

# Pediatric Transition to Adulthood

Deirdre Kelly

Co-Chair Pediatric Transition Group  
Forum for Collaborative Research

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Birmingham, UK



UNIVERSITY OF  
BIRMINGHAM



**NHS**  
Birmingham Women's  
and Children's  
NHS Foundation Trust

By your side

# Pediatric Liver Disease in Adult life

## Success:

Medical therapy/liver transplantation

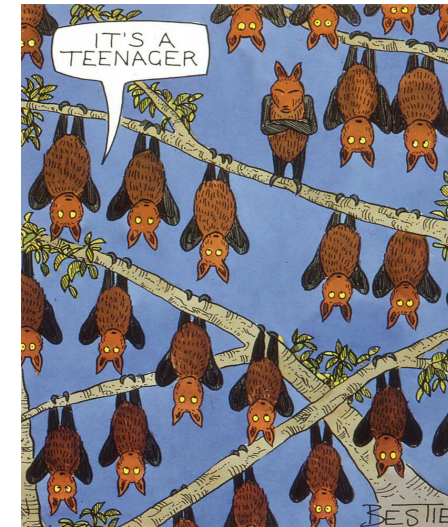
- Many children survive into adult life
- Long term effects of liver transplantation
- Natural history in adult life evolving

## Current Focus:

Manage transition in adolescents

Reduce non-adherence

Improve outcomes



# Liver disease in adolescents

## Transition from paediatric to adult services

Adolescence: range: 10-25 years

- Process of maturity - biological, psychological, social
- Develop cognitive skills and abstract thought
- Ability to control behaviour/take responsibility
- Make relationships with members of both sexes
- Gain independence from parents & carers
- Rebellion and poor self management
- Chronic illness /disease impacts on adolescent development
- ? Adolescence impact on disease outcomes

# Aim of the Pediatric Transition to Adulthood Working Group

1. Establish position of Transition services in US/UK/Europe
2. Focus on natural history of disease in long term survivors
3. Do transition outcomes vary in different diseases
4. How could trials continue from childhood into adulthood?
5. Establish objectives and outcomes for pilot project

# Members of Pediatric Transition to Adulthood Working Group

## Co- Chairs:

Deirdre Kelly: UK

Nitika Arora-Gupta: US

Veronica Miller FCR

Logan Donaldson FCR

Ruth De Bruyne ERN

Industry Representatives (tbc)

Adult hepatologists (tbc)

Patient and Community Representatives

Other experts – yes please!

# Outline proposal for Transition working group

Natural history of disease in adolescence into adulthood

- Do outcomes change when moving from childhood to adulthood?
- What are the effects of physiological or psychological changes on disease outcome
- Does risk-taking behaviour impact on outcomes
- What biomarkers could we use
- Potential survivor bias among those that live into adulthood
- Alagille's syndrome as a pilot group

# Pediatric Transition to Adulthood

Jorge Amil Dias

Porto, PORTUGAL

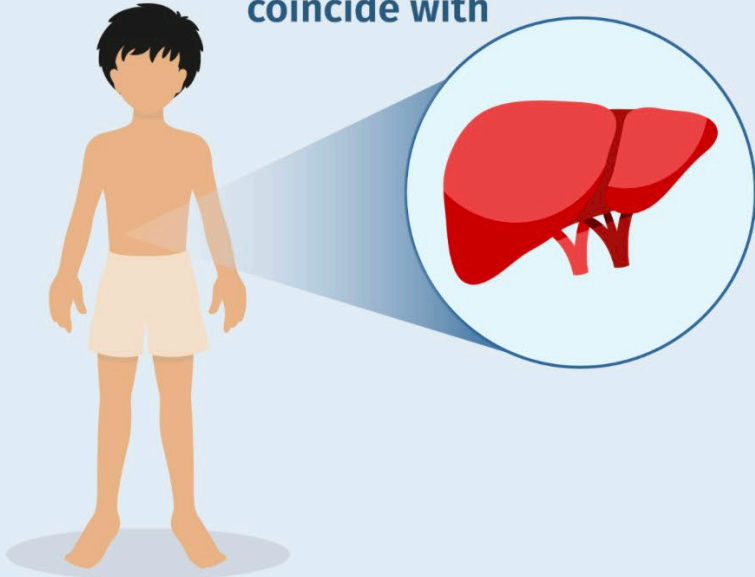
[Jorge.amil@outlook.pt](mailto:Jorge.amil@outlook.pt)

# **Transition of care into adulthood**

Healthcare transition is characterized as the planned movement of adolescents/young adults with chronic conditions from child-centered to adult-oriented healthcare systems

# Pediatric Risk Factors Associated With Death After Transfer to Adult Healthcare

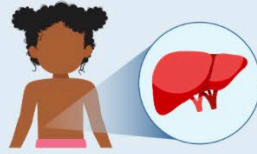
In pediatric liver transplantation (LT) patients, transition to adolescence and transfer to adult medical providers' care coincide with



- Increased non-adherence
- Shifting responsibilities between parent and caregiver
- Increased risk of untimely death or lost to follow-up

This affects their long-term outcomes

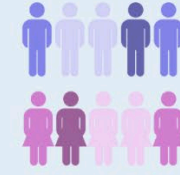
Analysis of long-term outcomes in transitioned pediatric LT recipients



93 monitored by adult providers



8 lost to follow-up



Demographics

Factors assessed

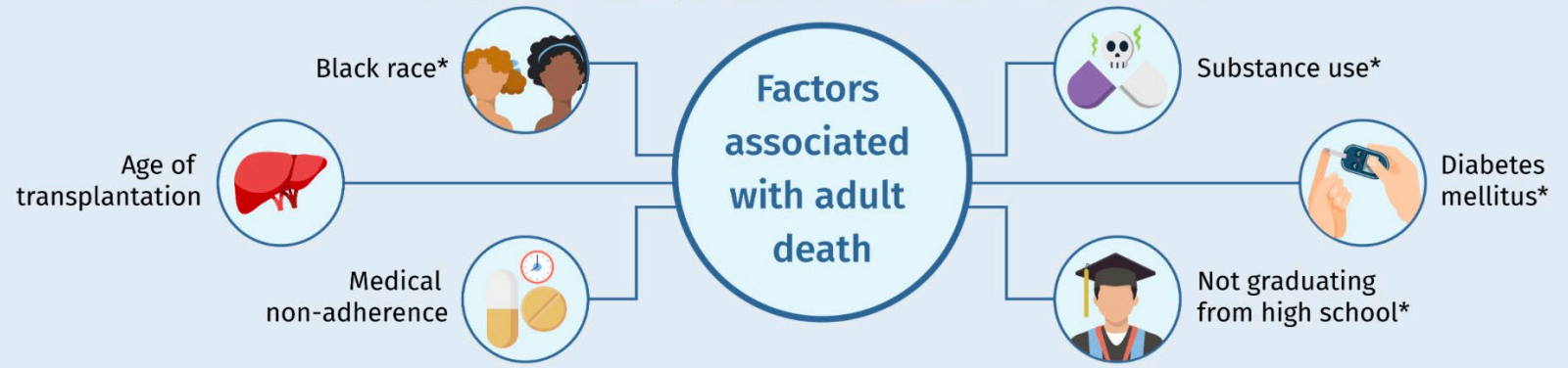


Clinical features and co-morbidities



Psychosocial factors

23 patients died post transfer to adult care providers



\*Significant on multivariate analysis while controlling other factors

- Not finishing high school before transfer
- Loss to follow-up

Individualized risk assessment of pediatric LT recipients can improve their outcomes and reduce the risk of death following their transition to adult care providers

# Awareness of healthcare transition

Online survey (EoE)

Unaware of HCT

- 78% of patients (n=75)
- 76% of parents (n=245)

# Heterogeneous process

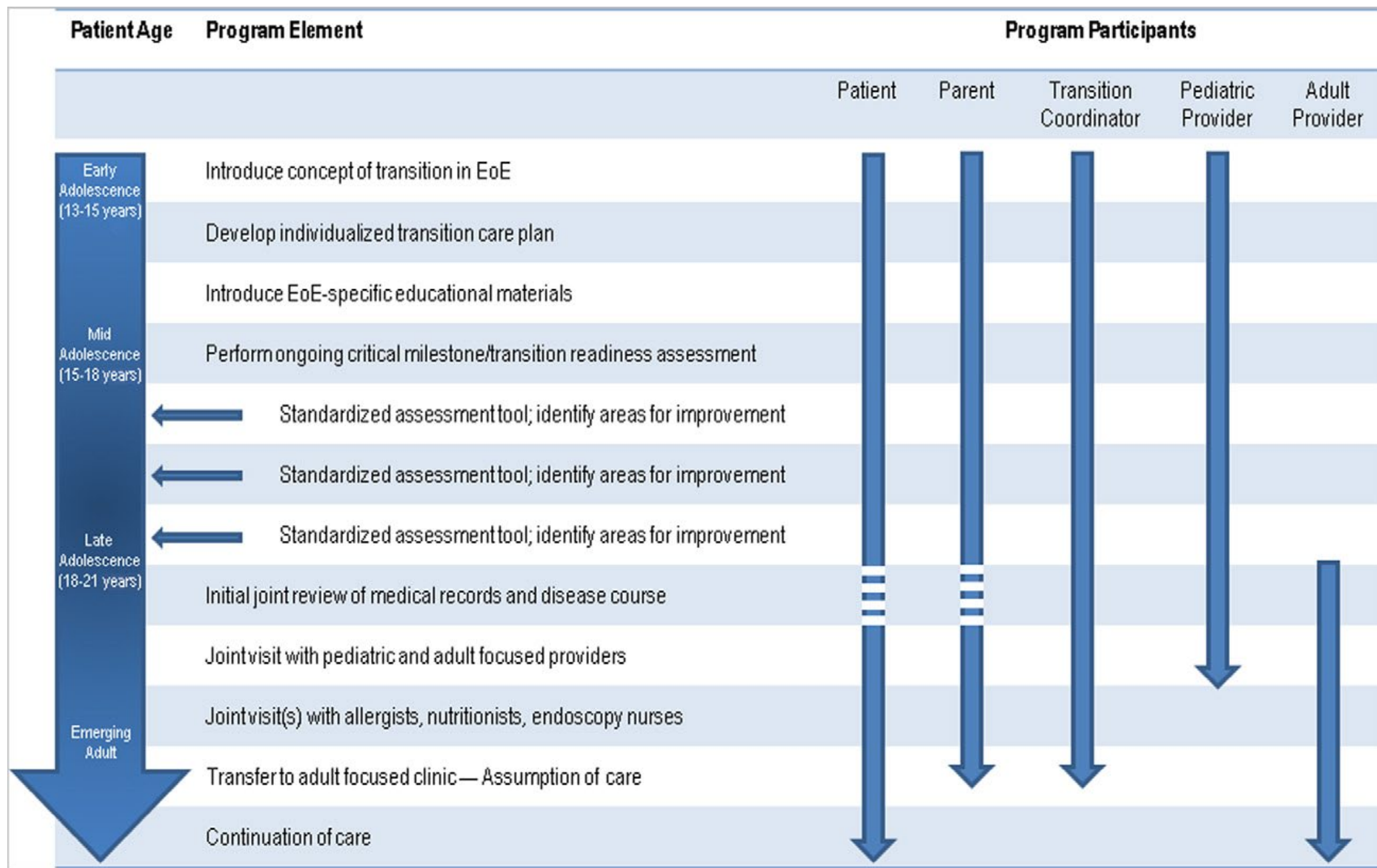
- Academic centers
- Specialised teams
- Multidisciplinary teams
  - Gastroenterologists, Allergologists
  - Nurses
  - Dieticians

# Common barriers to a successful transition

<b>Patient/parents</b>	Behaviour of adolescents
	Burden of chronic disease
	Parent involvement
<b>Providers</b>	Lack of training
	Pediatric condescending attitude
	Adult Gastroenterologists inexperience with adolescent behaviour
<b>System</b>	Lack of funding
	Lack of transition coordinator
	Reimbursement issues
	Different multidisciplinary teams
	Different institutions

# Transition coordinator

- Organises an **individualized** plan
- **Monitors** the progress
- Provides **support** to the different rules in each Unit
- Identifies and manages **missed appointments**
- Ensures **self confidence** and career planning
- Facilitates **communication** among providers, family and patient
- Identify when the patient **is ready** to finalize the transition process

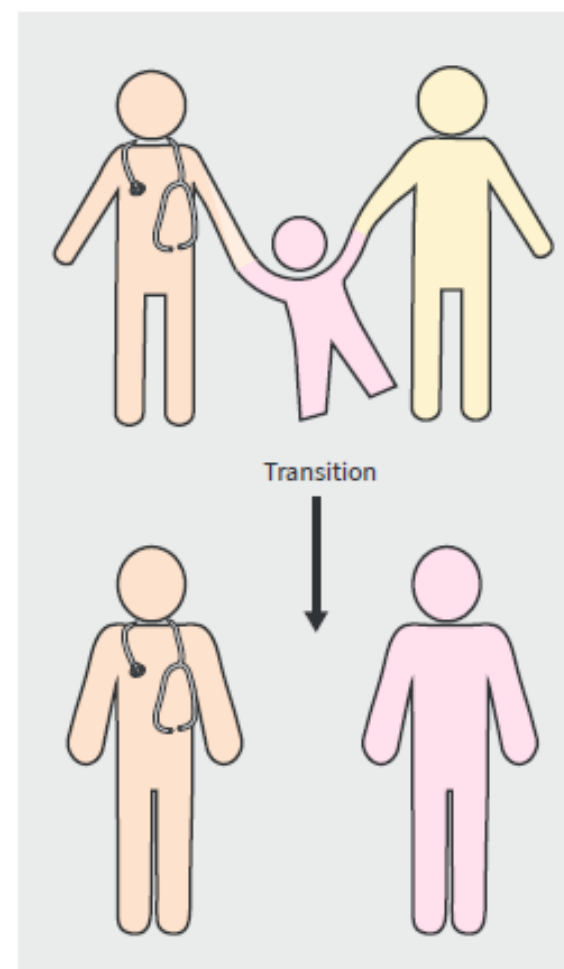


# Mistakes in transitional care for children and young adults and how to avoid them

Jorge Amil-Dias, Hans Törnblom, Moriam Mustapha and Patrizia Burra

Children and adolescents diagnosed with chronic diseases that may require life-long awareness and treatment have special needs that may impact their daily lives and those of their families. Paediatric diagnosis and management are usually provided in specialist facilities where parents are central in discussing therapeutic options, risks, and benefits. However, there comes a time when children must be transferred to adult healthcare facilities where the environment and guidelines are different. The awareness of transitioning to an adult healthcare setting was recognized years ago as a relevant process in managing paediatric patients. It can be defined as a "purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult-oriented health care".<sup>1</sup> There are different rules about the age limit of paediatric patients, but a transition program may be implemented according to these specific requirements. Some conditions are rare, and there may be fewer centres with expertise in adult care than in paediatric settings, e.g., intestinal failure. Finding the right reference centre to promote patients' transition when they reach adulthood may be challenging. Therefore, the transition process that ideally would be in the same institution may need cooperation between centres or even across countries, given the frequent mobility of young adults.

It has been well documented that the transition phase from paediatric to adult health care may be a moment of loss for follow-up, suspension of treatment or monitoring, and subject to risks of unnecessary complications or disease relapse.<sup>2-4</sup> Several factors beyond specific medical management may significantly impact chronic conditions' long-term prognosis and outcome.<sup>5,6</sup> Therefore, organizing a proper adolescent transition program is very important.<sup>2</sup> Several models have been implemented in many hospitals with varying results regarding satisfaction, control of the disease, and adherence to follow-up.<sup>4,7-9</sup> Frequently, some things need to be corrected in this process.<sup>10</sup> Here, we present eight mistakes made during the transition from paediatric to adult care, with evidence from literature and professional experience where possible.



# Activities

- UEGW 2022
  - Workshop involving P&P Associations
- UEGW 2023
  - Digestive Health Roundtable
- Booklet on Transition
- Masterclass on Transition
  - November, Porto (Partnership of UEG, ESPGHAN, EASL, ECCO)
- Syllabus on Transition of care



Transition is not a  
Moment, but a  
Process





**ERN Rare-Liver  
Health Care Transition  
Working Group  
Plans and progress**

**PCLD Workshop**

**14<sup>th</sup> May 2024**



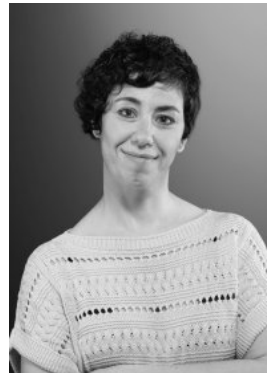
# Background Health Care Transition WG

- ✓ **Founded 2021**
- ✓ **Improve patient care for AYA with rare liver conditions before, during and after their “transfer journey” from pediatric to adult health care**
- ✓ **Involvement of all stakeholders**
  - pediatric - adult HCP
  - different professions (nurses, transition coordinators, psychologists, social workers, researchers, policy makers)
  - patient representatives/ePAGS
  - patients
- ✓ **Representation of the different disease specific WG within ERN Rare-Liver**

# Core Group



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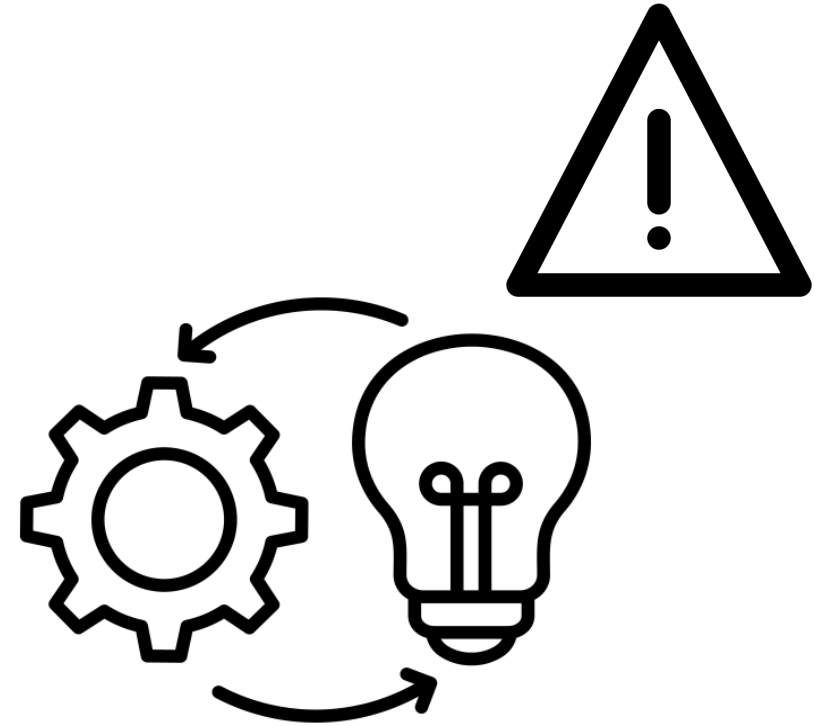
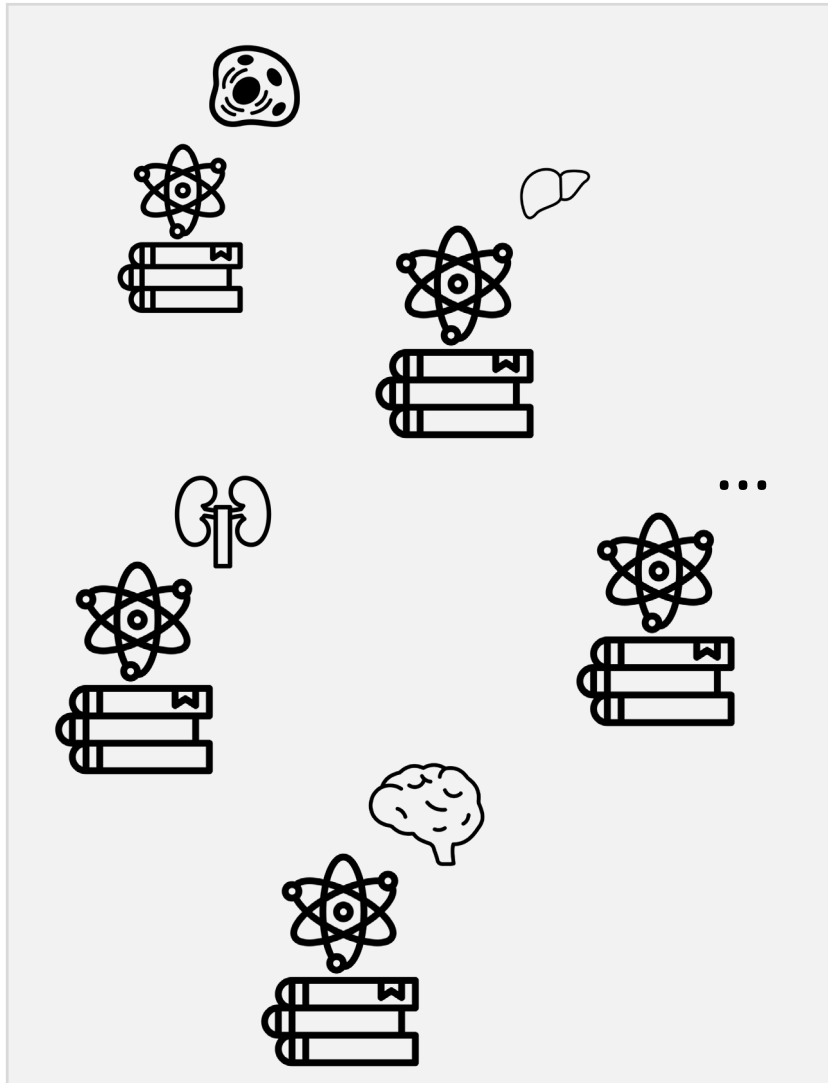
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To join forces/resources and to develop tools that address the minimal criteria of healthcare transition for rare liver diseases and are effective and implementable throughout Europe;

# Omnistakeholder networking event



## Transition of Care

a workshop to bridge the gap  
ERN Rare-Liver

MARCH 17-18, 2023  
GHENT, BELGIUM



Info and registration  
[ERN.RareLiver@uke.de](mailto:ERN.RareLiver@uke.de)



# Patient's and healthcare provider's input

## Method 1

Survey

healthcare providers

## Method 2

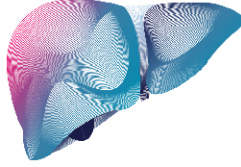
Interviews

patients

## Method 3

Padlets

patients



# Current transition management of adolescents and young adults with liver diseases: an European reference network rare liver survey

J. MADALENO<sup>1,7</sup>, M. SAMYN<sup>2,7</sup>, I. GONÇALVES<sup>3,7</sup>, Z. MARINO<sup>4,7</sup>, R. DE BRUYNE<sup>5,7</sup> and D. KELLY<sup>6,7</sup>

1. Liver Disease Unit, Internal Medicine Department; Centro Hospitalar e Universitário de Coimbra, Coimbra, Portugal; Faculty of Medicine, University of Coimbra, Portugal; 2. Paediatric Liver, GI and Nutrition Centre, King's College Hospital NHS Foundation Trust, London, United Kingdom; 3. Paediatric Liver Transplant Unit, Centro Hospitalar e Universitário de Coimbra, Coimbra, Portugal; 4. Liver Unit, Hospital Clínic de Barcelona, IDIBAPS, University of Barcelona, CIBEREHD, Barcelona, Spain; 5. Dept. Pediatric Gastroenterology and Hepatology, Princess Elisabeth Children's Hospital, Ghent University Hospital, Ghent, Belgium; 6. Liver Unit, Birmingham Women's and Children's NHS Trust and University of Birmingham, Birmingham, UK; 7. European Reference Network on Hepatological Diseases (ERN RARE-LIVER)



## Introduction

There is an increased risk for medical complications and morbidity surrounding transfer from paediatric to adult hepatology and transplant services. Health care transition (HCT) is the process of moving from a child/family-centred model of care to an adult or patient-centered model of health care.

## Aim

On behalf of the European Reference Network (ERN) RARE-Liver, the Transition Working group conducted a survey within Europe exploring current practice.

## Method

A questionnaire was developed and circulated electronically via ERN members and other national/international professional bodies (e.g., EASL, ESPGHAN).

Data was collected via an online survey hosted on the EU Survey platform (<https://ec.europa.eu/eusurvey/>).

## Conclusions

HCT is important for AYA with chronic liver diseases, but there are crucial limitations and variations in the current provision of transition services across Europe.

Lack of resources is the main reason for absence of a programme and support of official instances is clearly lacking.

Standardization of AYA management and specific training are required aiming to improve management and continuity of care during adolescence and into adulthood to achieve the best healthcare outcomes.

## Acknowledgements

We acknowledge all responders to the survey.

## References

- Vajro P, Fischler B, et al. The Health Care Transition of Youth With Liver Disease Into the Adult Health System: Position Paper From ESPGHAN and EASL. *J Pediatr Gastroenterol Nutr.* 2018; 66(6):976-990.
- Joshi D, Gupta N, Samyn M, Deheragoda M, Dobbels F, Heneghan MA. The management of childhood liver diseases in adulthood. *J Hepatol.* 2017; 66(3):631-644.
- Thompson FM, Ferguson JW, Kelly DA, Hirschfield GM. Liver disease in the young adult: the challenges and rewards. *Lancet Gastroenterol Hepatol.* 2019; 4(3):248-254.

## Contact information

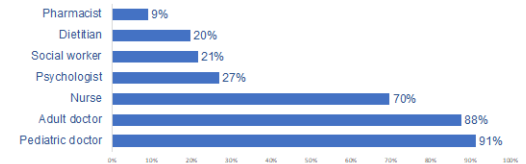
joamadaleno@chuc.m.in-saude.pt

## Results



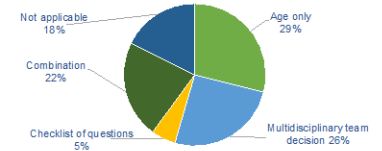
- A total of 90 responses (56% paediatric) from 67 centers in 27 countries were collected.
- 17 centres provided information from paediatrics and adults.
- HCT programme was available in 61% (n=41) centres, organized by paediatrics in 29%, adults 11% and jointly in 57%.
- Lack of resources was the main reason (56%) for not having a liver HCT programme.

### Team composition:



- Transfer to adult services is mainly driven by age, with 71% occurring by their 18<sup>th</sup>/19<sup>th</sup> birthday;
- Exceptions are allowed in 57% (n=32) (in cases of development delay);
- Patients are seen with parent/guardian in 51,8% cases (n=29); in 48,2% cases (n=27) are seen partly on their own.
- Only 30% of health care providers had specific training in the care of AYA

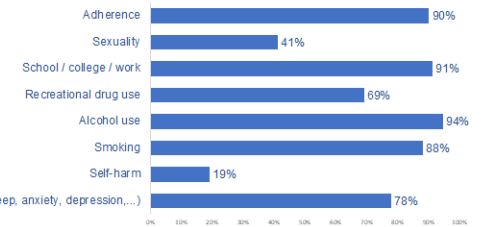
### Evaluation of readiness for transition:



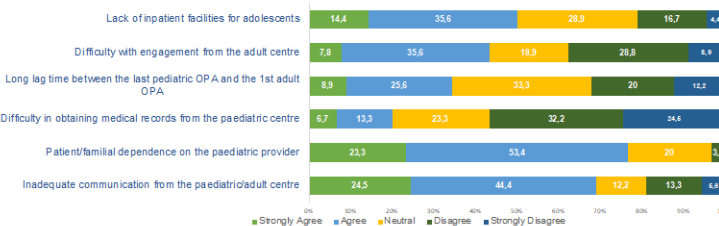
### Available resources for adolescents and young adults (AYA):



### Educational topics asked:



### Main barriers to adequate HCT:



- No feedback system between pediatric and adult services occurs in 45,5%.
- Evaluation system is in place in 60% (mainly healthcare provider and patient feedback) but only 6,7% evaluated patient outcomes (e.g., attendance to clinic, lost of follow up, mortality).
- Only 14,4% of respondents feel official instances see HCT as a priority in their country.

# Patient's and healthcare provider's input

WE WANT  
**YOUR FEEDBACK**

**Communication**




**Information and knowledge**




**Comfortable at adult department?**





ERN interviews with young people	
Young person (pre transfer) <input type="checkbox"/>	Young person (post transfer) <input type="checkbox"/>
Gender _____	Age _____
Country _____	
What are your expectations regarding the transfer to the adult clinic?	
How would the perfect transition look like for you?	
What would you like to be informed about in relation to the transfer to adult care?	
Is there something you would like to change in the health care of young people and in the transitions process? If, yes, what?	
If you would like to change anything regarding the transition trajectory, what would it be?	
What would you prioritize in the transition process?	

How was your experience during transition



Domain	Theme	Knowledge/care gaps and questions to inspire discussions in focus sessions
Communication	Honest communication	How can we effectively communicate information to young people regarding: (1) their disease and its prognosis, (2) their current health status, and (3) other topics such as adherence, alcohol consumption, mental health, and sexuality?
	Between pediatric and adult healthcare providers	How can healthcare providers bridge the communication gap between pediatric and adult care services effectively? What critical information needs to be exchanged? What are patients' expectations regarding shared information? Is there a need for a standardized transfer document, and if so, what would it look like?
	Between healthcare providers and patients	Which communication tools are most effective for engaging with young people, such as e-mail, video conferencing, mobile applications, or social media platforms? What challenges could healthcare providers and young people encounter when utilizing these tools?
Organization	Environment	What are the primary distinctions between pediatric and adult care departments? Which resources are most effective for introducing young people and parents with adult facilities, such as informational leaflets, videos, or guided ward visits? How can we provide adequate support to young people throughout their hospitalization?
	Continuity of care	How can we ensure continuity of care during transfers journeys? Does the age at transfer, whether it be 18, 21, or 25 years old, significantly impact the process? Is the appointment of a transition coordinator necessary and feasible in every healthcare center?
	Resources	What constitutes an optimal transfer journey for young people with rare hepatobiliary diseases? What are the essential components of this transfer journey? How can we effectively address the needs of young people, with limited access to local resources?
Education	Training of healthcare providers	What essential knowledge should healthcare providers possess regarding: (1) adolescent development, (2) pediatric hepatobiliary disease, (3) Sensitive topics and taboos? How can training be effectively delivered to professionals at local, national, and international levels? In what ways can young people actively participate in training and educational activities?
	Sharing of information	Which tools are effective for educating and dissemination information to young people, such as communication leaflets, graphics, or podcasts? What platforms are suitable for sharing information, including the internet, webinars or podcasts, How can young people actively participate in patient support groups?
	Peer support	What are the key components of a peer mentor program? Which forums are suitable for offering peer support? How can training of peer mentors be effectively managed, and who assumes this responsibility? In what capacity can a youth panel contribute, both on a global and local scale?

# Youth panel



- Bring patients together and give them a say in the European Reference Network for rare liver disease;
- Representatives of the Youth Panel participate in the various working groups, including the one on healthcare transition;
- Member of this Youth Panel participated in the EJP RD training for patient representatives and advocates on Leadership and Communication Skills on October 26-27, 2023, in Gdansk;
- Connections with the European Patient Forum Youth Group, who are highly interested in collaborating on this project.



# Cross-ERN framework on THC



# Outcomes and goals for 2024

1. **Most of the critical aspects and actions related to enhancing effective communication, relational continuity, and management continuity → definition concrete action points**
2. **Empower the Youth Panel**
3. **Template AYA liver healthcare document for health care providers (M Samyn, Z Marino)**
4. **Template AYA transition communication information leaflet (K Vanden Wyngaert, J Day)**
5. **Webinars**
  - How to communicate with AYA (J Suykens, J Day)
  - PSC (in progress)
6. **Work in progress (R De Bruyne)**
  - Video for peer-to-peer and physician-to-physician education (K Vanden Wyngaert, J Schrodt)
    - Q&A format (patients, youth panel and health care provider)
    - 2024: communication, PSC (based on input webinars)
  - AYA platform ERN website (J Schrodt)

# Getting it right: The transition from pediatric to adult healthcare

**Nitika Arora Gupta MD DCH DNB MRCPH**

**Professor, Pediatric Hepatologist**

**Emory University School of Medicine**

**Medical Director, Hepatology and Liver Transplant**

**Director, Adolescent Liver Transplant Transition  
Program**

**Children's Healthcare of Atlanta**

**Nitika.Gupta@emory.edu**



**Children's**<sup>SM</sup>  
Healthcare of Atlanta



**EMORY**

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

[Sona Chandra](#),<sup>1</sup> [Shannon Luetkemeyer](#),<sup>2</sup> [Rene Romero](#),<sup>2,3</sup> and [Nitika Arora Gupta](#)<sup>2,3,\*</sup>

### **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



# What can be done to make the transition easier?

Suggestion	Parents 19 parents	Patients 12 Patients	Total 31
Educate about their disease	14	4	18
Educate about insurance	13	4	17
Educate about college w/ transplant	13	3	16
Educate about drugs/alcohol/sex	13	4	17
Educate about medication	14	4	18
Educate about nutrition post transplant	12	3	15
Educate about total body care (hygiene, yearly exams, etc.)	13	7	20
Educate about support system	13	4	17
Make the kids listen	1	1	2
Give specific Instructions about new place	0	1	1
Meet other transitioned teens	1	0	1
Teen clinic	1	0	1
Nothing	4	3	7

## How can parents and patients be prepared for transition?

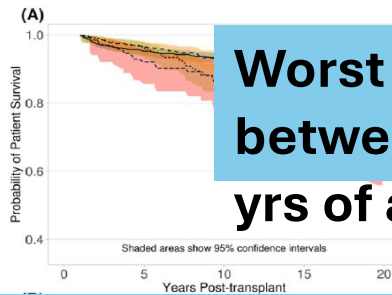
Suggestion	Parents (n=19 )	Patients (n=12)	Total 31
Parent Support Groups	16	3	19
Parents setting boundaries with children with chronic illness	2	1	3
Parents/caregivers letting go and be self responsible	8	5	13
Parents were not involved in care	0	4	4
Review how adult care center works	1	0	1
Parents need to be more involved	2	2	4

## What should be changed to help with transition of care?

Suggestion	Parents 19 Parents	Patients 12 Patients	Total 31
Earlier education about facility	10	4	14
Let kids learn and not remind them so often	4	6	10
Educate about insurance and what to do if you lose it	1	1	2
Educate about how to deal with pregnancy	1	0	1
Nothing	1	2	3

# 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. Ekong<sup>1</sup>  | Nitika A. Gupta<sup>2</sup>  | Read Urban<sup>3</sup> | Walter S. Andrews<sup>4</sup> 



**Worst patient survival in children transplanted between ages of 11-15 and 15-17 as compared to <5 yrs of age** (possible age—41 years)

B. The 25-year cohort transplanted between October 1,

**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.

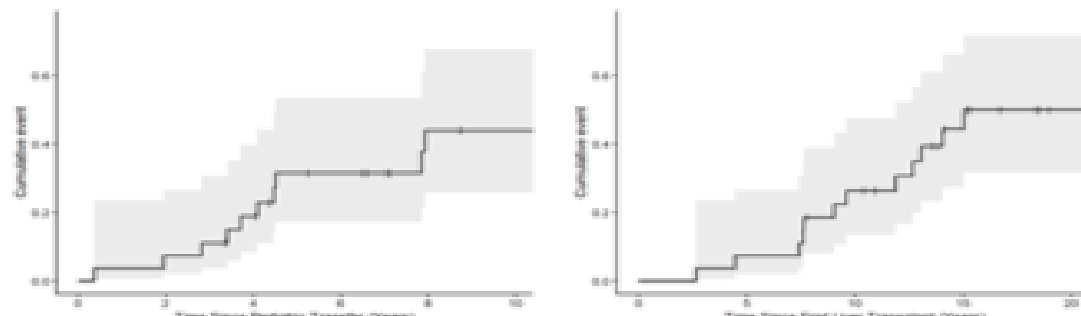
# African American Pediatric Liver Transplant Recipients Have an Increased Risk of Death After Transferring to Adult Healthcare

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

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***

Characteristic	Probability of Mortality (95% CI)
Time since pediatric transfer (years)	

***African Americans constitute majority of the deceased***

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%)

# Camp 'I own It'



# Career, Healthy choices, Money matters, Managing Medications Proficiency questionnaire (CHMMP)

Housing/money:  
Interest rates  
Check cashing  
Safe/affordable housing  
Rental application

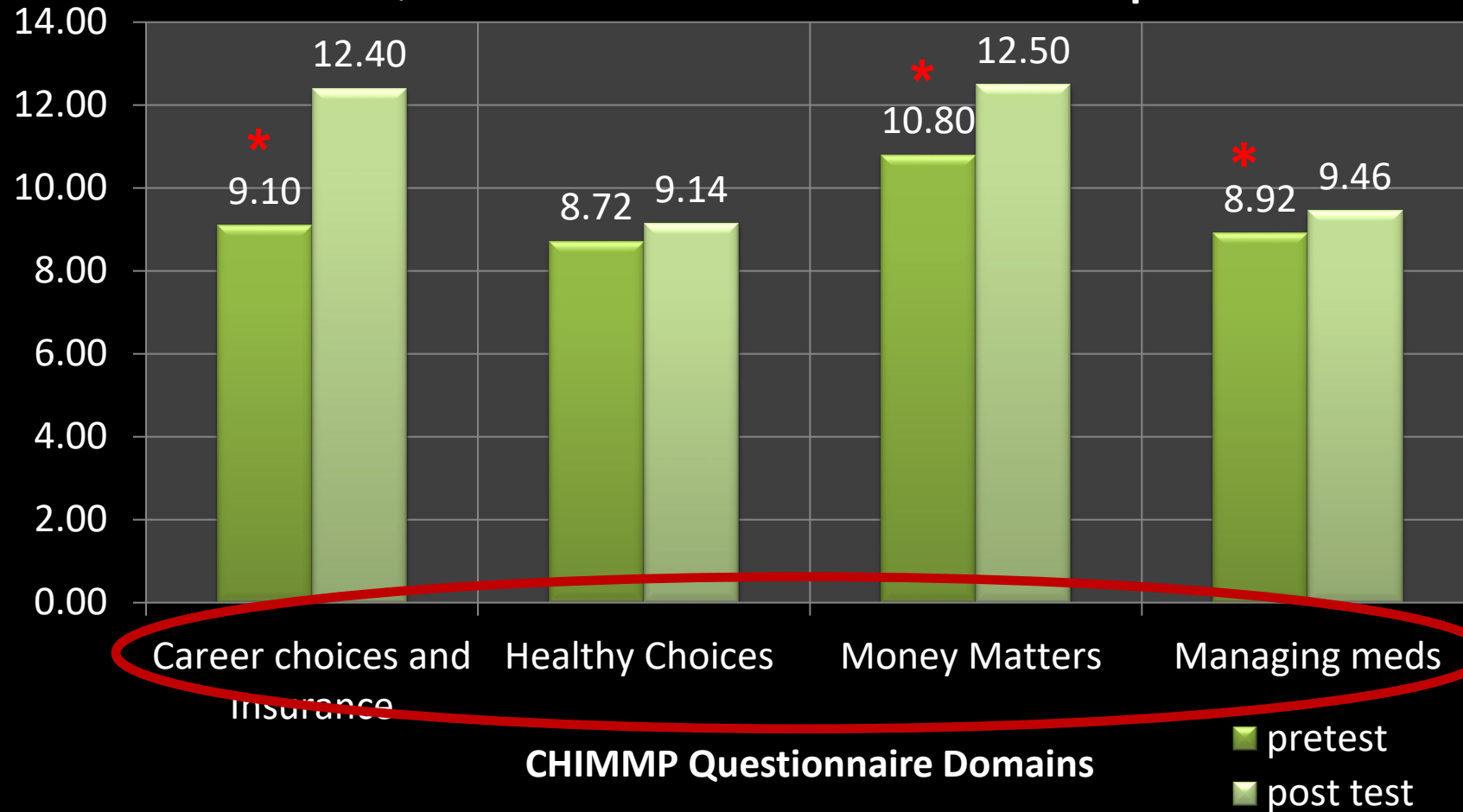
Self Care:  
Health insurance  
Making doctors appointments

Work/study:  
Income tax  
Reading a pay stub, child welfare, W4 payroll exemption

Career/Education:  
Financial aid information  
Locating internships  
Job training information

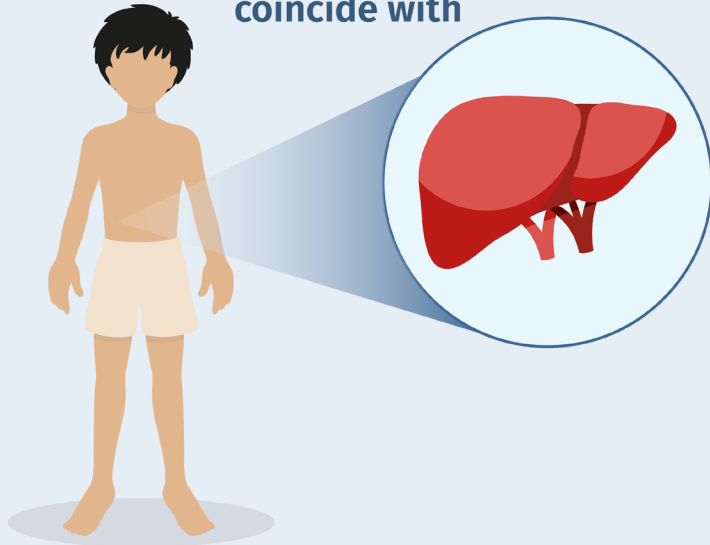
Forms

## Average Scores on each domain of the CHIMMP Questionnaire Before and After Camp



# Pediatric Risk Factors Associated With Death After Transfer to Adult Healthcare

In pediatric liver transplantation (LT) patients, transition to adolescence and transfer to adult medical providers' care coincide with



Increased non-adherence



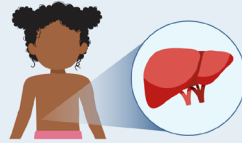
Shifting responsibilities between parent and caregiver



Increased risk of untimely death or lost to follow-up

This affects their long-term outcomes

Analysis of long-term outcomes in transitioned pediatric LT recipients



93 monitored by adult providers



8 lost to follow-up



Demographics

Factors assessed

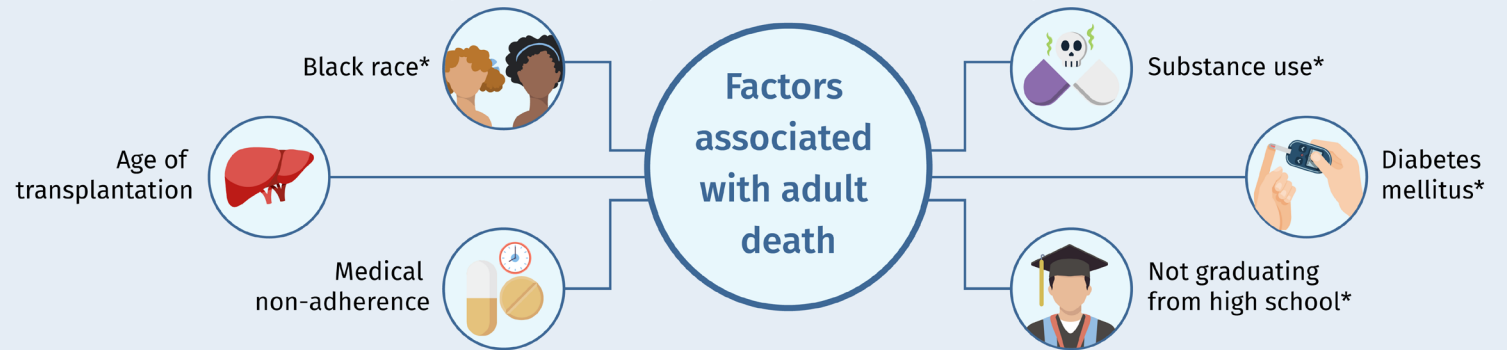


Clinical features and co-morbidities



Psychosocial factors

23 patients died post transfer to adult care providers



\*Significant on multivariate analysis while controlling other factors

Not finishing high school before transfer



Loss to follow-up

Individualized risk assessment of pediatric LT recipients can improve their outcomes and reduce the risk of death following their transition to adult care providers

# 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.

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Children's  
Healthcare of Atlanta

# Self awareness Initiative

## Questionnaire followed by tailored teaching





- Initial diagnosis for transplant
- Current medications
- Interpretation of liver tests

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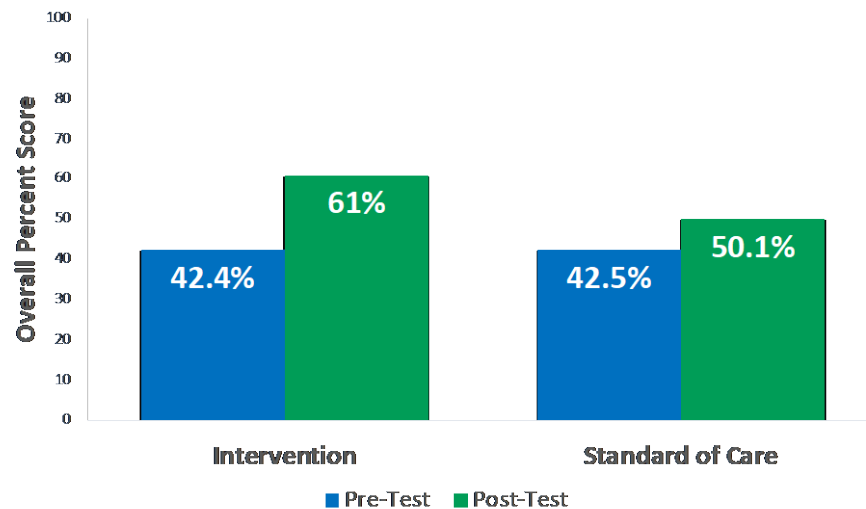
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## A Prospective Knowledge Assessment of Adolescent Liver Transplant Recipients after Tailored Education Intervention

Meera Shah <sup>1</sup>, Michael Mendoza,<sup>1</sup> Jacob Bilhartz <sup>1</sup>, and Nitika Gupta  <sup>1</sup>

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# Outcomes Of Pediatric Liver Transplant Recipients After Transfer From Pediatric To Adult Healthcare: A Report From The Starzl Network

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Kelly D. Wiley J. The adolescent liver transplant patient. *Clin Liver Dis*. 2014;18: 613-622.  
1. Karia N, Latcha A. Pediatric liver transplantation: A North American perspective. *Expert Rev Gastroenterol Hepatol*. 2016;10: 949-959.  
2. Bock MP, Banfield. Predictors of long-term outcomes after liver transplant. *Curr Opin Organ Transplant*. 2015;16: 499-504.  
3. Annunziato RA, Emw S, Shneider S, et al. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Article, Pediatric Transplantation*. 2007;11(5):608-614.  
4. Hery R, Frazee-Jones C, Wood J, et al. Long-term follow-up of pediatric liver transplant recipients. *Outcomes following transfer to adult healthcare in New Zealand. Article, Internal Medicine Journal*. 2015;45(5):580-582.  
5. Lawrence ZE, Martinez M, Lobritto S, et al. Adherence, Medical Outcomes, and Health Care Costs in Adolescents/Young Adults Following Pediatric Liver Transplantation. *Article, Journal of Pediatric Gastroenterology and Nutrition*. 2020;70(2):183-189.  
6. Stevens AF, Hall L, Gupta NA. TRANSITION of Pediatric Liver Transplant Patients to Adult Care: a Review. *Review, Current Gastroenterology Reports*. 2021;22(2):9.  
7. Chandra S, Luchterslager S, Bornek R, Gupta NA. Growing Up: Not an Easy Transition - Perspectives of Patients and Parents regarding Transfer from a Pediatric Liver Transplant Center to Adult Care. *International Journal of Hepatology*. 2015;2015.  
8. Krawczewski K, Pater SK, Ogden M, Antoniewski S, Luchterslager S, Dapkin H. Education, employment, and empowerment: Outcomes of an adolescent transplant care (of liver 10). *Pediatric Transplantation*. 2018;22(6).  
9. Mahan JD, Bell CL, Chumlea NI, Faria ME. Self-management and transition to adult health care in adolescents and young adults: A team process. *Pediatrics of Review*. 2017;38(7):305-319.  
10. Mitchell T, Goodling G, Adams L, MacChabun G, Casan G, et al. Transition to adult care for pediatric liver transplant recipients: the Western Australian experience. *Pediatric Transplantation*. 2017;21(1).  
11. Sagar N, Lathiaad JA, Lloyd C, Smith M, Curran BK, Adams DR, et al. Pediatric liver transplant recipients who undergo transfer to the adult healthcare service have good long-term outcomes. *American Journal of Transplantation*. 2015;15(7):1864-1873.  
12. Park BK, Nank RB, MacChabun CE, Krawczewski S, Bornek R, Gupta NA. Racial disparities in presentation and outcomes of pediatric autoimmune hepatitis. *Liver International*. 2013;20(2):196-204.  
13. Tharmann RV, Krawczewski S, Bornek R, Haffner TG, Chavali CT, Putari RE. Racial and socioeconomic disparities in pediatric and young adult liver transplant outcomes. *Liver Transplantation*. 2014;20(1):100-115.  
14. Kulkarni S, Stevens J, et al. African American Pediatric Liver Transplant Recipients Have an Increased Risk of Death After Transferring to Adult Healthcare. *J Pediatr*. 2021.  
15. Sherman F, Klaveman LC, Howell EA, Annunziato R. Racial and economic disparities in transplant outcomes: The not-so-hidden morbidity. *Review, Liver Transplantation*. 2014;20(1):4-6.

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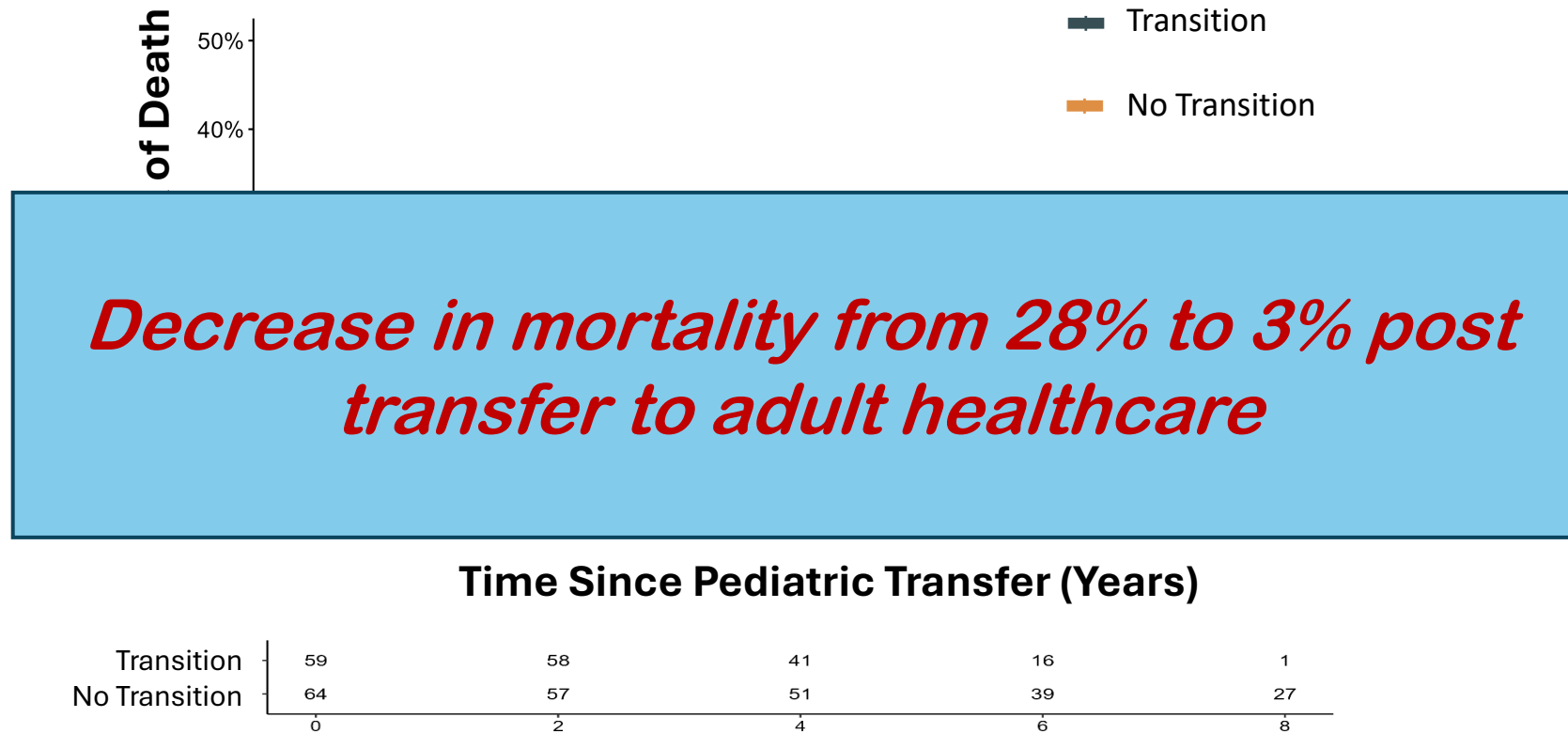
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Meera Shah <sup>1</sup>, Michael Mendoza,<sup>1</sup> Jacob Bilhartz <sup>1</sup> and Nitika Gupta  <sup>1</sup>

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**Multicenter study to assess knowledge of adolescent liver transplant recipients and correlate with outcomes after transition of care**

# Emory Data: Outcomes Following the Initiation of a Formal Transition Program and Novel Joint Pediatric-Adult Clinic



**Thank you**