Program Application N=7
- Ready to go N=19
Pediatric to Adult Transition

Future Plan

- Revise the booklet
- Develop a DVD or a web based educational tool
- Continue to transfer liver transplant recipients using this model
- Incorporate the kidney Tx program
- Evaluate the effectiveness of the program and revise as indicated
Bridging the Gap or Passing the Buck
Pediatric to Adult Transition Programs

Collaboration is Key!
LETTING GO!!!
Blast off to Adulthood
Transition

“I left my liver in San Francisco!”
Transplantation Transition
Teenager’s

- Questions
- Answers
- Discussion
References & Resources

- Got Transition www.gottransition.org/
- http://chp.ufi.edu/reserach/videos/tihct/