



## ORIGINAL TRANSLATIONAL SCIENCE

# 'My Transplanted Self': Adolescent recipients' experience of post-traumatic growth following thoracic transplantation

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**BACKGROUND:** Despite heart and lung transplantation being life-saving therapies for children and adolescents, little research has focused on recipients' lived experience post-transplant. This study captures the subjective experiences of adolescent thoracic transplant recipients, providing insight into the impact of life changes following transplantation in this population.

**METHODS:** A grounded theory approach guided an iterative process of data collection and data analysis. Adolescent heart and lung transplant recipients were recruited from a large Canadian pediatric teaching hospital to participate in one-on-one semi-structured interviews. Analysis using line-by-line coding and constant comparison methods facilitated reflection and agreement on categories and emergent themes.

**RESULTS:** A total of 27 heart and 5 lung transplant recipients (66% female) participated at a median age of 15.9 years and a median time post-transplant of 2.7 years. Participant narratives illuminated three themes describing (1) personal growth – an awareness of personal strengths and coping abilities, (2) relationship growth – a greater appreciation for family and friends, and (3) introspective growth – a developing life philosophy. Findings suggest that adolescents experience an emergent 'transplanted self', positioning thoracic transplantation as a potential catalyst for positive growth and personal change.

**CONCLUSIONS:** The study findings describe pediatric thoracic transplantation as potentially transformative in nature and sheds light on the application of post-traumatic growth theory. Practitioners and researchers are encouraged to acknowledge the possibility of growth, transformation, and positive change that may be possible within the adolescent thoracic transplant experience and leverage such strengths in clinical care.

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Thoracic transplantation is life-saving therapy for patients with end-stage heart and lung disease.<sup>1,2</sup> Significant surgical and medical advances in pediatric thoracic transplantation have substantially improved outcomes for children and adolescents, with five-year survival rates

approaching 80% for heart transplantation and 60% for lung transplantation.<sup>3-5</sup> The increasing survival of adolescent thoracic transplant recipients affirms the need for a deeper understanding of their lived experience post-transplant to tailor clinical care and management.<sup>6-8</sup>

Adolescence is accompanied by increasing responsibilities, evolving social relationships, vocational decision-making, and the formation of values and identity.<sup>9</sup> For adolescent transplant recipients, this period also requires finding stability and a sense of 'normal' within their unique transplant experience, despite their medical complexity.<sup>9,10</sup> While survival statistics are typically perceived as appropriate endpoints for considering transplant efficacy,<sup>4,5</sup> transplantation is more than the physical exchange of a failing and functioning organ.<sup>8,11</sup> Incorporating a new organ involves an integration of 'other' and 'self' and a reconceptualization of identity and perspectives,<sup>11,12</sup> which are critical considerations for those caring for adolescent transplant recipients.

In an ethnographic study, Green et al.<sup>13</sup> described the dichotomous nature of 14 adolescent heart transplant recipients' quality of life, highlighting their post-transplant responses about receiving an organ as both "grateful and resentful" and "managing and not managing". Another qualitative study by Anderson et al.<sup>12</sup> of six adolescent lung transplant recipients revealed that a "maelstrom of emotions" were associated with their transplant experience. The possibility of death as an outcome intertwined with the expectation and realities of transplantation as a promised "new life" were inextricably tied to both identity formation and a new sense of self.<sup>12</sup>

This paper completes a trilogy of publications, which give voice to adolescent thoracic patients and their experience with end-stage heart and lung disease.<sup>11,14</sup> Published findings describe patients' perceived challenges associated with their lived experience pre-transplant<sup>14</sup> and peri-transplant.<sup>11</sup> The current paper highlights adolescent thoracic recipients' perspectives post-transplant and contributes to the overall understanding of the pediatric thoracic transplantation journey.

## Materials and methods

### Design

The current paper stems from a program of qualitative research using grounded theory methods. Grounded theory aims to construct theories that are 'grounded' in data as represented by storied narratives of participants' lived experience, perspectives, shared interactions and attributed meanings.<sup>15-18</sup> This study was approved by the Institutional Research Ethics Board at The Hospital for Sick Children. International Society for Heart and Lung Transplantation ethics statement was strictly fulfilled.

### Participant recruitment

Participants were recruited from the Heart and Lung Transplant Programs at The Hospital for Sick Children in Toronto, Canada.<sup>19</sup> All heart or lung transplant recipients between 12 and 18 years of age, who spoke English and were a minimum of three months post-

transplant were eligible. A known healthcare provider contacted all eligible patients. Interested patients were invited to contact the principal investigator (SJA) and complete informed written consent prior to study involvement. A sample of 25 to 30 participants was sought through theoretical sampling to aid saturation of findings.<sup>16</sup>

### Data collection

One-on-one, semi-structured interviews were approximately one hour in length and conducted in-person by SJA, an experienced qualitative researcher. The interview guide was informed by clinical understanding and available literature<sup>20</sup> to explore transplant recipients' lived experience. Interview questions probed participants' life pre-transplant (e.g., Can you tell me about what life was like before you had a transplant?), post-transplant (e.g., What has life been like since you had a transplant?), and conceptions of health and well-being (e.g., What do good/bad days look like for you?). Consistent with grounded theory, the interview guide was revised iteratively to pursue emergent themes simultaneous to data analysis.<sup>16</sup> Interviews were auto-recorded and transcribed verbatim; written fieldnotes were documented for analysis.

### Analysis

All interviews were analyzed by three research team members (SJA, DN, RM). Analysis involved methods of constant comparison to review text line-by-line, linking key passages to codes within categories and facilitating emergent themes through researcher agreement.<sup>21</sup> Earlier data were revisited to ensure that coding was aligned and variations explored until the relationships between categories were well-established and categories saturated.<sup>15</sup> The research culminated in a proposed theoretical understanding of the 'lived experience' of adolescent thoracic transplant recipients. Strategies to enhance qualitative trustworthiness included prolonged engagement, peer debriefing, member checking and negative case analysis.<sup>22</sup> NVivo was used for qualitative data management.<sup>23</sup>

## Results

A total of 27 heart and 5 lung recipients participated in the study of an eligible 31 heart and 6 lung transplant recipients. The sample included 21 females (66%), with a median age of 12.2 years at time of transplant and 15.9 years at time of interview. The median time post-transplant was 2.7 years. Most participants (81%) identified as White and additional participants (19%) identified as Multiracial, Black or Asian. Demographic characteristics are summarized in [Table 1](#).

Participant narratives illuminated three themes describing (1) personal growth, (2) relationship growth, and (3) introspective growth. An exploration of these themes is presented below with additional supporting quotes in [Table 2](#). No notable differences were found between heart and lung transplant recipients or between participants of varied ages at transplant or times post-transplant.

### 1. Personal growth

The post-transplant period was a time for participants to self-reflect and recognize their personal strengths relative to

**Table 1** Participant Demographics.

Characteristics	
Participants, n	
• Heart recipients	27
• Lung recipients	5
Enrolment rate, (%)	
• Heart recipients	87.1%
• Lung recipients	83.3%
Sex female, n (%)	21 (65.6%)
Age at time of transplant, years, median (range)	12.2 (0.6–17.4)
Age at time of interview, years, median (range)	15.9 (12.0–18.4)
Time post-transplant, years, median (range)	2.7 (0.3–11.1)
Underlying heart diagnosis, n (%)	
• Acquired heart disease	17 (63.0%)
• Congenital heart disease	10 (37.0%)
Underlying lung diagnosis, n (%)	
• Cystic fibrosis	2 (40.0%)
• Bronchiolitis obliterans	1 (20.0%)
• Pulmonary hypertension	1 (20.0%)
• Non-cystic fibrosis bronchiectasis	1 (20.0%)
Number of transplants received, n (%)	
• One	26 (81.3%)
• Two or more	6 (18.7%)
Race/Ethnicity	
• White (i.e., French, Italian, Russian)	26 (81%)
• Black (i.e., African Canadian, South African)	2 (6%)
• Asian (i.e., Chinese)	1 (3%)
• Multiracial	3 (10%)
Attending school, n (%)	
• Yes	32 (100.0%)
• No	0 (0.0%)

overcoming challenges throughout their transplant experience. Participants spoke of feeling physically stronger after their transplant and, of equal importance, developing emotional strength and resilience. One participant explained: “[My transplant] made me a lot more of a strong person in terms of being able to handle physical and mental pain. And knowing that what I’ve gone through. . . I just feel like I’m much stronger on the inside” (P-28, lung). Another participant emphasized how receiving their transplant nurtured their self-efficacy: “I had to deal with so much. So, I think as a person, I’m a lot stronger. . . I always try to have faith. . . in what I’m capable of doing. I keep telling myself, ‘You are strong, you can do this’” (P-12, heart). Scars - as a physical and lasting memory of the procedures associated with transplantation - were also described as a symbol of growth and strength for many participants. For example,

one participant expressed how they were no longer self-conscious of their scars because of what it represented: “I used to think [my scar] was so ugly and I want it away, I don’t want it here. But the more I think about it, it’s amazing what happened, and it’s nothing to be ashamed of. It’s something you’ve been through” (P-22, heart).

It appeared that the experience of receiving a thoracic transplant provided participants with a ‘new baseline’ that could be used as a point of reference for potentially distressing or challenging experiences. In this context, participants described how transplantation changed their lives by offering them possibilities, courage and confidence to explore new opportunities. One participant shared: “[My transplant] made me a lot braver and more willing to do lots more things than I used to do. . . I know I’ve been through a heart transplant so I’m sure I can do a lot more things than I thought I could do” (P-24, heart). Personal changes were also reflected in personality: “Prior to my transplant, I was a pretty shy kid, and I didn’t like to talk to a lot of people. . . But after transplant, I think I’ve become more of an outgoing person. I don’t mind speaking to people, and I’m not shy like I once was. Giving me that confidence to continue life” (P-28, lung), as well as changes in life goals: “Before [my transplant], I never wanted to go to college and now I’m thinking that I should. I’ve always wanted to learn how to skydive. Those are two things that I want to live, I want to live through” (P-13, heart).

## 2. Relationship growth

Changes in interpersonal relationships was a prominent theme for participants post-transplant. Many participants emphasized how their transplant journey resulted in closer relationships with family members: “We were close before, but this has made us even closer” (P-15, heart). When probed of possible reasons for this relationship growth, participants described how family members were present and supportive during their transplantation, which provided them with the strength to continue: “My parents and my family being there. Every time they were always with me at the hospital, that is what helps. . . My mom used to always tell me that I’m a strong girl” (P-17, heart).

Participants also described a greater appreciation for their family relationships post-transplant: “My family. My mom and dad. . . God gave me a second chance to see and do stuff with them” (P-20, heart). As a result, many participants described the importance and value of spending quality time with family: “Before, [my family and I] were kind of like, ‘Yeah, it’s fun to hang out,’ but now it’s really important. It’s really important. You never know what is going to happen next. You want to spend as much time with them as you can” (P-15, heart). Another participant expressed: “[My mom and I], we do a lot of stuff together. I mean, if she’s just going out like grocery shopping, I’ll come with her” (P-30, lung).

Participants’ increased appreciation and re-prioritization of relationships post-transplant also extended to close friends. Many participants spoke of how they realized what real friendship meant during their hospital stays away from

**Table 2** Themes and Supporting Quotes.

#1 Personal Growth	
Recognition of personal strengths	<ul style="list-style-type: none"> <li>• "I'm really strong. . .and courageous." — P-5 (<i>heart</i>)</li> <li>• "You always have to be strong. At first you might get discouraged and like, 'I can't do this.' You always have to feel like, 'I can do this.'" — P-19 (<i>heart</i>)</li> <li>• "If I, like, fall down, it doesn't hurt as much as it used to. If I fell before, it used to hurt and I would cry all the time." — P-27 (<i>heart</i>)</li> </ul>
Scars as a symbol of growth and strength	<ul style="list-style-type: none"> <li>• "I've worn things where you can see [my scar], but now it's like, I don't care now. I have a scar, big deal." — P-22 (<i>heart</i>)</li> <li>• "If anybody wants to see [my scars], I'll show them. . .Don't let anyone treat you different just because you look different or that you had something wrong with you." — P-21 (<i>heart</i>)</li> <li>• "I want to show people what all transplant people have been through. It's not a joke, it's nothing to laugh about. . .We have been through a lot of pain. We stepped through fire and you have no idea." — P-20 (<i>heart</i>)</li> </ul>
Courage and confidence to explore new opportunities	<ul style="list-style-type: none"> <li>• "You figure if you can go through a heart transplant, you can do a lot of things." — P-24 (<i>heart</i>)</li> <li>• "After getting my transplant, I've done a lot of speeches. . .Giving me that confidence to continue life, and just hopefully be able to talk to my peers more." — P-28 (<i>lung</i>)</li> <li>• "I was never athletic. I was never into sports. I really didn't do many things. . .Now I see it as an experience doing stuff that I didn't do before. I never thought I would go to an Olympic game in my life. . .Suddenly, I'm going to Thailand for two weeks for the Transplant Games. That is awesome." — P-15 (<i>heart</i>)</li> </ul>
#2 Relationship Growth	
Closer relationships with family members	<ul style="list-style-type: none"> <li>• "Our family has become a lot closer together. And I do, I talk to my sisters a lot more often than I used to. Because they really showed me through the transfer process that they're there for me, especially my oldest sister. . .After my transplant, she was there every day after school coming to see me. She's definitely a big part of my transplant process and we've become really close." — P-28 (<i>lung</i>)</li> <li>• "My family and friends are very supportive; they are always there for me if I need them. They are always there to talk to if I need to express some feelings." — P-12 (<i>heart</i>)</li> <li>• "The most joy in life, I think family, my family. They have been very supportive." — P-3 (<i>heart</i>)</li> </ul>
Greater appreciation for family relationships	<ul style="list-style-type: none"> <li>• "[My family and I] are lot more closer. . .We are spending more time together; it seems like a treasure. When you have been away from your home for so long, it just seems like everything is so wonderful." — P-15 (<i>heart</i>)</li> <li>• "[My transplant] kind of opened [my family's] eyes a lot more and appreciated life a lot more, not to take for granted these things." — P-12 (<i>heart</i>)</li> </ul>
Closer friendships	<ul style="list-style-type: none"> <li>• "There was a lot of support around me of course, a bunch of friends. Some friends came and visited during my three months stay. A lot of friends came. On the phone every day." — P-2 (<i>heart</i>)</li> <li>• "My friends used to visit me. My best friend, she came over on my birthday, and she was like, 'Hey, how are you?' And I said, 'It's okay, I'm feeling okay.' And she would always tell me, 'It's okay, I don't mind if you want me to leave.' I would say to her, 'Don't leave, I feel better when you're here.' She was asking me good questions and bring me stuff." — P-16 (<i>heart</i>)</li> <li>• "I think that my friends, they're not so worried about maybe losing a friend." — P-28 (<i>lung</i>)</li> </ul>

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## #3 Introspective Growth

Increased gratitude for life and living more purposively	<ul style="list-style-type: none"> <li>• “You learn to be thankful for every day. Like a new, a different life, a new life.” – P-29 (<i>lung</i>)</li> <li>• “Every day is a good day for me because I’m alive and not gone. So it’s a good day. Every day that I wake up is a good day.” – P-11 (<i>heart</i>)</li> <li>• “Some people consider dying and then having a second life, you should treasure the second life because most people would say that there is so much to live for and that is what I’m thinking now. I’m trying to live life to the fullest.” – P-13 (<i>heart</i>)</li> </ul>
Responsibility to care for the organ	<ul style="list-style-type: none"> <li>• “I promised [the donor family] I would take care of the heart and keep it strong and healthy as long as possible. And it has given my life more meaning. Someone has given me a heart and a second chance and I can’t waste it.” – P-15 (<i>heart</i>)</li> <li>• “Someone lost their life and now I have. . . I’m really thankful and I do think about them.” – P-29 (<i>lung</i>)</li> <li>• “I give [my donor] my thanks of 1000 times. And to know that I mean it. I’m here for them and I’m living, living that life. That person, their – with their death came many benefits.” – P-28 (<i>lung</i>)</li> </ul>
Meaning of transplantation	<ul style="list-style-type: none"> <li>• “[Life is] better because I know so many more people, good people. More meaning to my life now. I had meaning before, but not as big as this. Transplant. . . it’s just different, not better. It would have been so much nicer if I hadn’t been through all the stuff. But then there is another part of me that thinks if it didn’t happen, then we wouldn’t have met all the wonderful people.” – P-15 (<i>heart</i>)</li> <li>• “Something you never think will happen to you, and it does happen, and sometimes you can be glad that it did happen. I know some people see it as a second chance, and that’s how I’m seeing it right now. . . Transplant gave me a new beginning.” – P-13 (<i>heart</i>)</li> <li>• “Not worrying anymore what life can have in store for you, what life can be. . . The best thing is to grow from it and getting stronger from it.” – P-12 (<i>heart</i>)</li> </ul>

## Transformative Experience

Transformative experience	<ul style="list-style-type: none"> <li>• “I just know that when you get a heart transplant, that it does change your life.” – P-1 (<i>heart</i>)</li> <li>• “It was almost like a light came on. I’m a whole different person. . . I feel different [in a good way].” – P-4 (<i>heart</i>)</li> <li>• “You just, you can’t be the same after something like [a lung transplant].” – P-29 (<i>lung</i>)</li> </ul>
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home: “You could really tell who your friends are. And they sent mail. I mean, we, we all really got into the whole snail mail thing. It was fun to get stuff in the mail” (P-30, *lung*). Participants also highlighted how close friends remained supportive following their transplant: “[My friends] think I’m a really strong person for having gone through that” (P-2, *heart*). This also included mutual feelings of pride: “My friends. . . I think that they’re very proud of me. . . I’m proud of them for helping me. . . Because without all my friends, I don’t think I would be here. . . They’ve been such a big help to me.” (P-28, *lung*).

## 3. Introspective growth

Collectively, participants identified having a greater appreciation for life, living intentionally, and considering

the ‘bigger meaning’ of their transplant journey. One participant reflected: “You have a life story to tell” (P-13, *heart*). Having experienced life before, during and after transplantation, participants spoke of life after transplant as filled with increased gratitude for everyday experiences. One participant explained: “[Life] seems to have more meaning. . . There is more to life now. Before transplant, let’s say there is a sculpture outside near a building and I would never notice it and now I’m like ‘Oh wow, look at that.’ You see things deeply now. I see more meaning in things” (P-15, *heart*). Participants further described appreciating what was previously taken for granted: “I think that every day is really a gift and you shouldn’t really take it for granted because you don’t know if tomorrow is going to come. Being healthy or safe is less than certain. You don’t know if you’re going to be here tomorrow, so live every day like

it's your last" (P-28, lung). For many participants, this new appreciation for life was associated with choosing to live more purposefully, intentionally, and in the present, as many recognized the uncertainty of life: "Live life to the fullest while you can, right? That's what I [do]" (P-6, heart); "I don't really worry about the future. I'm sure I will once it comes" (P-24, heart).

Participants appeared to recognize the value of the organ they received and revealed how they purposively accepted the responsibility to care for it. Some participants described the organ they received as a 'gift' that should not be wasted: "I can't think of [the heart] as a burden, because it saved my life. It's a responsibility. I have been given this wonderful gift and I have to take care of it. I don't want to waste what the family gave" (P-15, heart). Others expressed a consciousness for the donor and family: "I think about [my transplant] every night. I'm thankful for what I have, so that is why every night I pray about it: thank you and please keep me healthy and eternal rest for the donor and their family" (P-6, heart).

Some participants also questioned if their transplant experience represented a larger, purposeful meaning in their life. For example, one participant believed they received their organ because they had more in life to live and achieve: "[My transplant] made me feel, depending on what religion you have, for me it was God, he wanted me to do something more important. He had more things for me to do. Someone had bigger plans for me" (P-15, heart). Another participant described their transplant experience as fate: "Sometimes, I think, 'Oh my God, I've got someone else's heart who died.' Sometimes I think... sometimes it's fate. Maybe they died because they knew someone else needed a heart" (P-19, heart). Overall, participants interpreted receiving their organ as a "new beginning" (P-13, heart), "a new start" (P-27, heart) and "a second chance" (P-1, P-7, P-13, P-15, P-20, heart) at life.

## Discussion

Adolescent thoracic transplant recipients expressed how the experience of transplantation, in addition to improved physical health, fostered positive growth stemming from adversity and challenge. Participants in the current study cited changes related to personal, relationship and introspective growth that were expressed as positive outcomes within adolescents' development post-transplant. In this manner, the experience of pediatric thoracic transplantation was described as potentially transformative.

These findings appear consistent with literature in the area of post-traumatic growth,<sup>24,25</sup> a relatively unexplored phenomenon in the field of transplantation.<sup>26,27</sup> Post-traumatic growth is a theory that explains transformation following trauma, and holds that people who endure adversity, including life-threatening illnesses, can experience positive growth afterward.<sup>24,25,28,29</sup> Application of this theory suggests that traumatic events and circumstances can destabilize understandings about oneself and challenge the expected course of one's life. In turn, the attempt to cope and adapt within new life trajectories is initiated and some

individuals reestablish an understanding of the self within new perspectives that accommodate the trauma and changes in self-identity.<sup>24,25</sup> Post-traumatic growth theory posits that as new understandings evolve, individuals may recognize positive changes and transformation in both their functioning and well-being that exceed pre-trauma levels.<sup>30</sup>

Considering post-traumatic growth theory, the current finding that adolescents experience an emergent 'transplanted self' positions thoracic transplantation as a potential catalyst for positive growth and personal change. These findings build upon our previous research that highlight the perceived challenges associated with waiting for a transplant and immediately following transplantation,<sup>11,14</sup> suggesting distinct experiences across the timepoints for adolescent thoracic patients. Our published findings describe patients' pre-transplant life as "a struggle to survive" capturing elements of both physical limitations and social isolation,<sup>14</sup> and their peri-transplant existence as an adjustment to the presence of an organ from an unknown and deceased organ donor, with accompanying feelings of guilt and gratitude.<sup>11</sup>

In the current paper, which focuses on adolescents' lived experience post-transplant, all participants described positive growth namely *because* they had "went through so much and... had to deal with so much" (P-12, heart). This suggests that post-traumatic growth in transplantation may be an outcome that emerges over time, and one that builds upon the struggles and adaptations of the pre- and peri-transplant periods. Our findings are consistent with research that suggests a link between post-traumatic stress symptoms and post-traumatic growth, in that distress might help to initiate and maintain the process of growth.<sup>31,32</sup> Further, our findings invite a shift in thinking about strengths-based approaches and positive outcomes in clinical care, which contrasts the current focus on the negative physical and psychosocial sequelae of transplantation.<sup>1,2,6,7,10</sup>

There is reason, however, to consider why adolescent thoracic participants did not express challenges in the post-transplant phase of their journey, similar to descriptions in the pre- and peri-transplant phases.<sup>11,14</sup> It is possible that presenting with positivity and selectively choosing not to describe more difficult experiences was purposeful for reflecting a positive representation of self, particularly since participants were in the post-transplant phase when interviewed. Additional research exploring the possibility of enduring negative emotions post-transplant is warranted.

## Implications for clinical practice

There is a need to locate pediatric clinical and research practice for thoracic transplantation within a continuum of transformational growth.<sup>33-35</sup> Our findings suggest that practitioners and researchers need to acknowledge the possibility of growth, transformation, and positive change that may be inherent within the challenges surrounding adolescent thoracic transplantation and to leverage such strengths in clinical care. Incorporating routine assessment tools such as the Post-Traumatic Growth Inventory<sup>30</sup> could assist



practitioners to identify and assess positive outcomes of thoracic transplantation (e.g., recognition of personal strengths) and to foster facilitators that contribute to post-traumatic growth.<sup>35</sup>

Clinical assessment data that reflect elements of post-traumatic growth should be identified and contextually considered within a patient's experience of health and well-being post-transplant.<sup>36</sup> Adolescence may be the opportune time to intervene and implement strength-based, skill-building interventions to nurture post-traumatic growth before the transition to adult care settings.<sup>10,37</sup> Strength-based interventions, such as peer mentorship programs, may be implemented to provide support for adolescent transplant recipients to facilitate the development of age-appropriate competencies, self-management skills, empowerment and adjustment.<sup>38</sup> Additionally, therapy addressing existential or introspective topics may help adolescent thoracic recipients explore growth opportunities through positive reframing and meaning-making.<sup>39</sup> Adolescents experiencing long-term difficulties with transplant adjustment may benefit from trauma-informed care to challenge maladaptive thought patterns while focusing on emotional support and effective coping.<sup>40</sup>

### Study limitations

This study was conducted at a large pediatric tertiary care hospital and findings may not reflect patient experiences at other centres. Only English-speaking participants were recruited; thus, the experiences of non-English speaking thoracic transplant recipients were not captured. A larger recruitment of adolescent participants from multiple sites and a purposeful recruitment for specific subsamples of this patient population may allow for a comparative analysis that was not possible within the current study.

### Conclusion

The study findings show that adolescent thoracic transplant recipients may experience a meaningful and growth-enhancing transformation that reflects post-traumatic growth. Future qualitative studies could explore factors contributing to potential variations in post-traumatic growth experiences, such as gender, age at transplant, and demographic diversities. Additional research may yield valuable information for practitioners, serving to guide and inform aspects of assessments, interventions, and management in the adolescent transplant population.

### Authors' contributions

All authors contributed to the conception and design of the research and secured research funding. SJA performed data collection and all authors participated in data analysis and interpretation. SJA drafted the manuscript and all authors provided critical review and revision. All authors approve the final version of the manuscript submitted for publication.

### Disclosure statement

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### References

1. Suddaby EG. The state of pediatric heart transplantation. *AACN Adv Crit Care* 1999;10:202-16.
2. Benden C. Pediatric lung transplantation. *J Thorac Dis* 2017;9:2675.
3. Gruber S, Eiwegger T, Nachbaur E, et al. Lung transplantation in children and young adults: a 20-year single-centre experience. *Eur Respir J* 2012;40:462-9.
4. Hayes D, Harhay MO, Cherikh WS, et al. The International thoracic organ transplant registry of the International society for heart and lung transplantation: twenty-third pediatric lung transplantation report—2020; focus on deceased donor characteristics. *Journal Heart Lung* 2020;39:1038-49.
5. Singh TP, Hsieh E, Cherikh WS, et al. The International thoracic organ transplant registry of the international society for heart and lung transplantation: 23rd pediatric heart transplantation report—2020; focus on deceased donor characteristics. *J Heart Lung* 2020;39:1028-37.
6. Uzark K, Griffin L, Rodríguez R, et al. Quality of life in pediatric heart transplant recipients: a comparison with children with and without heart disease. *J Heart Lung* 2012;31:571-8.
7. ousino MK, Schumacher KR, Rea KE, et al. Psychosocial functioning in pediatric heart transplant recipients and their families. *Pediatr Transplant* 2018;22:e13110.
8. Lazor T, Grasemann H, Solomon M, Anthony SJ. Quality of life outcomes following pediatric lung transplantation. *Pediatr Pulmonol* 2017;52:1495-501.
9. Kaufman M, Shemesh E, Benton T. The adolescent transplant recipient. *Pediatric Clinics* 2010;57:575-92.
10. Putschoegl A, Dipchand AI, Ross H, Chaparro C, Johnson JN. Transitioning from pediatric to adult care after thoracic transplantation. *J Heart Lung* 2017;36:823-9.
11. Anthony SJ, Nicholas DB, Regehr C, West LJ. The heart as a transplanted organ: unspoken struggles of personal identity among adolescent recipients. *Can J Cardiol* 2019;35:96-9.
12. Anderson S, Wray J, Ralph A, Spencer H, Lunnon-Wood T, Gannon K. Experiences of adolescent lung transplant recipients: a qualitative study. *Pediatr Transplant* 2017;21:e12878.
13. Green A, Meaux J, Huett A, Ainley K. It has its ups and downs": adolescents' quality of life after heart transplantation. *Prog Transplant* 2011;21:115-20.
14. Anthony SJ, Nicholas DB, Regehr C, West LJ. A struggle to survive: the experience of awaiting pediatric heart transplantation. *Pediatr Transplant* 2014;18:868-74.
15. Creswell JW. *Qualitative Inquiry And Research Design: Choosing Among Five Traditions*. London: Sage Publications; 1998.
16. Strauss A, Corbin J. *Basics of Qualitative Research: Grounded Theory Procedures Techniques*. Thousand Oaks, CA: Sage Publications; 1998.
17. Charmaz K. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Sage Publications; 2006.
18. Charmaz K. Discovering chronic illness: using grounded theory. *Soc Sci Med* 1990;30:1161-72.

19. The Hospital for Sick Children (SickKids). About SickKids. 2021; <https://www.sickkids.ca/en/about/about-sickkids/>. Accessed January 29, 2022.
20. Kvale S. *InterViews: An Introduction to Qualitative Research Interviewing*: Steinar Kvale. Thousand Oaks, CA: Sage Publications; 1996.
21. Strauss A, Corbin J. *Basics of Qualitative Research*. Thousand Oaks, CA: Sage Publications; 1990.
22. Padgett DK. *Strategies for Rigor. Qualitative Methods in Social Work Research*. 2nd ed Thousand Oaks, CA: Sage Publications Inc; 2008:179-98.
23. Richards L. *Using NVivo in Qualitative Research*. Thousand Oaks, CA: Sage Publications; 1999.
24. Janoff-Bulman R. Posttraumatic growth: three explanatory models. *Psychol Inq* 2004;15:30-4.
25. Tedeschi RG, Shakespeare-Finch J, Taku K, Calhoun LG. *Posttraumatic Growth: Theory, Research, and Applications*. New York: Routledge; 2018.
26. Gangeri L, Scrignaro M, Bianchi E, Borreani C, Bhoorie S, Mazzaferro V. A longitudinal investigation of posttraumatic growth and quality of life in liver transplant recipients. *Prog Transplant* 2018;28:236-43.
27. Battaglia Y, Zerbinati L, Belvederi Murri M, et al. Exploring the level of post traumatic growth in kidney transplant recipients via network analysis. *J Clin Med* 2021;10:4747.
28. Kelly G, Morris R, Shetty H. Predictors of post-traumatic growth in stroke survivors. *Disabil Rehabil* 2018;40:2916-24.
29. Greup SR, Kaal SE, Jansen R, et al. Post-traumatic growth and resilience in adolescent and young adult cancer patients: an overview. *J Adolesc Young Adult Oncol* 2018;7:1-14.
30. Tedeschi RG, Calhoun LG. The posttraumatic growth inventory: measuring the positive legacy of trauma. *J Trauma Stress* 1996;9:455-71.
31. Kilmer RP, Gil-Rivas V, Tedeschi RG, et al. Use of the revised post-traumatic growth inventory for children. *J Trauma Stress* 2009;22:248-53.
32. Tedeschi RG, Calhoun LG, Cann A. Evaluating resource gain: understanding and misunderstanding posttraumatic growth. *Appl Psychol* 2007;56:396-406.
33. Cowen EL. The enhancement of psychological wellness: challenges and opportunities. *Am J Community Psychol* 1994;22:149-79.
34. Csikszentmihalyi M, Seligman M. Positive psychology. *Am Psychol* 2000;55:5-14.
35. Tedeschi RG, Kilmer RP. Assessing strengths, resilience, and growth to guide clinical interventions. *Prof Psychol Res Pr* 2005;36:230.
36. Lenz AS, Ho C-M, Rocha L, Aras Y. Reliability generalization of scores on the Post-Traumatic Growth Inventory. *Meas Eval Couns Dev* 2021;54:106-19.
37. Anthony SJ, Kaufman M, Drabble A, Seifert-Hansen M, Dipchand AI, Martin K. Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *Am J Transplant* 2009;9:614-9.
38. Anthony SJ, Young K, Ghent E, et al. Exploring the potential for online peer support mentorship: perspectives of pediatric solid organ transplant patients. *Pediatr Transplant* 2021;25:e13900.
39. Yaskowich KM. Posttraumatic growth in children and adolescents with cancer. *Diss Abstr Int: Section B: The Sciences and Engineering* 2003;63.
40. Picoraro JA, Womer JW, Kazak AE, Feudtner C. Posttraumatic growth in parents and pediatric patients. *J Palliat Med* 2014;17:209-18.