



## Training/Practice Contemporary Issues in Cardiology Practice

# The Heart as a Transplanted Organ: Unspoken Struggles of Personal Identity Among Adolescent Recipients

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### ABSTRACT

In adult heart transplant recipients, a transformation of the self has been observed simultaneous to the “emotional integration” of the heart following transplantation. However, the experiences of adolescents following heart transplantation are virtually unexplored within the current literature. Our qualitative findings address this gap and explore struggles with personal identity in adolescent heart transplant recipients. Twenty-seven heart transplant patients (67% female, age range: 12 to 18 years) from a large teaching hospital participated in 1-on-1 interviews, which were transcribed verbatim and coded, using methods of constant comparison within a grounded- theory approach. Emergent themes were identified and refined through team consensus. Many participants identified emotional and psychological concerns regarding accepting foreign hearts as their own. This manifested in a range of experiences such as sadness or guilt

### RÉSUMÉ

Chez les receveurs adultes de transplantation de cœur, nous avons simultanément observé une transformation de soi et l’« acceptation émotionnelle » du cœur après la greffe. Toutefois, les expériences des adolescents à la suite de la transplantation du cœur demeurent pratiquement inexplorées dans la littérature actuelle. Nos résultats qualitatifs permettent de combler cette lacune et d’examiner les luttes identitaires personnelles des receveurs adolescents de transplantation du cœur. Vingt-sept patients ayant subi une transplantation du cœur (67 % de filles, tranche d’âge : de 12 à 18 ans) dans un grand hôpital d’enseignement ont participé à des entrevues individuelles qui ont été transcrites textuellement et codées à l’aide de méthodes de comparaison constante dans le cadre d’une approche de théorisation ancrée. Les thèmes émergents ont été relevés et affinés par consensus au sein de l’équipe. Plusieurs participants ont relevé les

Research with adult populations has examined disturbances to self-identity that result following heart transplantation.<sup>1,2</sup> Despite knowledge that heart transplantation is a life-saving therapy for adolescents, little research has focused on the psychological impact of the transplant process on this population or has described subjective experiences of young heart transplant recipients. In an ethnographic study, Green et al. described the dichotomous nature of adolescents’ quality of life following heart transplantation, with post-transplant emotions about the experience of receiving a donor organ as alternating between grateful and resentful.<sup>3</sup>

This paper will present a focused discussion of findings related to self-identity and quality of life as adolescent heart transplant recipients “grapple to incorporate a new heart.” It is a conversation that is rarely explored and highlights recent qualitative research that addresses the experience of adolescent heart transplant recipients. Clinical recommendations will be presented.

### Material and Methods

The original qualitative research study was reviewed and approved by the Institutional Research Ethics Board at The Hospital for Sick Children, Toronto, Ontario, Canada. Informed written consent was obtained from all study participants.

Participants were recruited from the Heart Transplant Program at the Hospital for Sick Children. Criteria for eligibility included heart transplant recipients between the

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regarding the death of the donor. Adolescent participants also pondered the potential acquisition of personal qualities or characteristics of the donor. Many participants speculated extensively about the donor and “longed for” donor information. Findings point to the meaning-making processes that adolescent heart transplant patients endure as they grapple with the presence of a foreign, life-giving organ within their bodies and the potential impact on their psychosocial well-being. This paper encourages health care professionals to initiate discussions before and following transplantation that address adolescents’ concept of self and offers recommendations for clinical care.

ages of 12 and 17 years who were a minimum of 3 months’ post-transplant. Two patients were excluded because of developmental and/or cognitive delay as evaluated by the most responsible health provider or designate.

A health care professional in the Heart Transplant Program, who was known to patients, contacted prospective participants with a letter that described the study’s purpose and identified potential risks and benefits. Interested patients were asked to contact the principal investigator.

### Data collection and analysis

Qualitative methods enable participants to disclose about a specific experience from their own perspectives. Such methods provide valuable contributions to cardiovascular-disease outcomes research. The grounded-theory study described in this paper incorporated in-depth, semi-structured, face-to-face interviews with adolescent heart transplant recipients. Interviews were approximately 1 hour in length to ensure prolonged engagement of participant perspectives and they were conducted by a member of the research team (S.A.) with expertise in qualitative methodology. The interviews were audiotaped, transcribed, and entered into NVivo software (QSR International, Melbourne, Australia); field notes were made during all interviews. Relevant patient data, including sociodemographic and clinical characteristics, were collected from the Heart Transplant computer database to highlight illness trajectories and participant treatments.

As per grounded-theory methodology, data collection and analysis occurred simultaneously to support constant comparative analysis. When new patterns or themes emerged, earlier data were revisited to reassess developing themes and to understand the variation of patterns across the dataset. Three team researchers independently reviewed and coded the transcribed interviews to ensure inter-rater reliability. Team-process meetings were used to determine emerging patterns, themes, and theoretical constructs. A detailed audit trail was maintained to further ensure qualitative rigour. Our team has recently published a manuscript describing 1 thematic component of the full grounded-theory analysis;<sup>4</sup> the complete study manuscript is being prepared.

préoccupations émotionnelles et psychologiques concernant l’acceptation du cœur d’un inconnu comme leur propre cœur. Ces préoccupations se sont manifestées par un éventail d’expériences telles que la tristesse ou le sentiment de culpabilité en lien avec la mort du donneur. Les participants adolescents ont également considéré l’acquisition potentielle des qualités ou des caractéristiques personnelles du donneur. Plusieurs participants se sont posé de nombreuses questions au sujet du donneur et « ont brûlé d’envie » d’obtenir des renseignements sur le donneur. Les résultats montrent les processus de construction de sens que les receveurs adolescents de transplantation du cœur supportent puisqu’ils sont aux prises avec la présence dans leurs corps d’un organe vital provenant d’un inconnu et avec les répercussions potentielles sur leur bien-être psychosocial. Le présent article amène les professionnels des soins de santé à entamer avant et après la transplantation des discussions sur le concept de soi des adolescents et fournit des recommandations de soins cliniques.

### Results

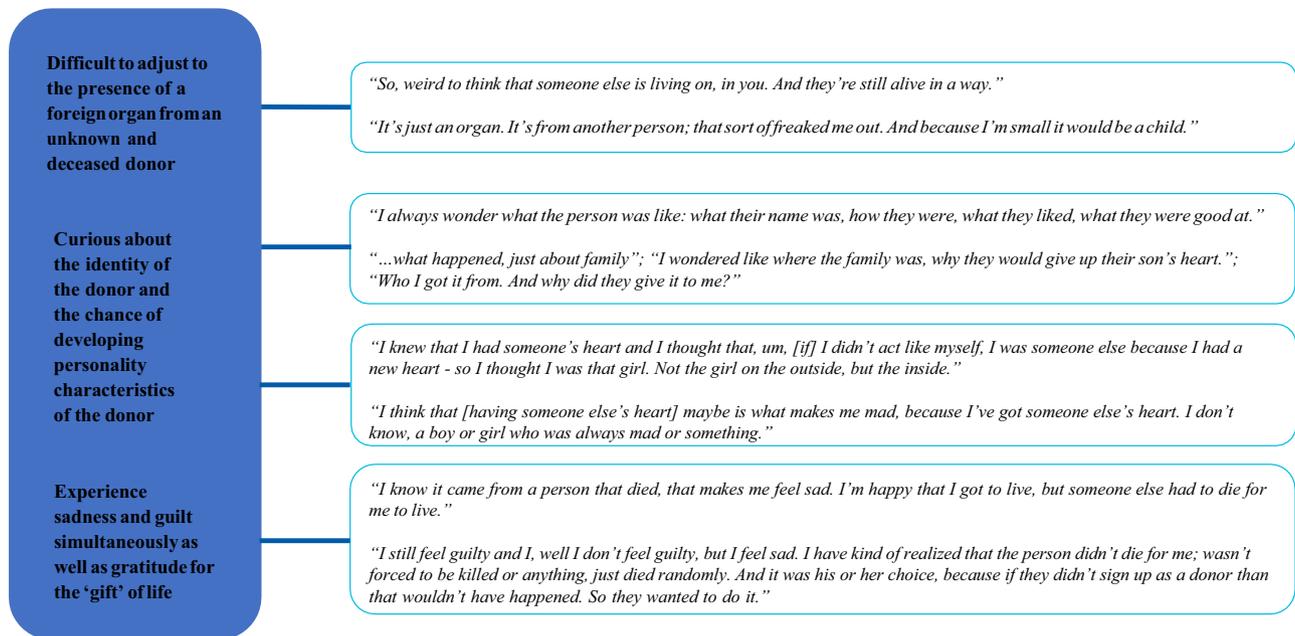
Of the 31 heart transplant recipients who were eligible, 27 participated in the study, and 4 declined involvement. The study population included 18 female participants (67% of sample), with a median age of 15.5 years (range of 12.2 to 18.4 years), and a median time post-transplant of 3.2 years (range 0.3 to 11.1 years); 17 participants had underlying diagnoses of acquired heart disease, and 10 participants had congenital heart disease. Most participants had undergone 1 heart transplant ( $n = 21$ ), and a small proportion had undergone 2 or more heart transplants ( $n = 6$ ).

### Findings

The described experiences related to identity and quality of life are representative of a diverse participant group and are equally representative across age and sex. Text quotes are provided; however, quotes are not attributed to a particular child by an identifier to avoid confidentiality concerns, as the sample was small and almost complete from the designated recruitment site.

Emergent themes depicted adolescent heart transplant recipients as profoundly affected by their transplantation experience (Figure 1). The process of incorporating a new organ into adolescents’ identity and sense of self was clearly consuming. As 1 participant described, the heart was not viewed as their own but was conceptualized as “someone else’s.” For most participants, their interview represented the first time that they expressed and disclosed their feelings related to the emotional and psychological difficulty of accepting a donor’s heart. The recipients’ process of learning to adjust to receiving donor hearts, from both a psychological and emotional perspective, was described as difficult for the following reasons: struggling to adjust to the presence of a foreign organ from an unknown and deceased donor; being curious about the identity of the donor and the chance of developing personality characteristics of the donor; and feeling sadness and guilt simultaneously as well as gratitude for the “gift” of life.

At the time of interview, most participants noted that they felt adjusted to the idea of incorporating a new organ into their identity; however, a few recipients noted that they



**Figure 1.** Findings related to self-identity and quality of life as adolescent heart transplant recipients “grapple to incorporate a new heart.”

still struggled with the idea, even following a significant time post-transplant. One participant affirmed: “You never forget.”

## Discussion

The adolescent participants in this study described how the transplantation process is more than the exchange of a faulty heart for a more competent one; it requires an integration of “other” and “self” and a reconceptualization of self. Yet, participants described how they struggled with reconceptualizing “self” and “other” when ascribing meaning to the donated heart. This struggle was manifested in feelings of sadness or guilt regarding the death of the donor and included thoughts or questions about potentially acquiring characteristics of the donor via their donor’s heart. Almost all participants in this sample voiced appreciation to the donor, with many speculating extensively about the donor’s identity and longing for donor information. Identification of tension in accepting the donor organ as “self” is novel within a adolescent population and provides new insights within this patient group.

Most participants in the current study acknowledged that they were reluctant to reveal their feelings about the process of adjusting to a new heart; they felt that there was a lack of discourse in which to locate their experiences. In 2008, Shildrick identified that health care professionals sometimes “tacitly discouraged [transplant recipients] from exploring the difficult questions regarding bodily integrity and self-identity, a silencing that implies that such concerns are not an issue.”<sup>2</sup> Yet, the current findings support that it is essential for health care professionals to acknowledge the disturbances to embodiment and personal identity that accompany heart transplantation.<sup>1,2</sup> Health care practitioners who understand the complex issues for heart transplant recipients can help to prepare adolescent patients for this transformative experience.

From a clinical perspective, a multifaceted and sustained approach is needed to equip adolescent transplant recipients with the skills they might require to assimilate a new heart. Nearly all pediatric heart transplantation programs include a pre-transplant psychosocial assessment conducted by a mental health practitioner (eg, social worker, psychologist, psychiatrist). This assessment presents an opportunity to introduce potential psychosocial concerns, acknowledge struggles faced by adolescent transplant recipients, and invite further discussions post-transplant. Systematic support and intervention is needed throughout the entire transplant process, with ongoing assessment of recipients’ psychosocial well-being as part of routine clinical care.

## Future directions

This research focused exclusively on perceptions of adolescent heart transplant recipients from a single institution in Canada. Even though the host institution is the largest pediatric transplant centre in Canada, with a diverse patient population, it is possible that the findings are not representative of adolescent heart transplant recipients internationally. A larger, geographically diverse study might allow for thematic analysis within and among subgroups of the participant population. Further, replicating this research with a younger cohort of heart transplant recipients could determine whether similar findings are present earlier in the developmental spectrum.

Although several participants expressed feeling “adjusted” at the time of the interview, the intricacies of understanding “what helped” during adolescent stages of psychological adjustment to transplant merits further exploration. A recent systematic review on interventions to improve adolescents’ psychological adaptation to chronic illness concluded that more research is needed to assess the effectiveness of peer support groups in this vulnerable age group.<sup>5</sup> A peer support mentorship program during adolescence may be a developmentally

timely and critical strategy to deliver self-management and social support to adolescent heart transplant patients.

Given the relative lack of research about psychosocial implications following pediatric heart transplantation, there is a need to create and contribute to a discourse that illuminates the experiences of these recipients. The current research has initiated a discussion on 1 intimate topic. The findings presented describe the experience of self-identity and quality of life as adolescent heart transplant recipients “grapple to incorporate a new heart.” It is a focused conversation that is rarely explored in current adolescent heart transplant literature, and—owing to the psychosocial challenges identified—health care professionals are encouraged to join the discussion. Increasing support targeted to the concerns of adolescent heart transplant recipients offers the potential to influence patient outcomes and improve well-being in this population.

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### **References**

1. Mauthner OE, De Luca E, Poole JM, et al. Heart transplants: identity disruption, bodily integrity and interconnectedness. *Health* 2015;19:578-94.
2. Shildrick M. Contesting normative embodiment: some reflections on the psycho-social significance of heart transplant surgery. *Perspectives* 2008;1:12-22.
3. 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.
4. Anthony SJ, Nicholas DN, Regehr C, West LJ. The experience of awaiting pediatric heart transplantation: a struggle to survive. *Pediatr Transplant* 2014;18:868-74.
5. Ahola Kohut S, Stinson JN, Giosa L, Luca S, van Wyk M. Systematic review of peer support interventions for adolescents with chronic illness: a narrative analysis. *Int J Child Adolesc Health* 2014;7:183-97.