

Post-transplant Transition from Pediatric to Adult healthcare

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Some facts: current status

- 4 million young adults in the United States turn 18 and reach adulthood every year.
- Of these, an estimated 18-20% are affected by chronic health conditions.
- Annually, in the US, approx. 750,000 patients with special health care needs transfer from pediatric to adult care facilities.

*Goodman DM, Hall M, Levin A, Watson RS, Williams RG, Shah SS, Slonim AD
Pediatrics. 2011 Jul; 128(1):5-13.*

Some facts: current status

- **Fewer than half receive adequate support and services for their transition to adult care.**
- **Racial & socioeconomic disparities exist, with these children receiving suboptimal care during transition.**
- **Transition from pediatric to adult care can be associated with adverse health outcomes.**

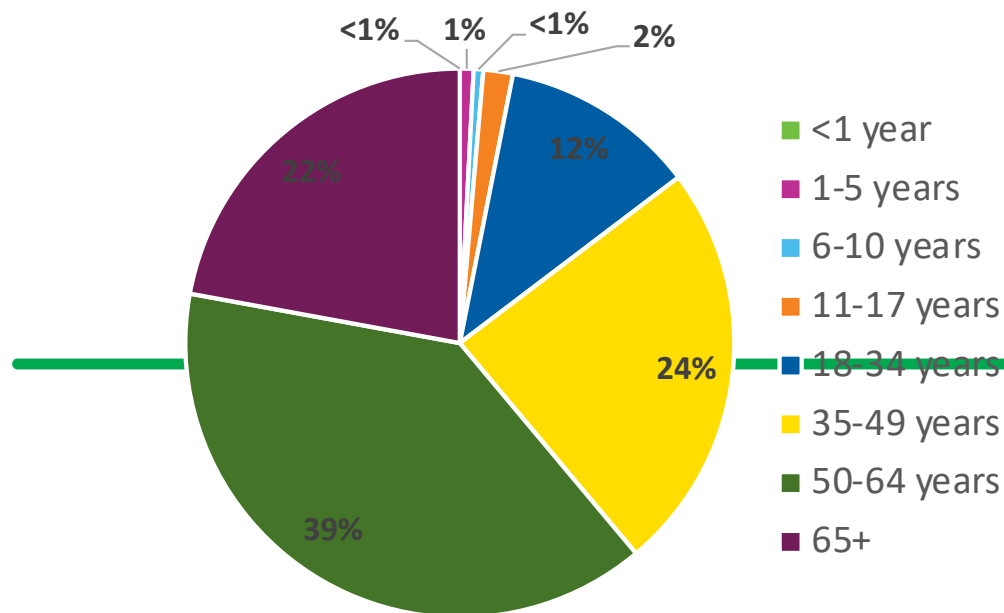
Some facts: Children vs Adults with kidney transplant



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2020 Kidney Transplants by Age of Recipient
Based on OPTN data as of 3/15/2021

↘ 3%



Age of Recipient	Transplants
<1	0
1-5 years	184
6-10 years	129
11-17 years	397
18-34 years	2,639
35-49 years	5,527
50-64 years	8,895
65+	5,046
Total	22,817



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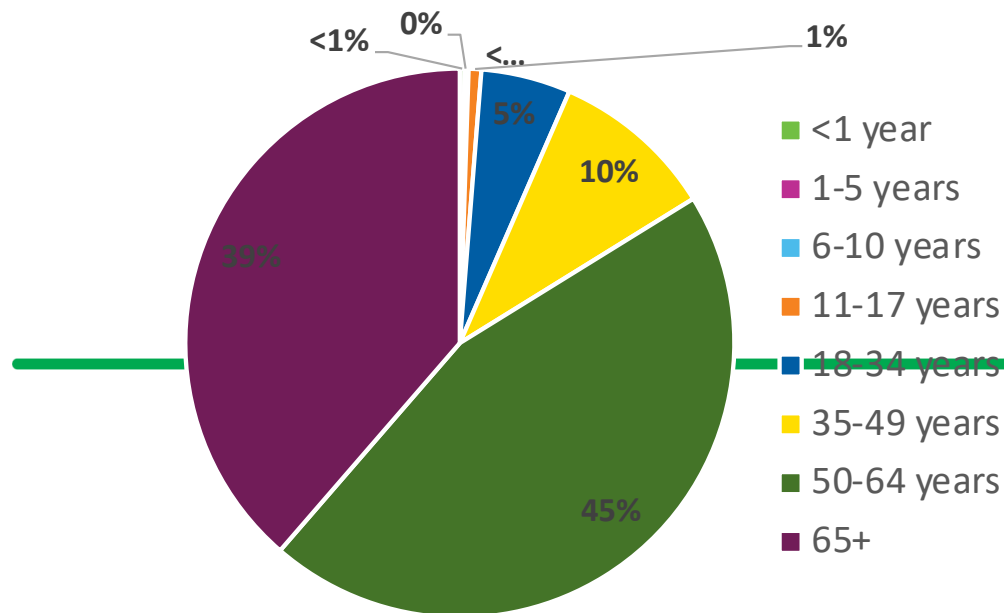
Some facts: Children vs Adults with lung transplant



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2020 Lung Transplants by Age of Recipient
Based on OPTN data as of 3/15/2021

↪ 2%



Age of Recipient	Transplants
<1	7
1-5 years	3
6-10 years	3
11-17 years	19
18-34 years	134
35-49 years	245
50-64 years	1,147
65+	981
Total	2,539



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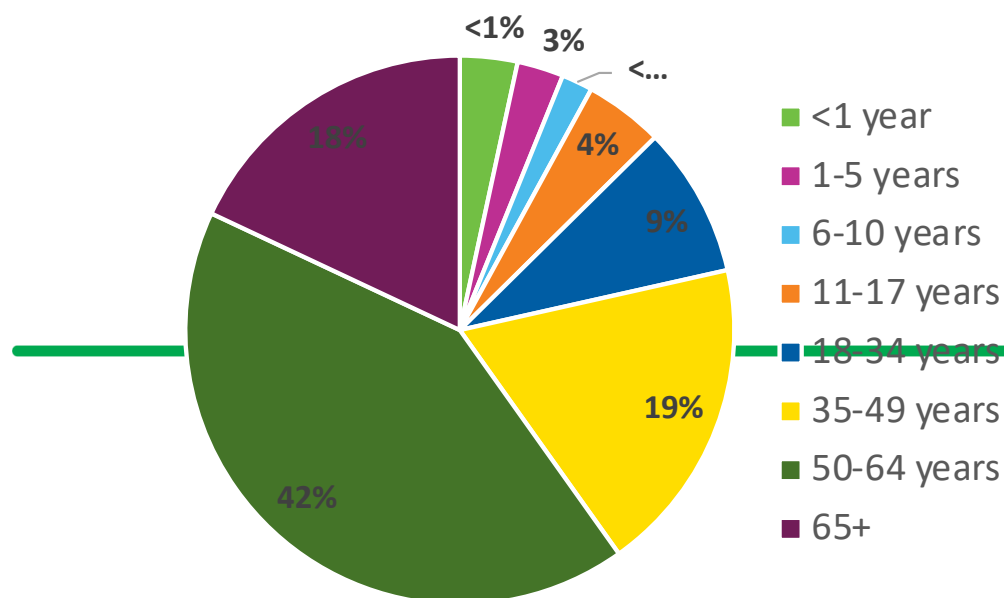
Some facts: Children vs Adults with heart transplant



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2020 Heart Transplants by Age of Recipient
Based on OPTN data as of 3/15/2021

↪ 13%



Age of Recipient	Transplants
<1	124
1-5 years	100
6-10 years	67
11-17 years	170
18-34 years	325
35-49 years	683
50-64 years	1,530
65+	659
Total	3,658



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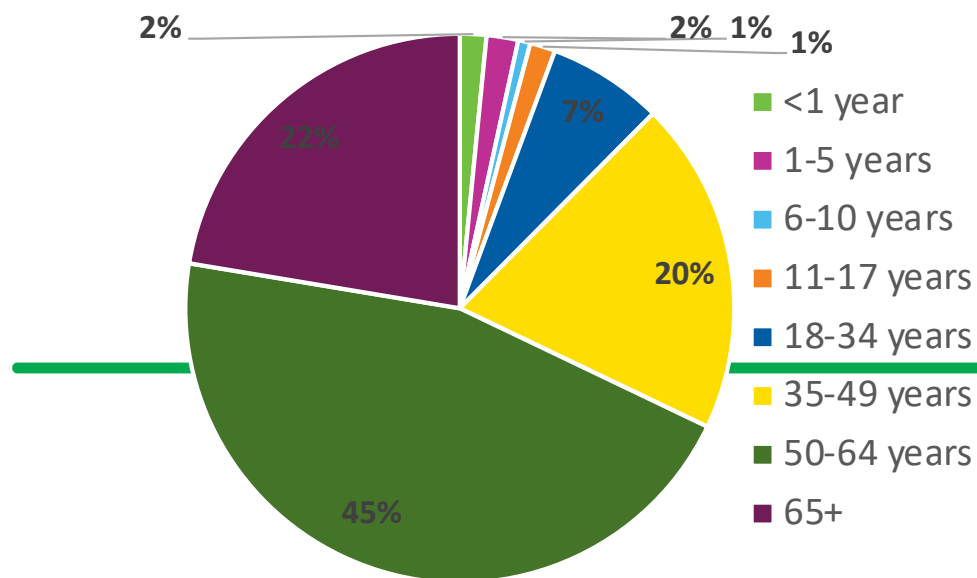
Some facts: Children vs Adults with Liver transplant



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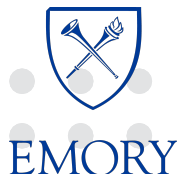
2020 Liver Transplants by Age of Recipient
Based on OPTN data as of 3/15/2021

↘ 7%



Age of Recipient	Transplants
<1	139
1-5 years	166
6-10 years	64
11-17 years	133
18-34 years	606
35-49 years	1,751
50-64 years	4,054
65+	1,993
Total	8,906

Children form approx. 2-13% of all transplants



Children have a much longer lifespan ahead of them as compared to adults!



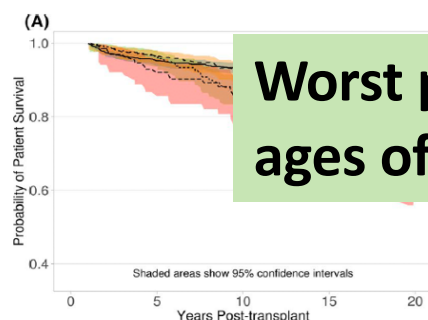
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**What are the patient outcomes
after they transfer to adult
healthcare?**



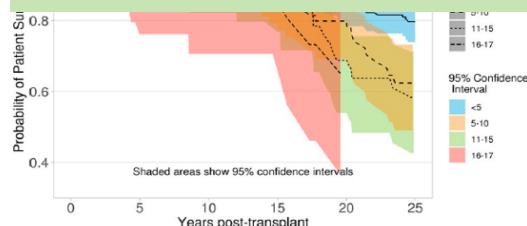
20- to 25-year patient and graft survival following a single pediatric liver transplant—Analysis of the United Network of Organ Sharing database: Where to go from here

Udeme D. Ekong¹  | Nitika A. Gupta²  | Read Urban³ | Walter S. Andrews⁴ 



Worst patient survival in children transplanted between ages of 11-15 and 15-17 as compared to <5 yrs of age

B. The 25-year cohort transplanted between October 1, 1987-December 31, 1990. and followed up till October 21, 2016



Older age at transplant is associated with worse patient and graft survival

> [J Pediatr](#). 2021 Mar 2;S0022-3476(21)00208-0. doi: 10.1016/j.jpeds.2021.02.069.
Online ahead of print.

African American Pediatric Liver Transplant Recipients Have an Increased Risk of Death After Transferring to Adult Healthcare

Mikaela Katz ¹, Scott Gillespie ¹, James P Stevens ², Lori Hall ³, Vasantha Kolachala ¹,
Ryan Ford ⁴, Keri Levin ⁴, Nitika Gupta ⁵

Affiliations + expand

PMID: 33667506 DOI: [10.1016/j.jpeds.2021.02.069](https://doi.org/10.1016/j.jpeds.2021.02.069)

1 in 4 young adult liver transplant recipients die after transfer to adult healthcare


African Americans constitute majority of the deceased

5 years	31.5% (17.1%, 53.4%)
10 years	43.9% (25.7%, 67.5%)
Time since first liver transplant (years)	
1 year	0%
3 years	3.7% (0.5%, 23.5%)
5 years	7.4% (1.9%, 26.5%)
10 years	26.3% (13.5%, 47.4%)
15 years	44.3% (27.2%, 66.1%)
20 years	49.9% (31.6%, 71.6%)

Kidney Transplant outcomes after transition

CLINICAL AND TRANSLATIONAL RESEARCH

Graft Failure and Adaptation Period to Adult Healthcare Centers in Pediatric Renal Transplant Patients

Samuel, Susan M.^{1,2,11}; Nettel-Aguirre, Alberto^{1,3}; Hemmelgarn, Brenda R.⁴; Tonelli, Marcello A.⁵; Soo, Andrea⁶; Clark, Camillia¹; Alexander, R. Todd^{7,8}; Foster, Bethany J.^{9,10} Pediatric Renal Outcomes Canada Group [Author Information](#) 

Transplantation: June 27, 2011 - Volume 91 - Issue 12 - p 1380-1385
doi: 10.1097/TP.0b013e31821b2f4b

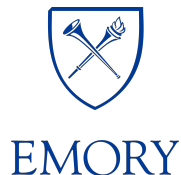
CLINICAL AND TRANSLATIONAL RESEARCH

Renal Allograft Loss During Transition to Adult Healthcare Services Among Pediatric Renal Transplant Patients

Koshy, Susan M.^{1,7}; Hebert, Diane^{2,3}; Lam, Kelvin⁴; Stukel, Therese A.^{4,5}; Guttman, Astrid^{3,4,5,6}

[Author Information](#) 

Transplantation: June 15, 2009 - Volume 87 - Issue 11 - p 1733-1736
doi: 10.1097/TP.0b013e3181a63ed9



What patient factors affect these outcomes?



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**Last to
Mature**

The Teen Brain **STILL UNDER CONSTRUCTION**

Dynamic mapping of human cortical development



Source: "Dynamic mapping of human cortical development during childhood through early adulthood," Nitin Gogtay et al., Proceedings of the National Academy of Sciences, May 25, 2004; California Institute of Technology.

Foresight

Planning

Risk/Reward Evaluation

**Dissociate decision making and
strong emotion**

**Delayed maturation in children with chronic
diseases in psychosocial spheres and autonomy**

Image: National
Institute of Mental
Health



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The adolescent transplant patient



Long term survival is limited by chronic rejection and graft loss which is more common in adolescents

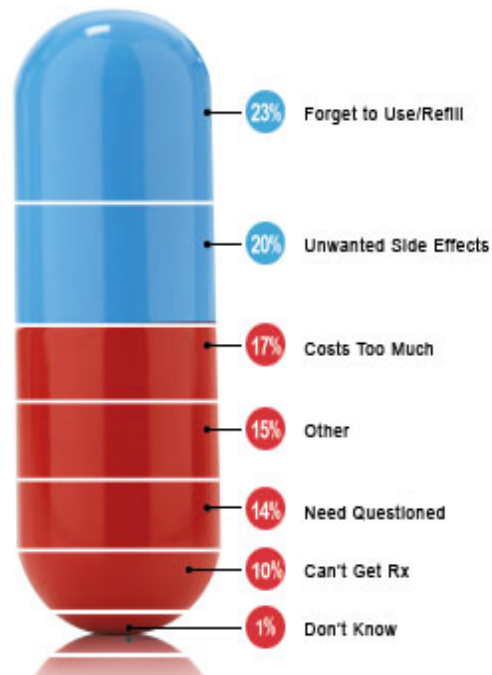
Substance abuse peaks and suicide rate is triple in 18-24 yr olds vs that of 12-17 yr olds

Mortality rate of 18-24 yr olds is >twice of those aged 12-17

Up to a third of adolescents may be non adherent

Non Adherence

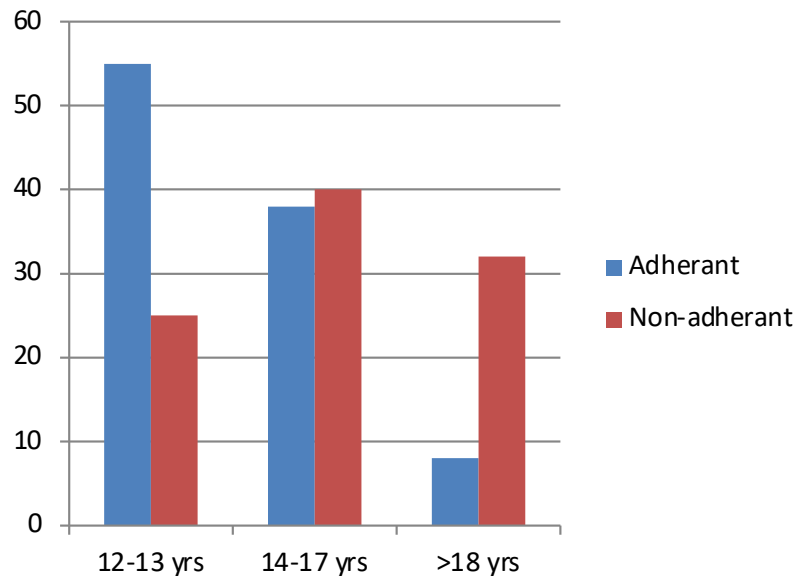
Reasons Cited for Poor Medication Adherence



Cigna pharmacy Mgt survey

- ***I forget when I am watching TV***
- ***Not at home and did not bring at a friends***
- ***Too Busy***
- ***Too ill***
- ***Don't want to take it***
- ***Fit in***
- ***Why me?***

Risk factors for non-adherence



Risk factors:

- Years post Tx
- Single parent home
- Female sex
- Medicare/medicaid
- Parental stress and anxiety
- Dysfunctional families

Functional outcomes after transplant

> [Pediatr Transplant](#). 2013 Nov;17(7):605-11. doi: 10.1111/petr.12126. Epub 2013 Aug 1.

Factors predicting health-related quality of life in pediatric liver transplant recipients in the functional outcomes group

Poor cognitive, intellectual, and Health related quality of life after transplant

ORIGINAL ARTICLES—LIVER AND NUTRITION

Functional Outcomes of Pediatric Liver Transplantation

Alonso, E. M.; Neighbors, K.; Mattson, C.; Sweet, E.; Ruch-Ross, H.; Berry, C.; Sinacore, J.

[Author Information](#) ✓

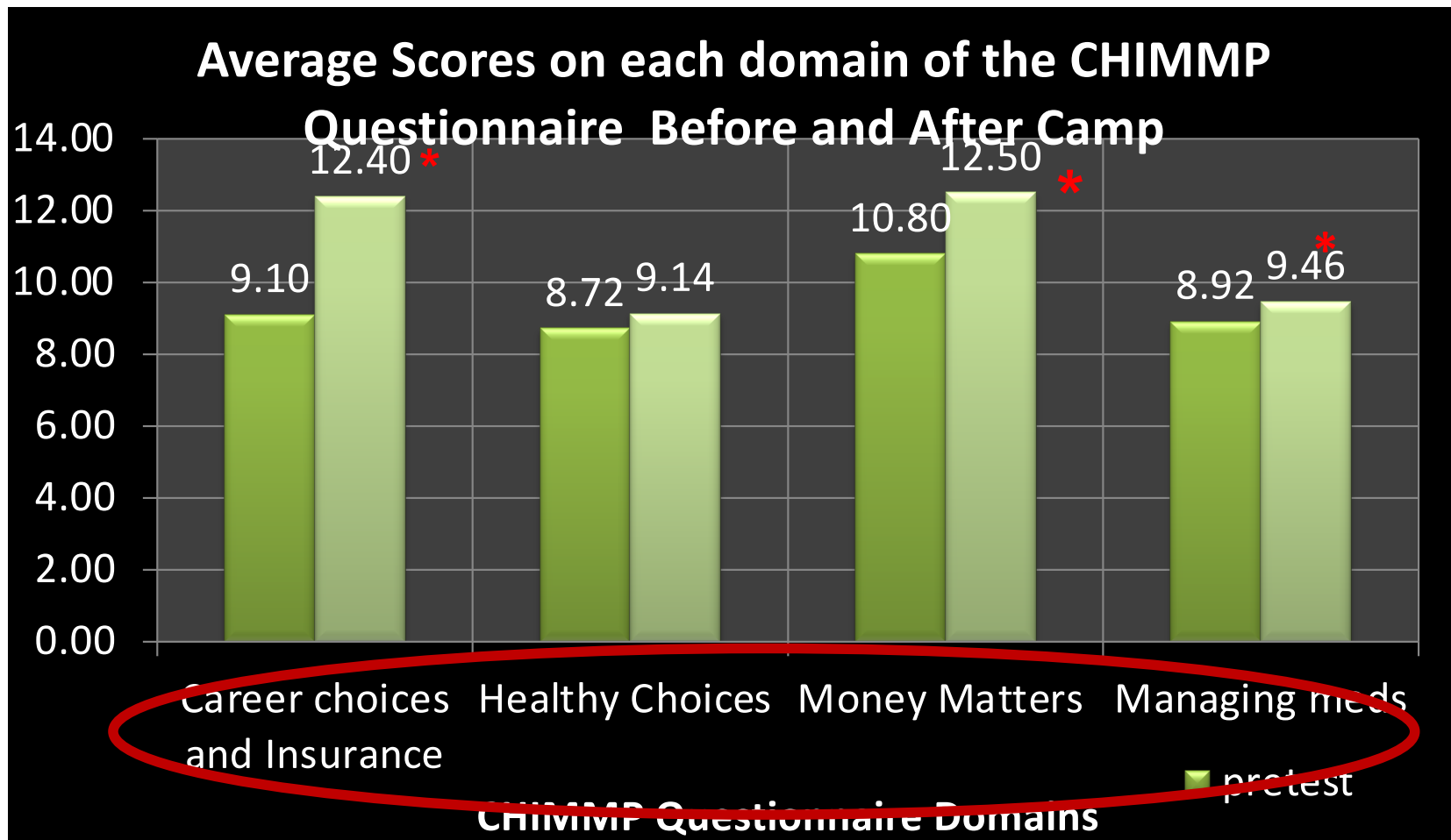
Journal of Pediatric Gastroenterology and Nutrition: August 2003 - Volume 37 - Issue 2 - p 155-160



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Education, enjoyment, and empowerment: Outcomes of an adolescent transplant camp (I own it)

Keerthana Kesavarapu, Sirish K. Palle, Molly Dugan, Shannon Antinerella, Shannon Luetkemeyer, Nitika Gupta ✉

First published: 19 June 2018 | <https://doi.org/10.1111/petr.13236>

What system factors affect these outcomes?

[Int J Hepatol](#). 2015; 2015: 765957.

PMCID: PMC4670658

Published online 2015 Nov 22. doi: [10.1155/2015/765957](#)

PMID: [26682071](#)

Growing Up: Not an Easy Transition—Perspectives of Patients and Parents regarding Transfer from a Pediatric Liver Transplant Center to Adult Care

[Sona Chandra](#),¹ [Shannon Luetkemeyer](#),² [Rene Romero](#),^{2,3} and [Nitika Arora Gupta](#)^{2,3,*}

Conducted a survey of Transferred patients

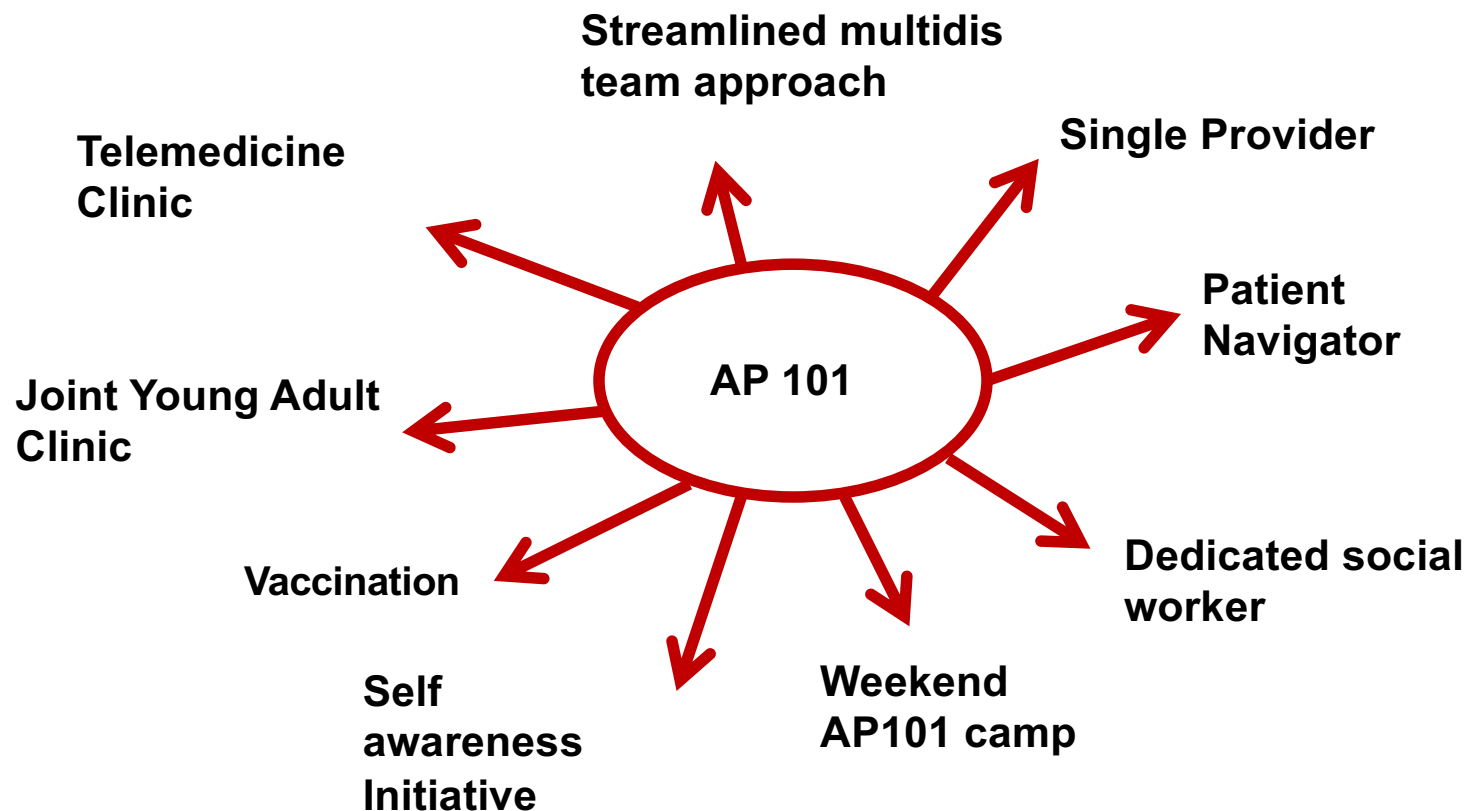
What can be done to make the transition easier?

How can parents and patients be prepared for transition?

What should be changed to help with transition of care?

- Time until first contact with adult hospital
- ER visits prior to first contact with adult facility
- Patients evaluated for a second transplant

Adolescent Program 101 (AP101) Initiatives



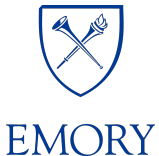
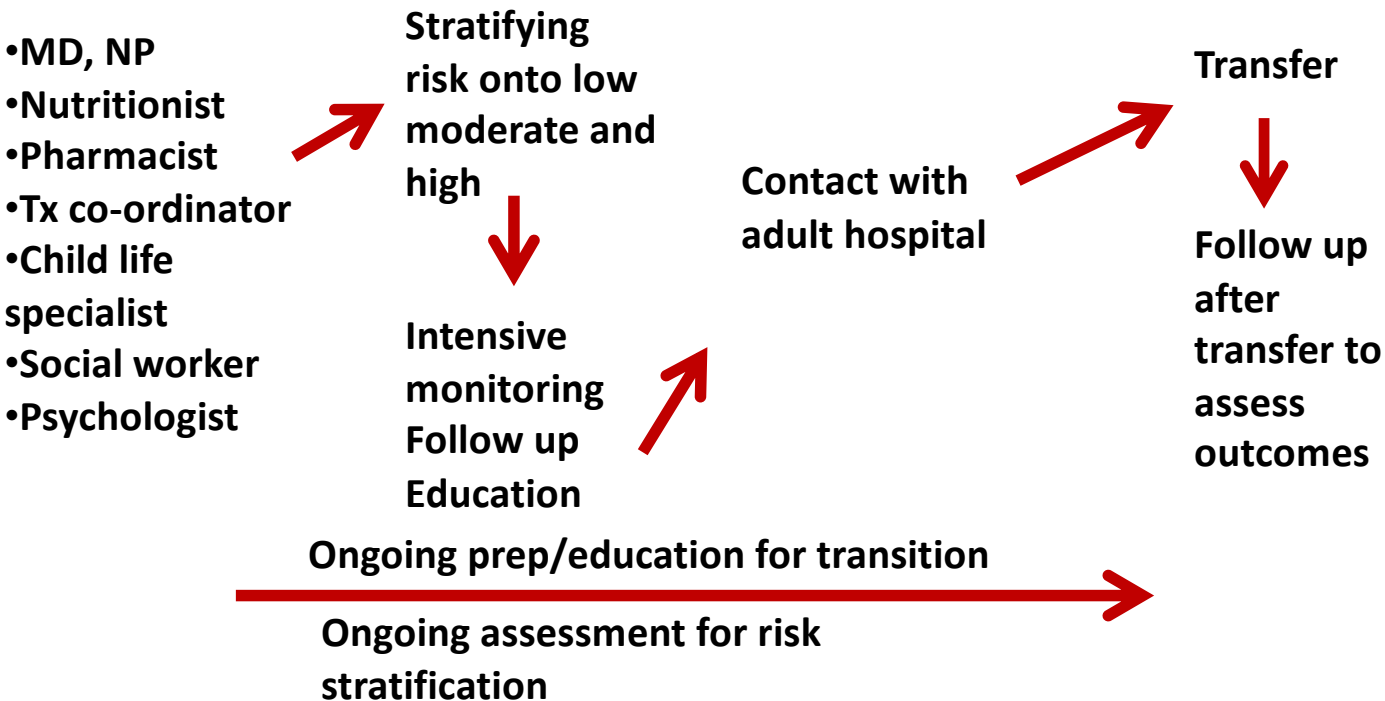
What should a Transition clinic look like?



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Transition clinic



Transition clinic

>14 yrs of age, >1 yr from transplant

- MD, NP
- Nutritionist
- Pharmacist
- Tx co-ordinator
- Child life specialist
- Social worker
- Psychologist

14-16 yrs , with optional parent step out

Onto low moderate and high

16-18 yrs, with parent update

Contact with adult hospital

>18 yrs of age with 'optional/encouraged' parent update

Follow up

Encourage buddy visit

Assess outcomes

Intensive monitoring
Follow up
Education

Ongoing prep/education for transition

Ongoing assessment for risk stratification



Choa-Emory young-adult joint clinic

- Close collaboration with the pediatric and adult liver transplant teams
- Designated transferring pediatric provider and receiving adult provider
- Pre-planning for eventual transfer
- Attended by 2 hepatologists
- In-person sign out with the patient & family



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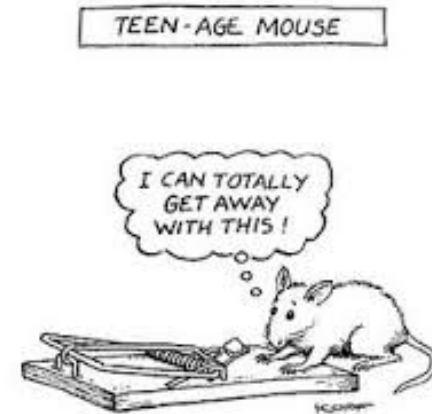
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Summary

- Awareness of the adolescent brain
- Identification of issues other than organ transplant metrics
- Recognition of individual patient needs: One size **DOES NOT** fit all!
- Some teenagers need more help than others
- Structured Transition clinic, Dedicated transition Team
- Objective measures and checklists are important but tracking outcomes is key!



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[Review](#) > [Curr Gastroenterol Rep.](#) 2021 Jan 29;23(3):3. doi: 10.1007/s11894-020-00802-1.

TRANSITION of Pediatric Liver Transplant Patients to Adult Care: a Review

James P Stevens ^{1 2}, Lori Hall ², Nitika Arora Gupta ^{3 4 5}

Affiliations + expand

PMID: 33523312 DOI: [10.1007/s11894-020-00802-1](#)



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