Transitioning Adolescents to Adult Care

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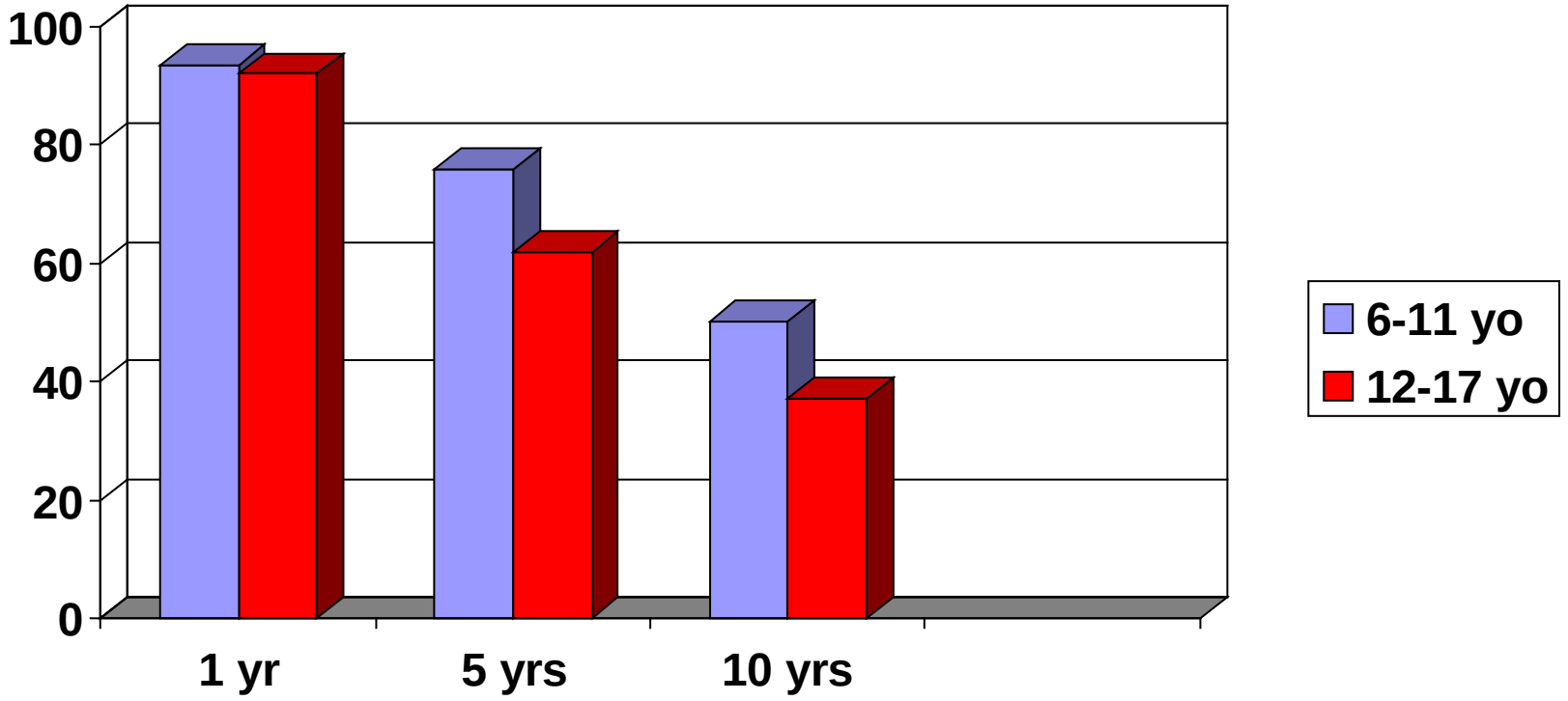
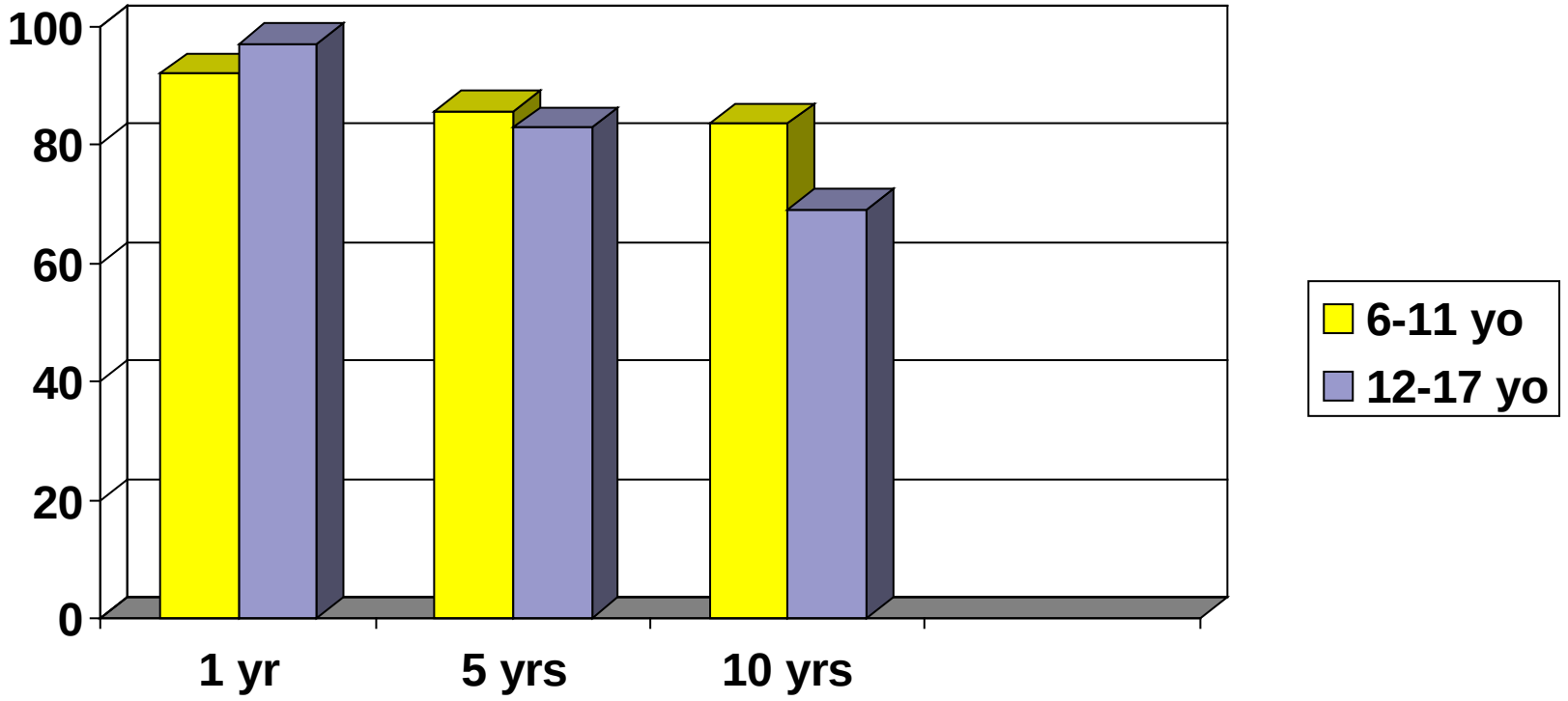
Graft Survival Following Deceased Kidney Transplantation



OPTN/SRTR Annual Report; Table 5.12c. Data as of 5/1/08

Graft Survival Following Deceased Liver Transplantation



OPTN/SRTR Annual Report; Table 9.10a. Data as of 5/1/08

Transition

" a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from child to adult-centered care."

Blum et al. J Adol Health 1993: 14:570-6

Goals of a Transition Program

- Provide coordinated, uninterrupted and patient-centered care
- Promote progressive independence and autonomy → adequate self-management
  - Promote a sense of control to participate in decision making
- Support continued adaptation to a chronic condition

First Efforts: Adapting Pediatric Care

- Providers/families ignored hospital policies
- Pediatric facilities established more adult oriented services using pediatric staff
- Pediatric providers have modified their practice and broadened their knowledge base
- Informal, patient-specific patchwork care has developed
- Informal programs with shared management

Reiss J et al. Pediatrics 2002; 110(6): 1307-14.

Challenges to Transition

- Philosophy
  - Family focused pediatric approach vs. the responsible self-care focus in the adult setting
- Protocols
  - Few established/experienced transition programs
  - Minimal preparation for the “event”
    - Transfer vs. transition

Challenges to Transition

- Transplant team issues
  - Pediatric team unable to “give up” patient
    - Long, established and personal relationship
    - Patient/family focus with dependent child
    - Extended team
  - Adult team with less experience managing the “old” pediatric patient
    - Short term relationships; less personal
    - Individual focus with autonomous adult
    - Has higher expectation for independence
    - Limited team

Challenges to Transition

- Parent Issues
  - Have difficulty relinquishing responsibility and promoting independence
    - Enmeshment
    - Interdependence
    - Overprotection
      - Encourages disengagement

Challenges to Transition

- Young adult issues
  - Need to transition and are generally ready to be involved when prepared and transitioned appropriately
  - Long relationship with pediatric team
  - Chronological vs. developmental age
  - Dependency on parents
  - Ongoing pediatric-oriented medical problems

Challenges to Transition

- Adolescents may not master developmental tasks
  - Limited expectations by pediatric staff and family
  - Minimization of adolescent concerns
  - Reluctance to discuss key issues
    - Sexuality
    - Vocation
    - Social independence

Perceptions of Transition

- 14 adolescent heart tx recipients and 17 parents
- Predominate attitude of adolescents was apathy; parents had overwhelming fear and anxiety
  - None expressed a strong desire to be more independent
- Both perceived a negative difference in quality of care and atmosphere of the adult setting
- Both felt that the adult and pediatric centers should have good collaboration and communication with an overlap in care

Anthony SJ et al. Am Jl of Transplant 2009 9:614-619

Transition Experiences

- Adolescents are anxious and feel abandoned (Minicozzi, 2000)
- May withdraw or avoid formal health services until they have a medical crisis (Holmes-Walker et al 2007)

Financial Issues

- Type of health care coverage affects health care utilization
  - Managed care vs. non-managed care insurance
  - Policy changes
    - Pre-existing conditions
    - Dependency
  - Lapses in coverage
  - Disability

Financial Issues

- Transplant center and hospital budgets
  - Staffing
  - Space
  - Costs vs charges
- Potential high cost of transition program must be seen in the larger perspective of possible savings with decreased healthcare costs, employment, less use of resources

National Initiatives

Healthy People 2010

US Dept of Health and Human Services

Goals:

- Increase quality and years of healthy life
- Eliminate health disparities

Healthy People 2010

Pediatrics 2002; 110(6): 1304-08.

Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs

American Academy of Family Physicians

American College of Physicians

American Society of Internal Medicine

Healthy People 2010

- **Transition to Adulthood**
  - Youth with special health care needs, as adults, must be able to expect good health care, employment with benefits, and independence.
  - Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings.
  - Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose.

http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm

Healthy People 2010

Pediatrics 2002; 110(6): 1304-08.

- Identify healthcare professional who assumes responsibility for care.
- Develop training programs/certifications for primary care residents/physicians
- Provide a current medical summary for a common knowledge base
- Create a transition plan by age 14
- Achieve appropriate accessibility to services and resources
- Ensure affordable, continuous insurance coverage

Healthy People 2020

- A ten-year national initiative that sets goals and objectives for promoting health and preventing disease.
- Builds from objectives and goals set for *Healthy People 2010*
- *http://www.healthypeople.gov/HP2020/*

Healthy People 2020
AH HP2020-10

- *Increase the percentage of vulnerable adolescents who are equipped with the services and skills necessary to transition into an independent and self-sufficient adulthood.*
  - Increase the percentage of adolescents with special health care needs who receive the health care services necessary to make transitions to adult life, including independence and adult health care. (AH HP2020-10a)

- Data Sources
  - National Survey of Children with Special Health Care Needs
  - Centers for Disease Control
  - National Youth in Transition Database
  - Administration for Children and Families

Adolescent Transition to Adult Care in Solid Organ Transplantation: A consensus conference report.

Bell LE et al Am J of Transplant 2008; 8:2230-42

- Health care provider responsible for transition coordination and health care planning
- Written health care transition plan
- Current health summary
- Achieve critical tasks prior to transition
  - Develop skills to assume self-care
  - Improve medication adherence
- Promote educational and vocational planning
- Guide family and adolescent regarding health and medication insurance

Transition Programs

Stages of Transition

University of Wisconsin Children's Hospital
Pediatric Cystic Fibrosis Team
Craig Becker MSW, Darci Pfeil NP

- Stage 1: Ages 8 -10
  - Explain what it means to have CF
  - Understand why some people have CF and others do not
  - Begin to learn how your lungs work
  - Begin to learn how your body uses food
  - Help your parents remember your enzymes

Stages of Transition

- Stage 3: Age 13
  - Understand my respiratory baseline and changes that may occur
  - Independent with airway clearance
  - Independent with enzymes
  - Can list medications and amount I take
  - Answers questions independently in clinic

Stages of Transition

- **Stage 6: Ages 18-21**
  - Remain independent with airway clearance and enzymes
  - List medications and doses
  - Is independent during clinic visits
  - Continue to understand yearly tests and reasons
  - Continue to make choices about work, friends, drinking, and smoking that keep me healthy
  - Call pharmacy for med refills
  - Call the CF center and speak directly with staff if there are any problems
  - Secure financial coverage/insurance

Health Care Transitions

- Produced by the Institute for Child Health Policy at the University of Florida

- Florida Dept of Health, Children's Medical Services
  - John Reis PhD, Author
  - Randall Miller, Project Coordinator
  - Mohini Raum, Designer

http://hctransitions.ichp.ufl.edu

Institute for
CHILD HEALTH POLICY
UNIVERSITY OF FLORIDA

Health Care Transitions

- Goals
  - *"Beginning at age 12, all teens and young adults with special health care needs who are enrolled in the CMS Network and their families receive the services needed to make transitions to all aspects of adult life, including adult health care, work, and independence."*

Health Care Transitions

http://hctransitions.ichp.ufl.edu/hct-promo/

- *Envisioning My Future*
  - About Transition: ages 12-14
  - New Responsibilities: ages 15-17
  - Taking Charge: ages 18+
- Tips for Parents
- Tips for Youth

Transition Checklist

Ages 12-14: *Check the items that are true for you:*

- ❑ I can describe how my health condition affects my daily life
- ❑ I can name my medications and the amount and times I take them
- ❑ I answer at least one question during a health care visit
- ❑ I can call my doctor's office to make or change an appointment
- ❑ I have talked with my doctors/nurses about going to different doctors when I am an adult

Good 2 Go Transition Program

The Hospital for Sick Children
Toronto, Ontario

- Based on the Shared Management Model
  - Early therapeutic alliance
  - Gradual shift in responsibility
  - Role change over time
  - Active participation in health care in an age-appropriate manner

http://www.sickkids.ca/good2go/

Good 2 Go Transition Program

- Core Team
  - Psychologist
  - Clinical Nurse Specialist
  - Adolescent pediatrician
  - Social Worker
  - Administrative Assistant

Good 2 Go Transition Program

The Hospital for Sick Children
Toronto, Ontario

Goal:

- "*to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves, maintain health-promoting behaviors, and utilize adult health-care services appropriately and successfully*"

Good 2 Go: Role Transition

Age/Time	Provider	Parent/Family	Youth
Early	Has major responsibility	Caretaker	Receives care
Increasing age	Provides support to parent/youth	Manager	Participates
Increasing age	Consultant	Supervisor	Manages
Adult	Resource	Consultant	Supervisor/CEO

Good 2 Go Transition Program

- Resources
  - Readiness checklist
  - Transition clinic
  - My Health Passport
  - Education days
  - Graduation certificate
  - Transition groups
  - Staff training
  - Research/program evaluation

Adolescent Health Transition Project

Center on Human Development and Disability
at the University of Washington, Seattle

- Designed to facilitate the transition from pediatric to adult health care for adolescents with special health care needs
- Resource for information, materials, and links in health transition issues

http://depts.washington.edu/healthtr/

Adolescent Health Transition Project

http://depts.washington.edu/healthtr/

- Care Plans for Teens
  - Getting to Know Me
  - What's the Plan?
  - In Case of Emergency
- Portable Medical Summary
- Transition Timeline
- Adolescent Autonomy Checklist
- Transition letters
- Build Your Own Notebook
- Tips for Talking to Your Health Care Provider

Stages of the Transition Process

1. Preparation program in the pediatric transplant setting
2. Active transfer strategies
3. Consolidation and evaluation in the adult setting

Issues to Consider

- Hospital-wide program vs. transplant
  - May be easier to obtain hospital support and funding
- Staffing for adult and pediatric programs
- Educational materials and resources
- Establish a transition clinic as a first step to the adult program

Key Elements of Transition

- Designated transition coordinator
- Assess readiness: planning to the actual transition must begin at least 2 years prior to the move
- Ongoing support for the family
- Pediatric professionals need to “let go”
- Each team needs to understand the other’s perspective
- Strategies to ensure communication
- Ad hoc transition processes do not support the needs of the young adult

Transition Coordinator

- Serves as a resource person for the adolescent: psychosocial "safety net" (Tuchman et al 2010)
- Facilitate a smooth transition
- Guide family and young adult through the system
- Schedule and track appointment
  - Missed appointments common after transition and associated with complications (Holmes-Walker et al 2007)
- Address psychosocial and health care coverage issues
- Link to other physicians and services needed post-pediatric care
- Role of coordinator greater in unstable families (McDonagh 2005)
- Success of role associated with engagement of the entire team

Transition Readiness

- Capacity of the adolescent and his/her support system (family and medical providers) to prepare for, begin, continue and finish the transition process (Betz CL, 2007)

Periodic assessment of readiness: maturity, adherence, self-management skills

Ongoing transition planning intervention and support (transition coordinator)

Tuchman et al 2010

Transition Readiness Assessment Questionnaire (TRAQ)

Sawicki GS et al. Jl of Ped Psychology Advanced Access Dec 29, 2009

- 33 item questionnaire to assess readiness for transition for youth with special health care needs
- Measures skills to successfully transition and progress in education, work, daily life
- Tool validation: 192 youths with CF, diabetes, cerebral palsy, hematologic disease
  - TRAQ domains demonstrated high internal consistency
  - Older age and an activity-limiting condition associated with higher scores in Self-Management
  - Female gender and activity-limiting condition associated with higher scores in Self-Advocacy

Stages of Change: TRAQ

- Precontemplation: I do not need to do this
  - Has no intention of taking action
- Contemplation: I do not know how, but I want to learn
  - Intends to take action within 6 months
- Preparation: I am learning to do this
  - Has taken some behavioral steps
- Action: I have started doing this
  - Has changed behavior for < 6 months
- Maintenance: I always do this when I need to
  - Has changed behavior for > 6 months

TRAQ Domains

- Domain 1: Self-Management
  - Do you take your meds correctly and on your own?
  - Do you fill a prescription if you need to?
  - Do you call your doctor about unusual changes in your health
  - Do you apply for health insurance if you lose your current coverage?
- Domain 2: Self-Advocacy
  - Do you answer questions asked by your MD or nurse?
  - Do you help plan/prepare meals?
  - Do you keep a calendar or list of medical appointments?
  - Do you apply for a job, work or vocational services?

Assessing Outcomes

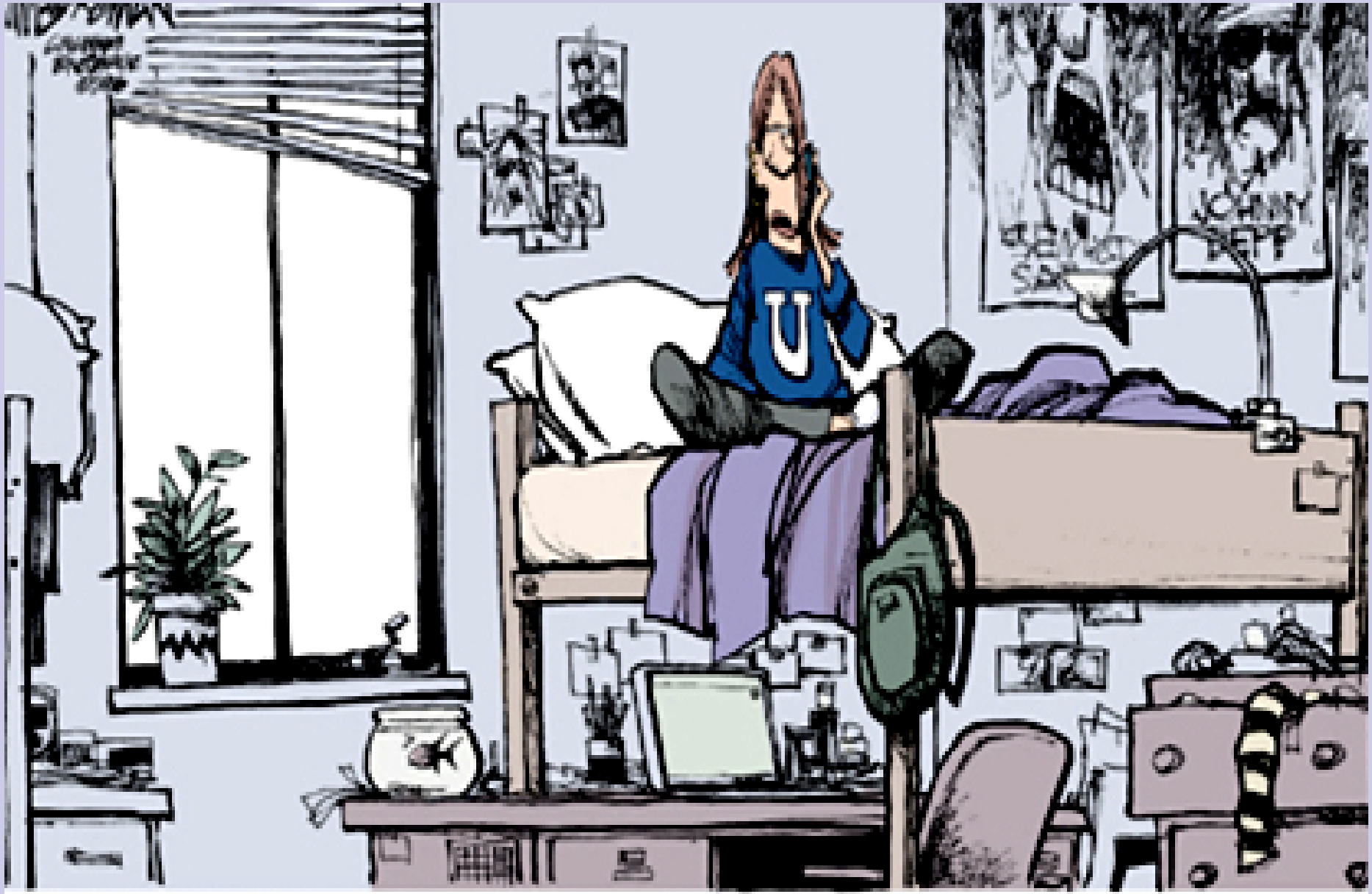
- Paucity of empirical research and EB guidelines
  - Models based on clinical experience or best-practice approaches
  - Published literature is mostly descriptive and reports qualitative outcomes (satisfaction, perceptions)
- Database of transition care performance indicators
  - Provides outcome data to guide program development
- Measurable outcomes pre- and post-transition
  - Hospital admissions
  - Adherence
  - Immunosuppression levels
  - Stable labs/graft function

Assessing Outcomes

- Potential areas of research (Bell LE et al, 2008)
  - Do formal transition programs improve medical and psychosocial outcomes?
  - Which elements of transition are most important to impact outcome?
  - How can readiness be assessed?
  - Transition cost analysis

What Can Be Done

- Identify a core committee within the team
- Assess adolescents with a readiness checklist
- Create a care plan for the youth and family by age 14 or earlier and update annually
- Follow guidelines for routine and preventative care
- Design a plan of action
  - Indicate the person responsible for each step
  - Set a timeline for completion
- Create a Health Passport with the youth


"YES, MOTHER, I TOLD YOU. I'M DOING FINE ON MY OWN AT COLLEGE.... HEY, COULD YOU LOG ON AND FIND MY SCHEDULE, ORDER MY BOOKS AND CALL ME WHEN IT'S TIME FOR CLASS?"