

# The Lasting Impact of the Transplant Experience from the Perspective of the Well Sibling: An Unheard Voice

Stacey Lerret, PhD, RN, CPNP-AC/PC, CCTC, FAAN  
Professor, Medical College of Wisconsin  
Children's Wisconsin, Milwaukee, WI

Shelley Chapman, DNP, RN, CPNP, CCTC  
Medical College of Wisconsin  
Children's Wisconsin, Milwaukee, WI

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S. Lerret



# Background

- Solid organ transplantation is a chronic illness requiring complex medical management that impacts the family system
- Caregiving for a family whose child has a chronic illness becomes more complicated
  - Increased responsibility
  - Family finances, and social, mental and psychological health affected
- Experiences of well siblings are not well described
  - Previous research focuses on parental caregivers

# Purpose

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- Understand the well child's perspective of having a sibling who received a pediatric solid organ transplant and living with a chronic illness.



# Research Question

How do siblings of pediatric transplant recipients describe their individual- and family-based experiences?





# Theoretical Framework

Rolland's Family Systems Illness Model, a strengths-based framework for chronic illness and family development, guided study conceptualization and development.

# Methods

## Sample

- Siblings (12-17 years of age) of a transplant recipient

## Setting

- Virtual via Zoom

## Procedures

- Families were recruited from two pediatric transplant programs (liver and kidney)
- 30–45 minute semi-structured interview (via Zoom) and demographics via email link
- Child received \$60.00 gift card for participation

## Analysis

- Frequencies for demographics
- Inductive content analysis for qualitative data

# Sample Characteristics (n = 12)

Characteristics	Participant, n (%)	Transplant Sibling, n (%)
<b>Gender</b>		
Female	2 (17)	5 (42)
Male	9 (75)	7 (58)
Non-binary	1 (8)	Na
<b>Age</b>	Mean 15.2, sd 2.1 years (range 12-17 years)	Mean 13.3, sd 2.5 years (range 9-17 years)
<b>Race</b>		
Black	1 (8)	1 (8)
White	11 (92)	11 (92)
<b>Ethnicity</b>		
Hispanic/Latino	2 (17)	2 (17)
Non-Hispanic/Latino	10 (83)	10 (83)
<b>Family Order</b>		
1 <sup>st</sup> child	5 (42)	1 (8)
2 <sup>nd</sup> child	4 (33)	4 (33)
3 <sup>rd</sup> child	2 (17)	5 (42)
4 <sup>th</sup> or higher child	1 (8)	2 (17)
<b>Transplant Type</b>		
Kidney	Na	7 (58)
Liver	Na	5 (42)
<b>Time Since Transplant</b>	Na	>5 years = 12 (100)

# Results: Themes



Impact of the Transplant on Family

Impact of Transplant on Social-Emotional Development

New Family Meanings

Reflecting on the Transplant Experience





# Theme 1

## Impact of Transplant on Family

# Impact of the Transplant on Family

## Family Transplant Story

Participants recall the time their sibling had their transplant, noting the absence of parents and disruption in routine

**“Well, I kind of got ignored for a long time. I spent a lot of time with grandma and didn't really see [transplant sibling] as much because he was at the hospital. And my parents were at the hospital, too.”**



Some could recall more details than others, but all remember the initial hospital stay and changes at home.

**“From what I remember, one day the whites of his eyes were yellow, and my parents were really worried.”**

# Impact of the Transplant on Family

## Disruption and Change to Family System

Changes in how the participant and siblings interacted and played

**“He can’t rough house, be careful around him. Make sure you don’t hit him in the wrong spot.”**



Changes in how the household functioned to protect sibling (not having friends over, playing mostly outside, etc).

**“I know we struggled sometimes to like all be able to do different things because a lot of the time my parents were with [transplant sibling] at the hospital.”**



Participants recognized the strains placed on entire household including emotional and financial

Wish parents had more support, relied heavily on extended family

# Impact of the Transplant on Family

Constant Fear of  
Illness Heightened  
by COVID-19

Anxiety of transplant sibling becoming ill was always present amongst families

**“Whole family stuck in a sort of fear that things might go wrong for him. I feel like most people who have healthy families don’t go through that.”**



Increased ramifications of COVID-19

Increased time in virtual school, extra hygiene precautions, limited activities outside the home.

# Impact of the Transplant on Family

Transplant Influences the Model of Caregiving in the Family

Older sibling's taking on more responsibility at home – but not involved in medical care for sibling.

**“I am usually in charge of my youngest brother...I am the one who helps him with whatever he needs.”**



Participants feel as though they grew up faster.

**“I think part of having her as my sister, and dealing with the medical stuff and all that from an early age, made me grow up a little faster”**



Extended family members (primarily grandparents) integral while parent(s) were focused on transplant sibling.

A pair of hands is shown from a top-down perspective, cupping a heart-shaped object. The heart is primarily pink with a yellow outline and a yellow section on the right side. The background is a solid, muted blue-grey color.

Theme 2  
Impact of Transplant on  
Social Emotional  
Development

Impact of  
Transplant on  
Social-  
Emotional  
Development

Sibling as  
Forgotten or  
Ignored

Stems from transplant sibling receiving more attention and parental support.

**“Well, I kind of got ignored for a long time. I spent a lot of time with grandma and didn't really see [sibling] as much because he was at the hospital. And my parents were at the hospital, too.”**



Participants felt as though they were less important and struggled with the lack of parental support.

**“It can feel kind of rough, and it can make me feel a little less important than him.”**



Participants understand why their sibling received more attention, but it still impacted their childhood.

**“But they [the parents] also try to like to make sure that just because, like [transplant sibling] has a medical illness, and she is always like getting attention, that it doesn't feel like she's the *only* one getting attention. Which is a really hard thing to do, but they definitely still try to divide up their parenting and make sure they're not just focusing on one kid.”**

Impact of  
Transplant on  
Social-  
Emotional  
Development

Impact on Mental  
Health

Fear, anxiety, and worry that sibling will get sick again

**"I don't think any of my friends have to deal with the stress factor, knowing that the sibling could be gone at any moment."**



Know that the uncertainty and anxiety they feel will continue into the future

**"It's sad, but knowing that something could happen in an instant and its life changing..."**



When sibling is sick or hospitalized, it is difficult for well sibling to go through their normal routine knowing the sibling is not well

**"I had to go to work and school throughout it, and it was just like it just wasn't as easy, because I knew like there's a third of my family missing when I'm done with it all when I go home, and that that was tough."**



Impact of  
Transplant on  
Social-  
Emotional  
Development

Impact on Social  
Relationships

Information shared with peers varied

**“So, then people are like, ‘Oh, why, why is your sister so short?’ And I’ll be like, ‘Well, partially because she had a kidney transplant and it stunted her growth.’ Everyone’s always like, ‘Oh, I didn’t mean to like offend you or anything,’ Like no, it doesn’t offend me. I can talk about it.”**



Miss activities with friends due to sibling’s illness

**“I know we struggled sometimes to like all be able to do different things because a lot of the time my parents were with [transplant sibling] at the hospital.”**



Not significant effect of overall friendships but could influence their ability to have friends over or their ability to do things with friends.

**“I go to my friend's house's lot like I don't think any of them have really been inside my house because we got to keep [transplant sibling] from not being sick, and that can be hard.”**

Impact of  
Transplant on  
Social-  
Emotional  
Development

Impact on  
Emotional  
Responsiveness

More compassionate and empathetic because of the sibling's illness

**"I think it's given me a lot of compassion for the people with illnesses and disabilities..."**



Sibling's condition made them mature faster

**"I feel like I've been an adult for 3 years. Which is weird. And it does sometimes feel like you missed out on a lot of younger child experiences."**



Increased maturity beyond developmental age – tries to be a good role model for other siblings.

**"I'm the responsible one" [in friend groups]**

Impact of  
Transplant on  
Social-  
Emotional  
Development

Participant's  
Perception of  
Sibling who  
Received  
Transplant

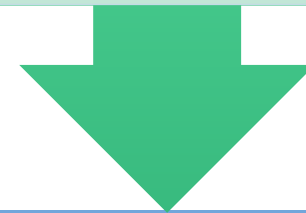
Mixed findings with some relationships becoming closer, some unchanged, and some loss of closeness.

**"But after he came home, he's never really been the same, I don't know. We just haven't been as close."**



Participants note changes in their sibling's personality due to increased attention on them.

**"I don't think people would really think about how like just the transition between living in a hospital constantly and having every everyone concentrating on like you specifically. Like that transition from being the center of attention to not anymore, like how it affects this person's personality."**



Participant's feel as though their sibling missed out on opportunities due to their illness.

**"Well, I definitely think it's kind of a common understanding with all of us that he missed out on a lot of opportunities like a lot of things he could have done."**



Theme 3  
New Family Meanings

New  
Family  
Meanings

Influence of  
Sibling's  
Transplant on  
Participant's  
Future

Future need for donation weighs on them – what if they cannot help.

**“What if I’m not the donor? What if I can't donate? What else can I do? You know?”**



Knowing sibling will have to deal with this for life is hard for them

**“It's just that maybe later in life when we're both out of the house, I might have some more like responsibilities with [transplant sibling] and just making sure he's taking his medicine and getting checked up on then.”**



Family Adaptation and Resiliency

The “new normal” that the families adapted to has made many of them closer.

“I feel like a lot of it just kinda goes unsaid, like we all know, like this is something that he has and works through every day. And I think we've just again all been together through it all. We all know, we're all aware, and try and don't let it hunker down on our day-to-day too much.”

Reliance on FaceTime during times sibling is hospitalized

“I can just facetime my mom, and it does kind of suck like that [he's] in Milwaukee, but other than that, Facetime works really good.”

Creating positive memories

Make a Wish

Organizing fundraisers for transplant

Grateful for their transplanted sibling and appreciates every moment together, they will always be there for each other

“Everybody just feels pretty tight knit...It's a special, pretty unique feeling.”



Theme 4  
Reflecting on the  
Transplant Experience

Reflecting  
on the  
Transplant  
Experience

Participant's  
Experience of  
Loss Related to  
Relationship with  
Parents

Recommend checking in with the well sibling, especially during times of illness

**"I think just being open about it and checking in on like everybody, and not just the sick kid is nice. And to give and be there for the other kids, too, and not just make the full focus on the sick one."**



Share information/provide reassurance

**"I think a lot of the reassurance that doctors give to the parents could be given to the kids as well."**



Have a solid support system for the well-siblings in place

**"So, pay attention to your kids because my parents don't really know anything about us now."**



# Reflecting on the Transplant Experience

## Guidance for Healthcare Interactions

Frustrated that healthcare does not have all the answers

**"Just explain all the medical jargon, all the medical terms, and everything that is being said, because it's really confusing."**



Appreciated when healthcare explained transplant

**"Because I know the people at the hospital like walked me and my brother through like what was happening like and showed us on like a doll and stuff."**



Appreciate consistency and familiarity of members of healthcare

**"But nothing made my day more as a little kid....and we get the little hospital passes and it would be the same woman there....she knew us by name, and she would always smile and make jokes, and that made that experience so much better."**



Provide reassurance

**"If a kid is in for an operation and the doctor comes out and says like, Hey. everything's going great. He's a very strong kid. We've got this under control. He should be out of here soon. I feel like a lot of that [can be] given to the kids as well. We did get some of that when we would go in and he'd be sick. It was like, Hey, your brother's sick right now, but we're taking care of him, and he'll be okay. And that was pretty much all we needed to hear his little kids"**

# Reflecting on the Transplant Experience

## Advice to Other Siblings and Families

### Remember that they are not alone

**“I’d say there’s a lot of other people like you. So, the biggest thing is to not feel alone and know that in feeling alone you’re forgetting that you have a sibling that is dealing directly with it. They’re probably your biggest partner when it comes to that.”**



### Stay calm and know that things will get better

**“Talk to them (the transplant sibling). Ask them what’s going on. Ask them how you can help.”**



### Connect with the sibling who had the transplant

**“.....just kind of be there for, like your brother or sister....I feel like it definitely...makes you like mature like faster and try not to be as hard on them. I still try to be hard on him, because he’s still my younger brother. but I just can’t be like. you know, beating them up every day because that’s not very good”**

Reflecting  
on the  
Transplant  
Experience

Possible  
Strategies to  
Improve the  
Transplant  
Experience

Engrain importance of all hospital staff talking with and acknowledging siblings during visits

Peer Support Groups

**“I think it would have been nice to kind of talk to someone who knew a bit of what I was like going through other than like someone in my family.”**

Increasing “visitation” or access to sibling/family during hospitalizations

Share information at developmental level with siblings

# Strengths

01

Adolescents provided thoughtful and reflective responses during interviews.

02

Exemplifies the chronicity of organ transplant on entire family, not just patient who receives transplant

03

One of few studies addressing sibling perspective for transplant population

# Limitations

Demographically  
homogenous  
sample group

Several years  
between  
transplant and  
interview

Focused on  
adolescent siblings

# Conclusions

When asked if the study participants had any question for the study team, a subset questioned why the study was being done and how would their information be used.

These findings affirm that the transplant event is universally distressing and impacts the well sibling's life in the moment and for years afterwards.

Opportunities are present to raise the awareness of healthcare providers to provide care through a family lens that can positively impact the patient and the family.

These findings are a preliminary step toward a more family inclusive model of care that fully engages the well sibling.



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