From Pediatrics to Adulthood:
A Multidisciplinary Approach to Transitioning Transplant Care

TODAY'S PRESENTERS

Jon Savant
PA-C
Physician Assistant
Children's Hospital of Philadelphia®

Jill Plevinsky
PhD
Pediatric Transplant Phycologist
Children's Hospital of Philadelphia®

Debby McGrath
MSW
Social Worker
Children's Hospital of Philadelphia®

THE Alliance | *Equipping a Modern Profession of Lifesavers in Organ Donation & Transplantation*

Thursday, May 30 2024, 3:00pm – 4:00pm ET

Continuing Education Information

Evaluations & Certificates

Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
- We highly encourage you to provide us with your feedback through completion of the online evaluation tool.
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- Group leaders, please share the follow-up email with all group participants who attended the webinar.

Deanna Fenton
Senior Manager, Program Development and Operations
THE Alliance

Need Assistance?

Contact Us via Zoom Chat, or
info@organdonationalliance.org
786-866-8730

Meet Our Moderator

Talia Giordano MSW, LCSW
Director, Family Services and Caregiver Lifeline Program
GIFT of LIFE Howie's House

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Transition from Pediatrics to Adult Care

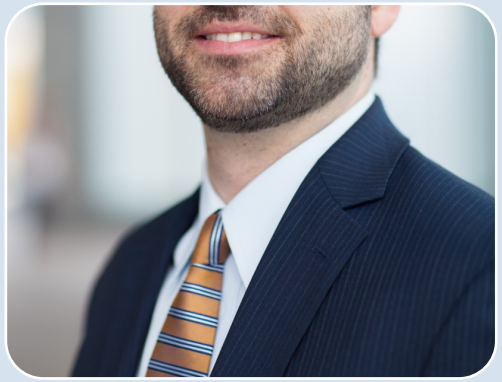
The Alliance Live Advancement Series

May 30, 2024

Children's Hospital of Philadelphia®

Talia Giordano, MSW, LCSW

Moderator



Jon Savant, PA-C

Physician Assistant, CHOP Kidney Transplant Program

Jill Plevinsky, PhD

Pediatric Psychologist, CHOP Liver and Lung Transplant Programs

Debby McGrath, MSW

Social Worker, CHOP Lung Transplant Program

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Learning objectives

1) Identify aspects of transition readiness and transition to adult care unique to solid organ transplant recipients

2) Describe how transition readiness affects medical outcomes in solid organ transplant recipients

3) Describe the role of pediatric psychology in supporting the transition to adult care

4) Describe the role of social work in promoting transition in the lung transplant program

Transition Readiness and Transition in Solid Organ Transplant Recipients

Promoting self-management and transition readiness

- Getting ready to transfer to an adult center is a process – and that process is called **transition**.

- Transition involves the **slow**, **planful**, **gradual** shift in responsibility of healthcare tasks from parents to their teenagers.

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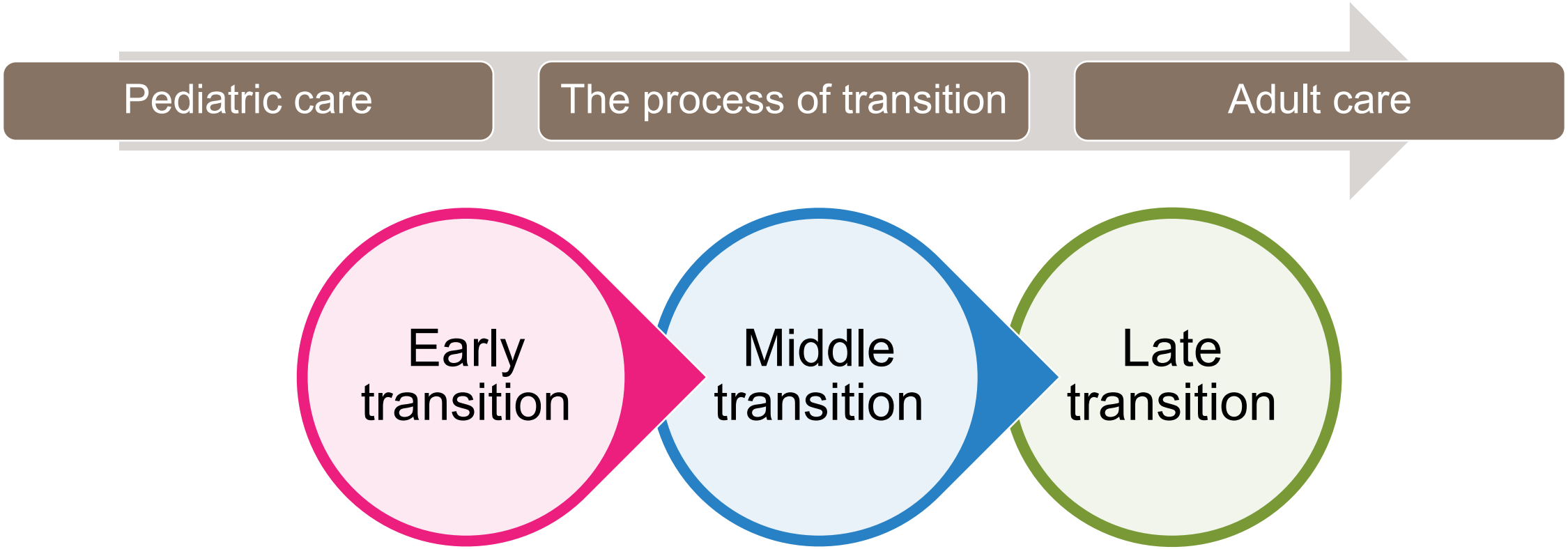
Developmental model of transition



Fredericks et al. (2010)

Special considerations in young adults with SOT

- Health counseling
- Medications
- Immunosuppression extra considerations
- Family planning
- Neurocognition/ brain development
- Psychiatric comorbidities/ Substance abuse
- Education/ Employment

Measurable patient outcomes in solid organ transplant

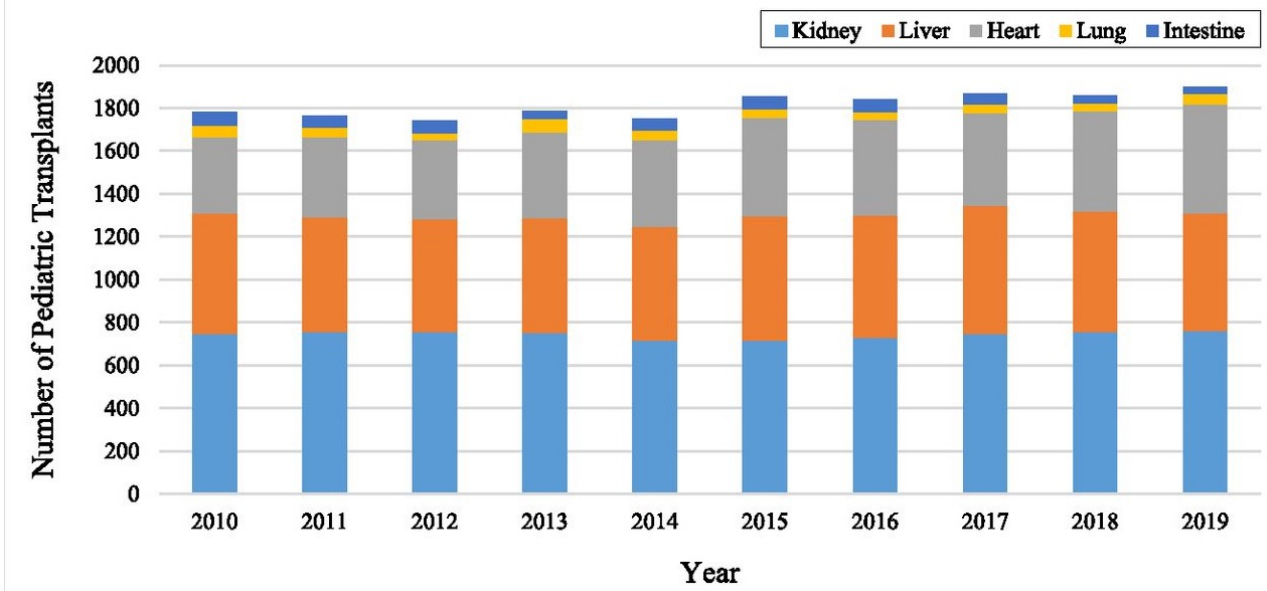
- Disease-specific outcomes
  - Adherence to immunosuppressant medications
  - Rejection episodes, lab values, return to dialysis, re-transplantation, death
- Non disease-specific outcomes
  - Clinic attendance
  - Number of ER visits, hospitalizations
  - Patient satisfaction, quality of life
  - Self-management skills

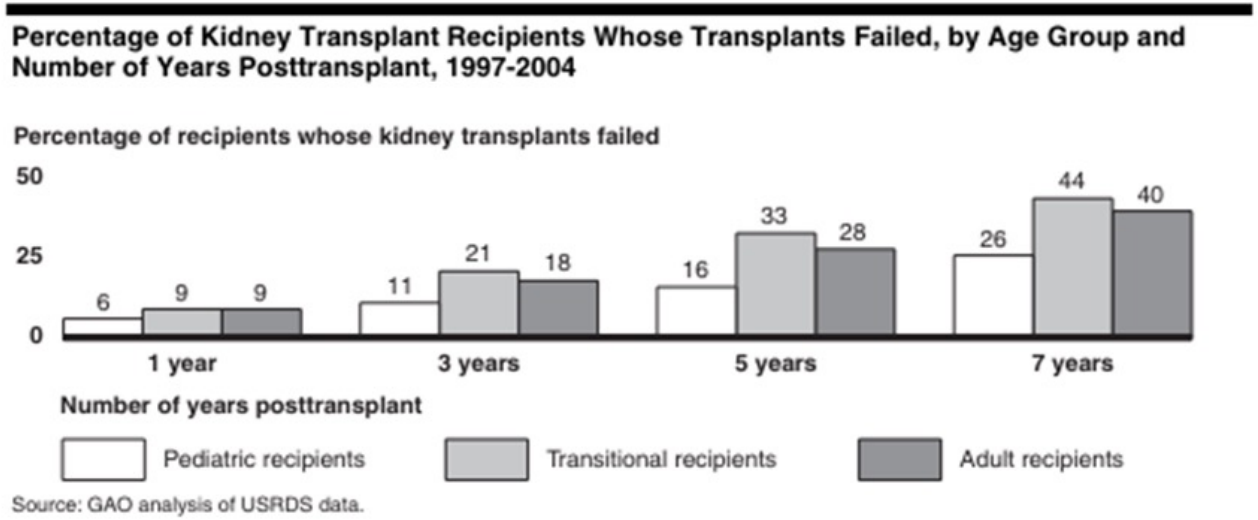
Coyne et al. (2017)

Transition and Medical Outcomes in Solid Organ Transplant Recipients

Background

- >50,000 pediatric SOT since 1988, with 5 year patient survival rates 75 – 88%
- > 1,500 late adolescent/ young adult solid organ recipients who have at least five-year graft survival in the U.S.
- Highest documented rates
  - Acute rejection
  - Death censored graft loss
  - Chronic rejection → graft loss





Katz (2020); OPTN (2024); GAO (2007)

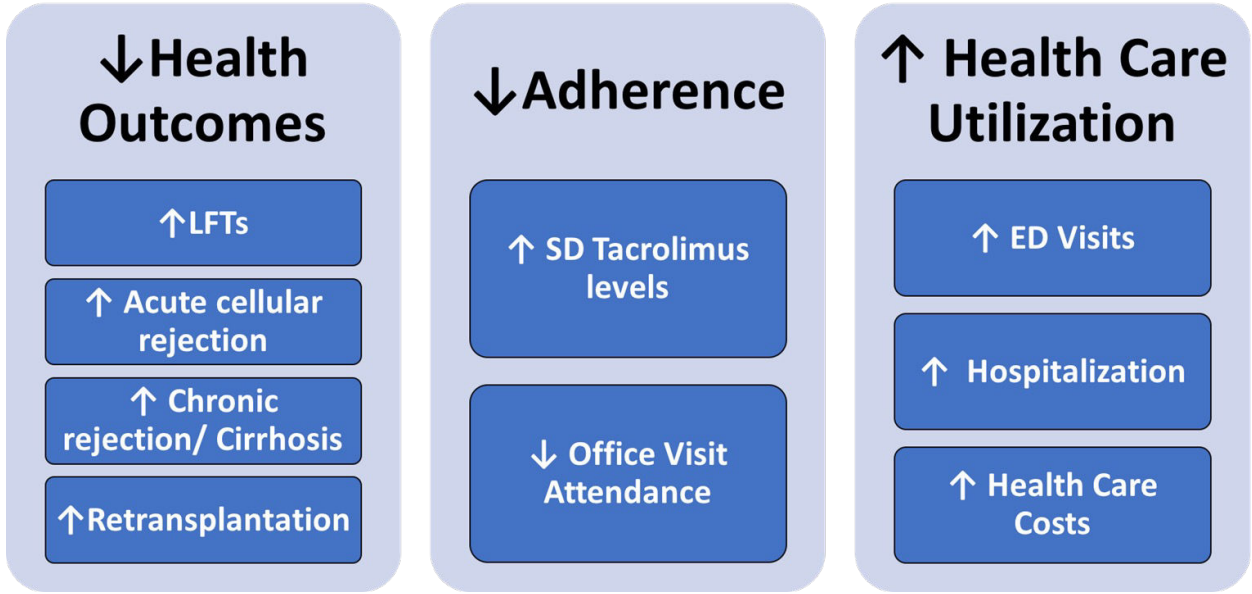
"High risk window"

- Regardless of age at transplant, graft failure rates increase ~12 y/o and peaks 17–24 years
  - Consistent across patient demographic (sex, race/ethnicity, insurance) and clinical (CKD type, pre-txp dialysis history, donor type, organ matching characteristics/ antibodies) information and center characteristics (e.g., transplant volume, year of transplant)
- Higher rates of mortality, substance abuse, suicide

Matsuda-Abedini et al. (2023); Foster (2011), Van Arendonk (2013)

Transition outcomes

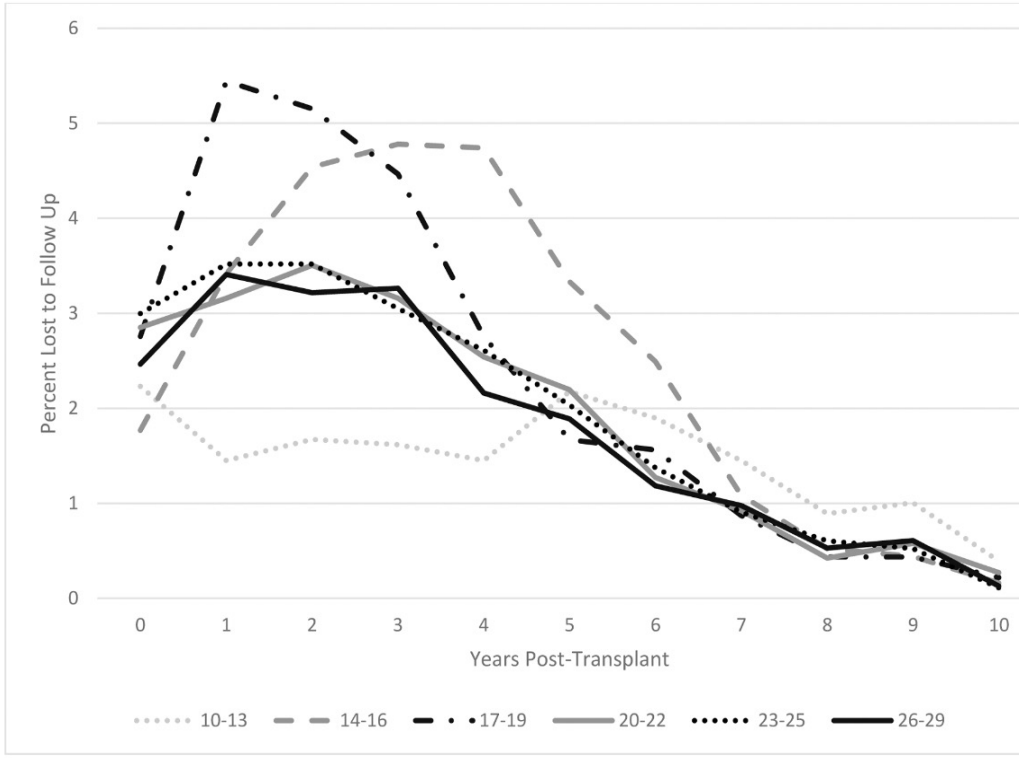
- Continuity of care for young adults associated with lower costs, improved outcomes
  - Lack of effective transition → fragmentation of health care and ↑ adverse health outcomes



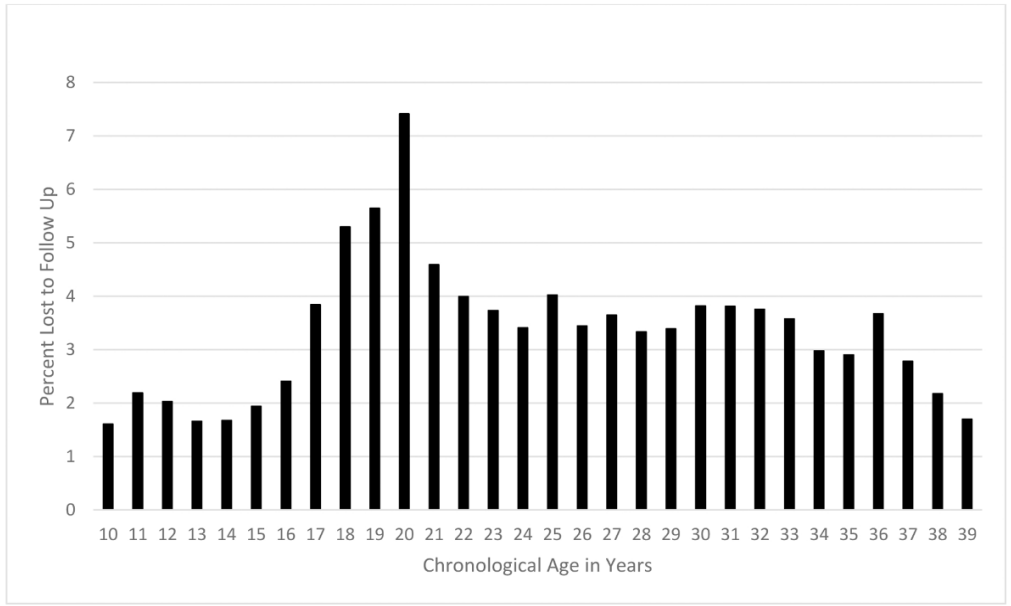
Lawrence (2020)

Loss to follow-up (LFU)

- SRTR data (>16K kidney txp, 10-29 y/o)
- LFU = >1 year without clinic follow-up (excluding death/ graft loss)
- 22% were LFU, with highest rate in 20 y/o (7.4%)
- Highest rate observed after transfer of care (3.98x greater odds of LFU)



Percent Lost to Follow Up Annually Posttransplant, by Age at Time of Transplant, between January 1, 2005 and December 31, 2015 based on SRTR Data



Percent Lost to Follow Up Annually Posttransplant, by Chronological Age, between January 1, 2005 and December 31, 2015 based on SRTR Data

Melanson et al. (2021)

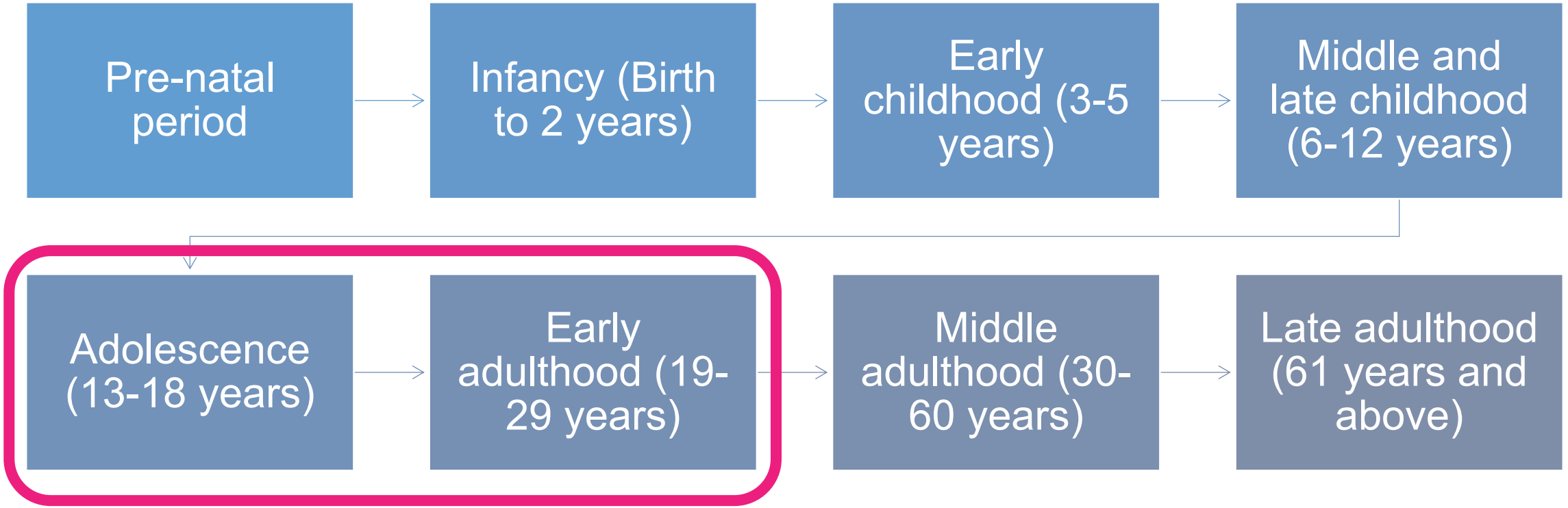
The Role of Pediatric Psychology

What is a pediatric psychologist?

- Pediatric psychology is a field of research and practice that addresses:
  1. Psychological aspects of illness and injury, and
  2. Promotion of health behaviors in children, adolescents and families in a pediatric healthcare setting.

- We address psychological issues in the context of a child's development and emphasize relationships between children, their families, their school and social environments, and the healthcare system as a whole.

Stages of human development



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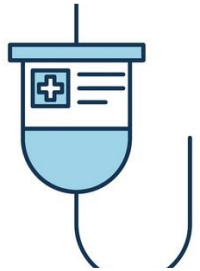
Developmental tasks of adolescence and young adulthood

Adjust to a new physical sense of self	Adjust to sexually maturing body and feelings	Develop and apply abstract thinking skills	Define a personal sense of identity
Adopt a personal value system	Renegotiate relationship with parents/caregivers	Develop stable and productive peer relationships	Meet demands of increasing mature roles and responsibilities

Self-management in pediatric solid organ transplant

Oral medications

Vitamins/ supplements



Infusion treatments

Labs

Clinic visits

Medical testing

Surgical surveillance

Healthy habits

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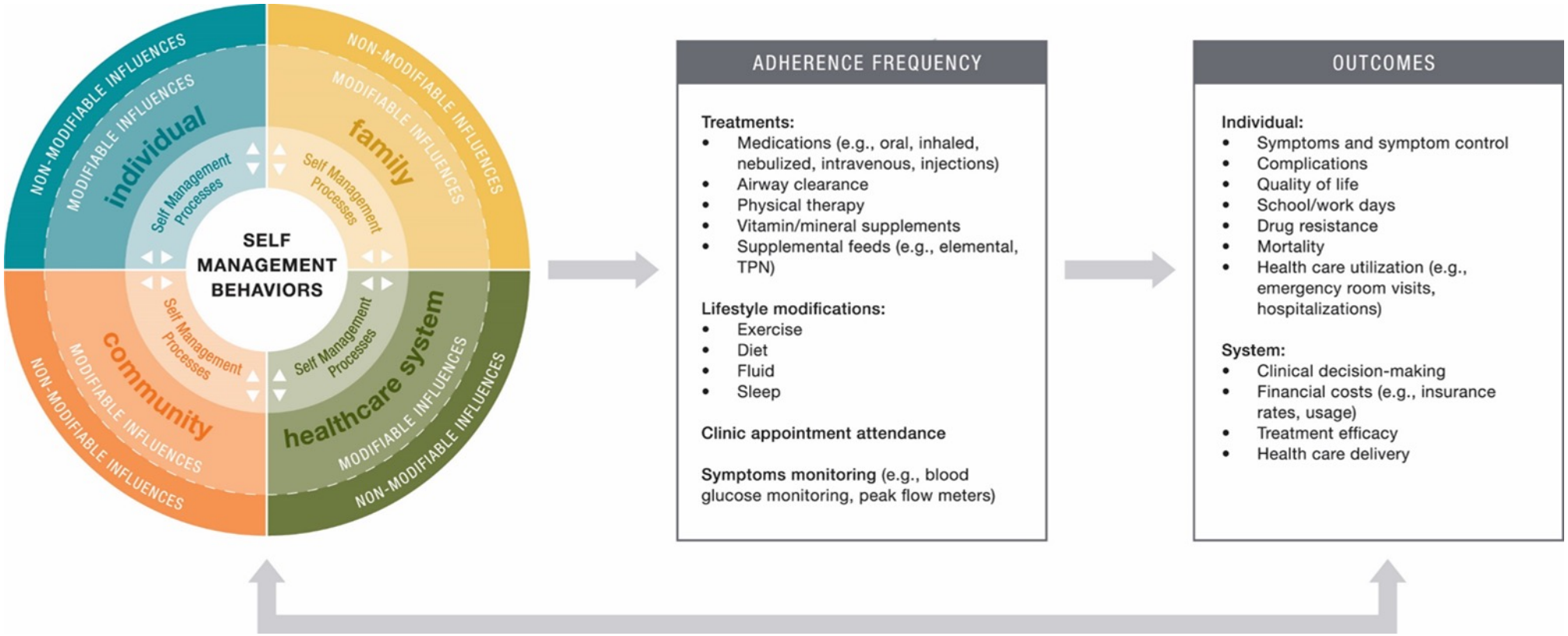
Pediatric self-management model



[32] Modi et al. (2012)

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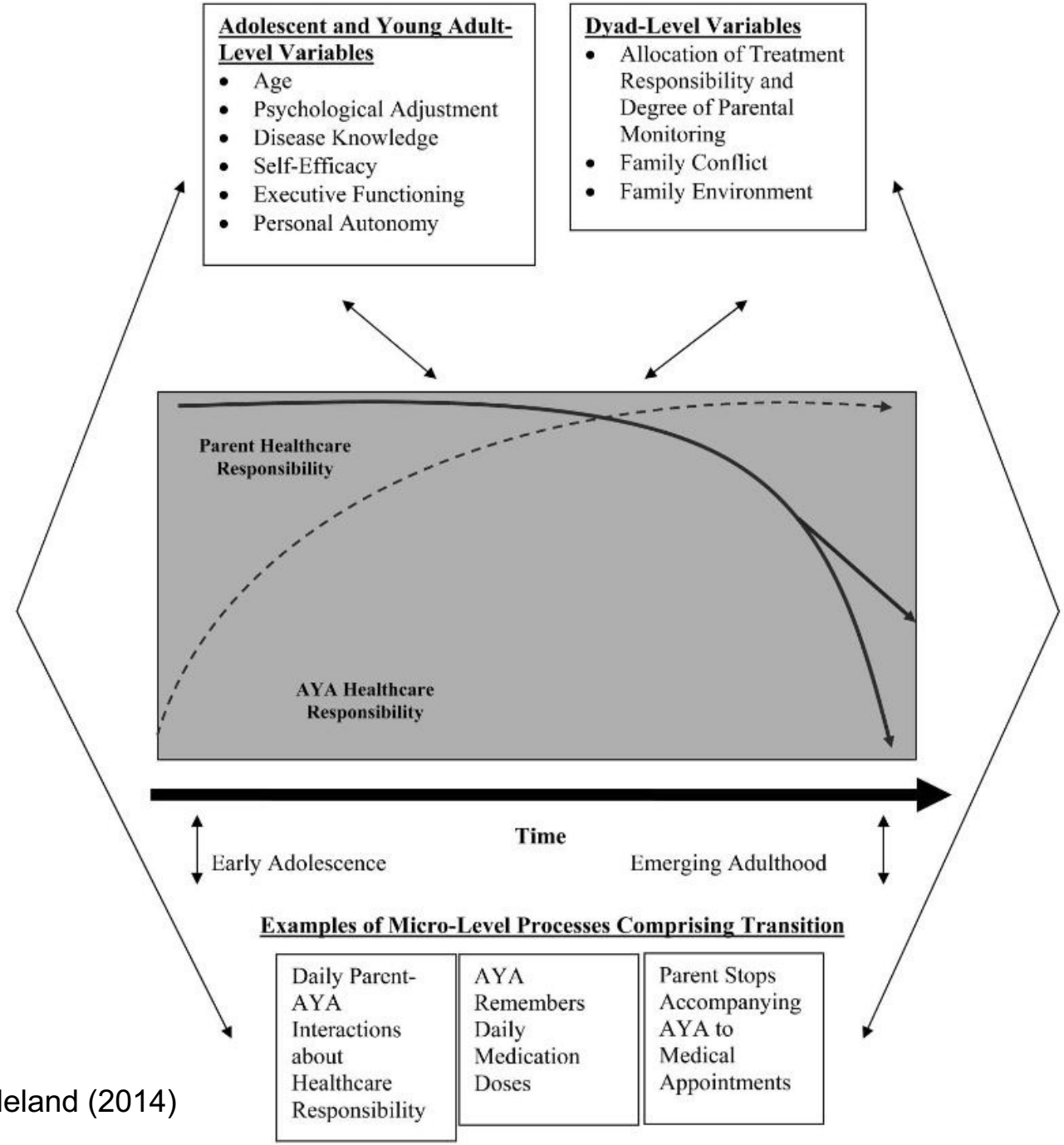
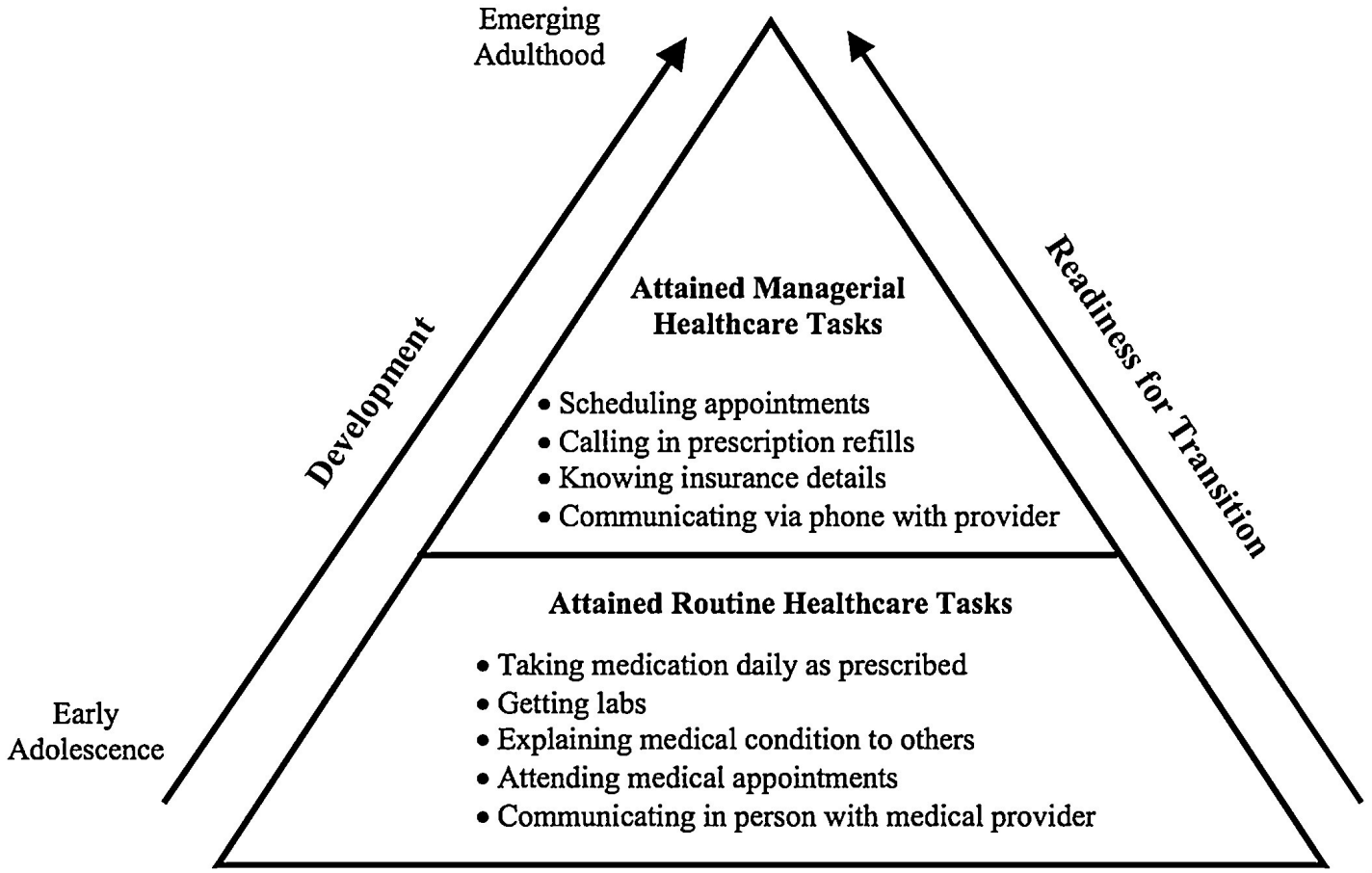
What does self-management have to do with transition?

- Adolescence and young adulthood is a vulnerable developmental stage
  - Adolescents and young adults are at risk for poor self-management across chronic conditions
  - There are unique challenges to managing a chronic medical condition during adolescence and young adulthood
  - Patterns of behavior established in adolescence tend to persist into adulthood
- **Promoting adherence and self-management during adolescents (age 12+) is associated with a more successful transition and eventual transfer to adult care**



Reed-Knight, Blount, & Gilleland (2014)

Hierarchy of healthcare transition readiness skills



Rea et al. (2021)

How can pediatric psychologists help?

Motivational interviewing

Promotes change through empathy and building self-efficacy

Problem-solving skills training

Promotes self-efficacy by identifying barriers to change and brainstorming strategies/solutions to reduce specific barriers

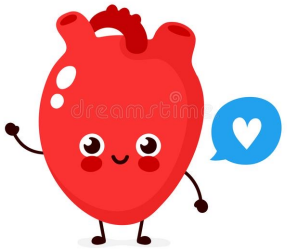
Goal-setting

- Taking responsibility for filling their pill case with parent oversight
- Downloading a medication tracking app
- Creating a recurring calendar event to remind them to get routine labs

Problem-solving skills training

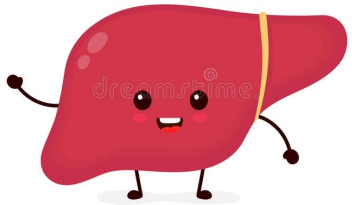
Identify the problem	• What gets in the way of taking your medication?
Set a goal	• Let's set a specific goal for taking your medication (e.g., 50%).
Brainstorm solutions	• Let's come up with things that might help you with this problem – anything goes!
Rate each solution	• Give each solution a "thumbs up" or "thumbs down".
Choose a solution to test	• Think about which of these solutions are most helpful/that you're willing to test.

Routine psychology visits

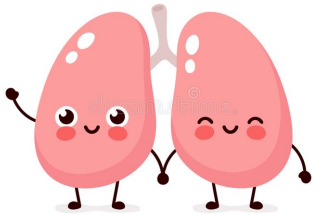


Heart Transplant Program
• Multi-disciplinary clinic including psychology and social work

Kidney Transplant Program
• Multi-disciplinary teen clinic including psychology, social work, and pharmacy



Liver Transplant Program
• Annual post-transplant psychosocial visits with psychology



Lung Transplant Program
• Annual post-transplant psychosocial visits with psychology and social work

The Role of Social Work

- Social workers are often the informal brokers of this complex and nuanced process.

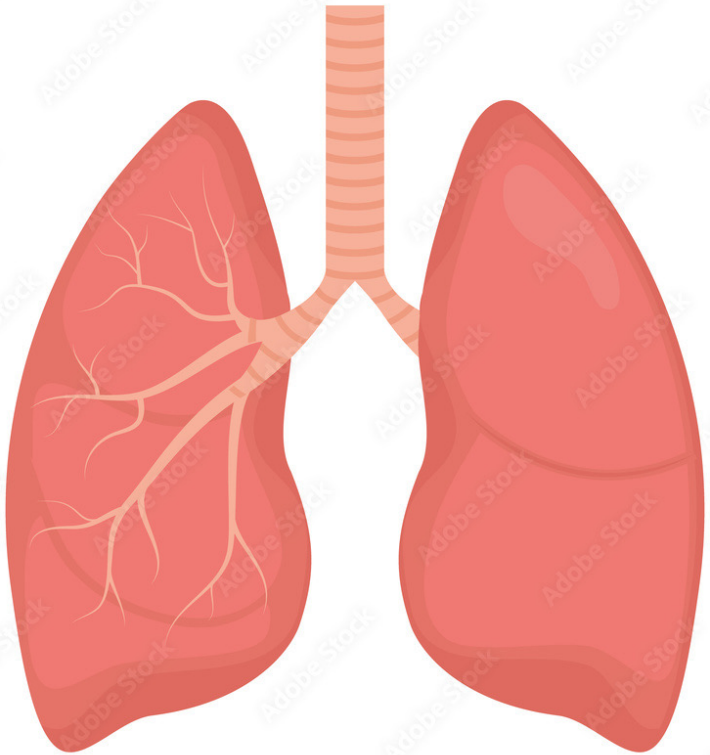
- We are uniquely trained to complete biopsychosocial assessments to understand the needs of patients and families and address psychosocial factors.

- Our extensive knowledge of resources and systems, along with a sophisticated understanding of relationship issues, family dynamics, cultural implications, and collaboration with the healthcare team all encompass the development of a successful transition plan.

How do social workers support the transition process?

See patients without caregivers starting at age 14	Assessments to understand the needs of patients and families	Address psychosocial factors
Knowledge of resources and systems	Family dynamics (e.g., preparing caregivers)	Collaboration with the healthcare team

Case Example



Ann is a previously healthy 17 year-old female who lives with her mother, stepfather, and two half sisters diagnosed with acute lymphoblastic leukemia requiring three cycles of chemotherapy and bone marrow transplant within eight months.

As a result, she developed GVHD affecting her skin, liver, eyes, and lungs and was subsequently diagnosed with bronchiolitis obliterans and referred for evaluation for lung transplant, listed, and transplanted at age 18.

Ann initially did well, graduated high school, and demonstrated adherence to her medical regimen.

Then, Ann started asking for increased independence. Social work assisted her with transportation, applying to community college, and education on insurance options. Psychology engaged Ann in therapy, and the medical team worked on medication knowledge all with little input from her caregivers.

One year later, Ann's adherence decreased and risk behaviors increased. She frequently fought with her family, left home overnight and engaged in substance use.

The transplant team followed her closely and despite multiple referrals to transplant psychology, attendance was sporadic.

At age 20, Ann was diagnosed with confirmed chronic rejection with increased respiratory symptoms and admissions requiring supplemental oxygen and BiPAP. Her mental health also continued to suffer and family conflict and substance use persisted. Palliative care became involved to discuss goals of care.

Given her age, Ann was not eligible for re-transplant at CHOP requiring transfer to an adult center; transition was discussed at every visit, the transplant team met with the adult center, and social work attended Ann's first visit at the adult center.

Transition was completed 8/21…

So we thought…

- Despite transfer, Ann frequently reached out to CHOP to be seen by the pediatric team again and frequently presented to our emergency room.

What would you do?
What went well?
What could've been done better?

What we did

- Closely collaborated with the adult center
- Promoted patient's trust with the adult center
- Provided education to patient why the adult center is where she needs to receive her care

Key takeaways

- Take the time to develop a trusting, nonjudgmental relationship with your patients and their families
- Visit with adolescent/young adult patients without caregivers present, and encourage continued caregiver involvement
- Frequently discuss transition and eventual transfer
- Collaborate with your multi-disciplinary teams and adult centers

Additional resources for adolescents/young adults approaching transition

- American Society of Transplantation (AST) Pediatric Transition Portal: www.myast.org/education/specialty-resources/peds-transition#
- Got Transition: www.gottransition.org
- Offices of Intellectual/Developmental Disabilities
- Supplemental Security Income (SSI)
- National Council on Independent Living: www.ncil.org
- Liberty Resources: www.libertyresouces.org
- Administration of Community Living: www.acl.gov
- National Community Resources: www.findhelp.org
- Community Resources Connects: www.communityresourcesconnects.org

Parent advocacy agencies

- Parent Education, Advocacy, and Leadership Center (PEAL): www.pealcenter.org
- Vision for Equality: www.visionforequality.org
- Parent to Parent: www.p2pusa.org
- National Disability Rights Network: www.NDRN.org

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Q&A
QUESTIONS & ANSWERS