

Quality of Life of Children Receiving Multi-Solid-Organ Transplants are Excellent: Results from the 'UNIQUE' Study



Understanding Children With Multi-Organ Transplants' Quality of Life

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Disclosure of Conflicts of Interest

Alicia Paessler

Nothing to disclose



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Background

- Increasing number of children multi-solid organ transplant (MSOT) candidates
- Unique challenges compared to single transplant recipients
- Quality of life (QoL) can link directly to clinical outcomes – e.g. medication adherence
- No studies at all on QoL in MSOT recipients

Aim

To review the long-term clinical outcomes and gain a better understanding of the quality of life of all patients receiving more than one different solid organ transplant during childhood between 2000 and 2021 in the UK.



Clinical Outcomes

Previously presented in more detail

- Overall Patient Survival:
 - 1 Year: 98%
 - 3 Years: 95%
 - 5 Years 93%
 - 10 Years 89%
- Overall Kidney Graft Survival:
 - 1 Year: 91%
 - 3 Years: 85%
 - 5 Years: 83%
 - 10 Years: 77%
- All comparable to single organ transplant recipients in the literature
- Children receiving simultaneous liver and kidney transplants have fewer episodes of acute liver rejection and were less likely to lose their liver and/or kidney allografts than children receiving sequential liver and kidney transplants ($p < 0.01$).
- Mortality was 15% ($n=14$) over a 20 year period
 - 85% ($n=12$) prior to 2010



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Methods

- All surviving patients with MSOT <18y in UK in 2000-2021
- NHS HRA Ethics Approval
- NHSBT
- Five recruiting centres
- Parents and patients invited to complete questionnaire
- 7 Categories – About My Medicines I and II, My Transplant and Others, Pain and Hurt, Worry, Treatment Anxiety, How I Look and Communication
- Ages 2-4, 5-7, 8-12, 13-18, 18+
- Scores out of 100, higher score = better QoL
- Opportunity for additional comments

PedsQLTM
Transplant Module

Version 3.0

YOUNG CHILD REPORT (ages 5-7)

- Quantitative analysis including statistical significance testing and clinical significance testing
- Comparisons between current age / age at transplant / transplant types
- Thematic analysis of free text responses
 - 2 co-authors independently identified codes and themes
 - Themes then compared between co-authors and assimilated



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2000 MSOT age <18y in UK 2020



N=92

Surviving patients n=78

Patients identified by local transplant centre

n=46

Consented and participated in QoL arm of the study
N= 31 families (29 patients, 24 parents)

Simultaneous



N=20

Sequential



N=8

Sequential



N=3



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Median age at time of participation: 16 years

Age range at time of participation: 4-32 years

21 children 15 adults at time of participation

Median time since transplantation: 7 years (range 0.3-17.5 years)



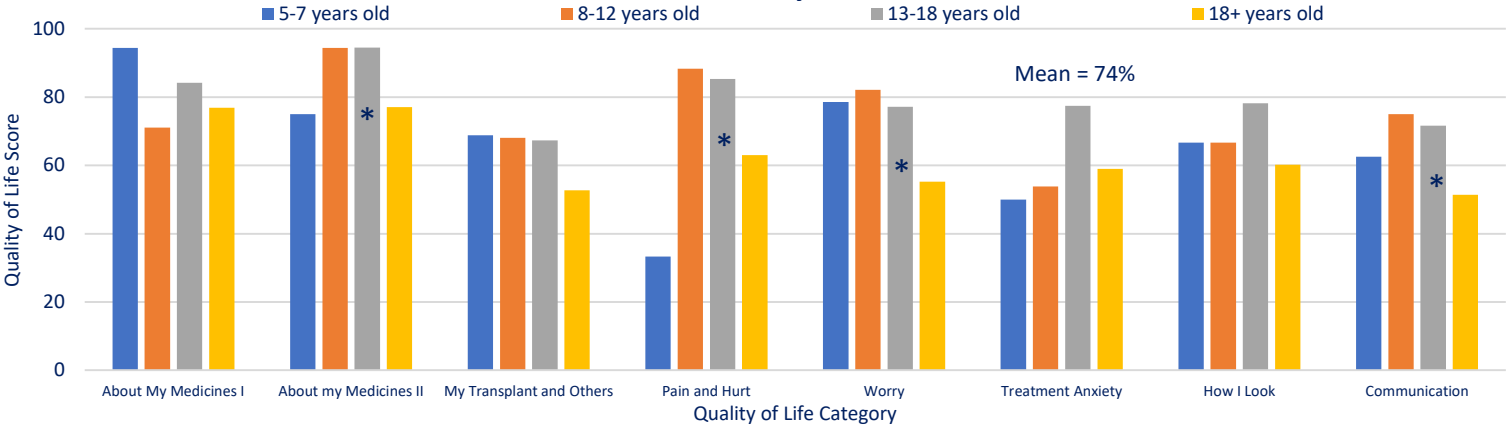
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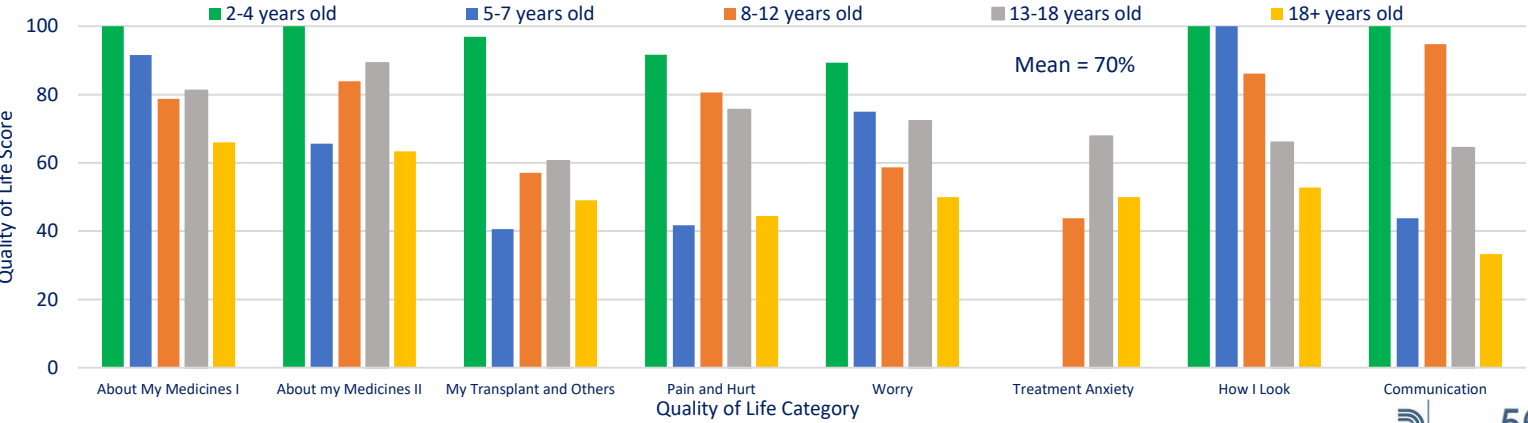


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Patient Quality of Life



Parent Reported Quality of Life



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Results

- Those transplanted at younger age had higher quality of life scores across every category ($p < 0.01$)
 - Age <4: 79.5%
 - Age 5-7: 78.6%
 - Age 8-12: 73.4%
 - Age 13-18: 56%
 - This trend was not identified in clinical outcomes
- No significant difference between transplant types ($p = 0.94$)
- No significant difference by time since transplantation ($p = 0.39$)



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"I see the person I was before my transplants as a completely different person to who I am now"

"We are so grateful the combined transplant was an option for her"

"Right now, I feel like I can take on the world and nothing is stopping me"

Improvement in Physical Symptoms

Absence of fear / anxiety

Overall Improvement in QoL

"The last 3 years since his transplants have been the best 3 years of his life"

"I would imagine, if he'd been older before his health problems began, he would have a vastly different experience, and would feel differently about how it relates to himself and who he is"

"Coming to hospital makes me think of and remember the transplant, particularly my second one as I was then old enough to remember it"

Sense of Self

Positive Impacts

Negative Impacts

Age at Transplantation

Impact of Transplantation

Gratitude

Empowerment

Psychosocial impacts

Physical Impacts

"This has caused PTSD in our son, he feels like he has missed out on his childhood."

"I worry whether I will have to have another transplant"



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'Normality'

'Normal Life'

"Apart from a few aspects, I have a fairly normal life"

"He lives a very normal life"

"I'm very used to it all"

"I think that for my son, growing up whilst going through these experiences made them easier to bear as it was all so normal"

"It now feels like a bit of normality"

Feeling Different to Others

"I want to be like everyone else"

"He struggles to socialise with his peers, he realises his condition makes him different to his peers"

"I have always felt different to others my age but never really in a negative way"





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"Once my daughter transitioned to adult care it became very difficult, there was no one key person co-ordinating care like there was in paediatrics"

"Difficulty getting employment due to potential employers' concerns about impact of health issues on attendance or performance"

"I get angry about all the hospital appointments"

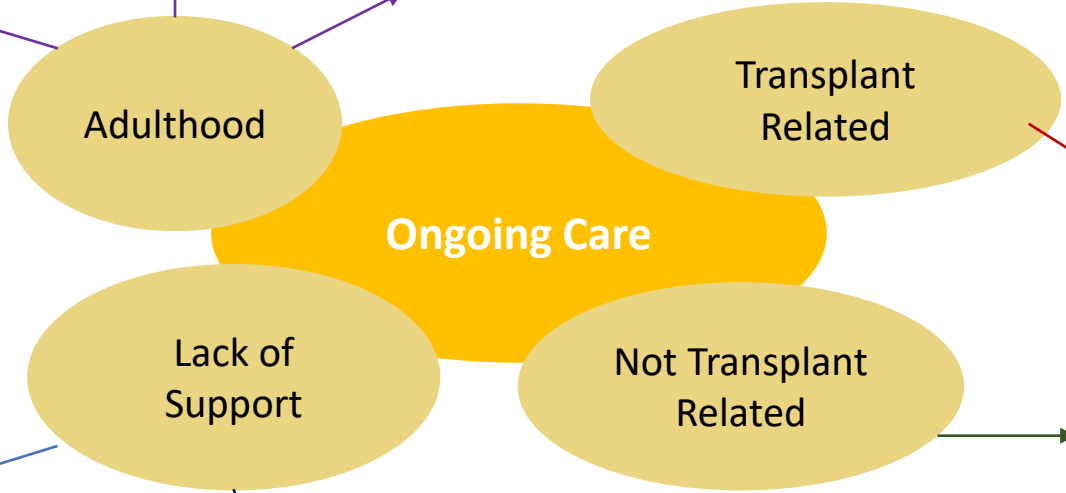
"I have additional needs that affect my ability to independently understand and communicate about my transplant"

"No real support available for ongoing emotional or psychological problems"

"The doctors are amazing but they cannot support him mentally"

"As a person becomes older and is able to think more realistically about their life, it brings some difficult questions"

"I have found that as I grow older, I worry more and more about my future and the longevity of my transplanted organs"



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Taking MSOTs into the Future

Psychosocial Health

Physical Health

Formal Support

Peer Support

"Transplanted children struggle with dental health, tooth discolouration makes them feel embarrassed. Please set a criteria for their dental health."

"Encourage children to be an ambassador of their health condition and involve them in a group meeting where all transplanted children meet and share their thoughts. Doctors should be present as well so they can have a healthy discussion"

"Psychological support is very necessary, they need to be reviewed regularly by psychologists to stay confident and content"



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Conclusion

- Quality of life can be excellent post-MSOT
- Need for a full multidisciplinary approach, especially during transition to adult services
- Quality of life reported to be better in children transplanted at an earlier age
- Children with conditions leading to end-stage disease in multiple organs should be assessed as potential transplant candidates.



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Clinical Outcomes and Quality of Life of Patients Receiving Multi-Solid-Organ Transplants in Childhood Are Excellent: Results From a 20-Year Cohort Study

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Questions?



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