

Exploring the ethical considerations of direct contact in pediatric organ transplantation: A qualitative study

Jordan Joseph Wadden^{1,2}, Jordan Hermiston³, Alice Virani^{4,5}, Tom D. Blydt-Hansen^{6,7},
Ranjeet Dhaliwal⁸, Shelby Gielen⁸

¹Ethics Department, Ontario Shores Centre for Mental Health Sciences

²Department of Philosophy, University of British Columbia

³Family Services, BC Transplant

⁴Ethics Services, Provincial Health Services Authority

⁵Department of Medical Genetics, University of British Columbia

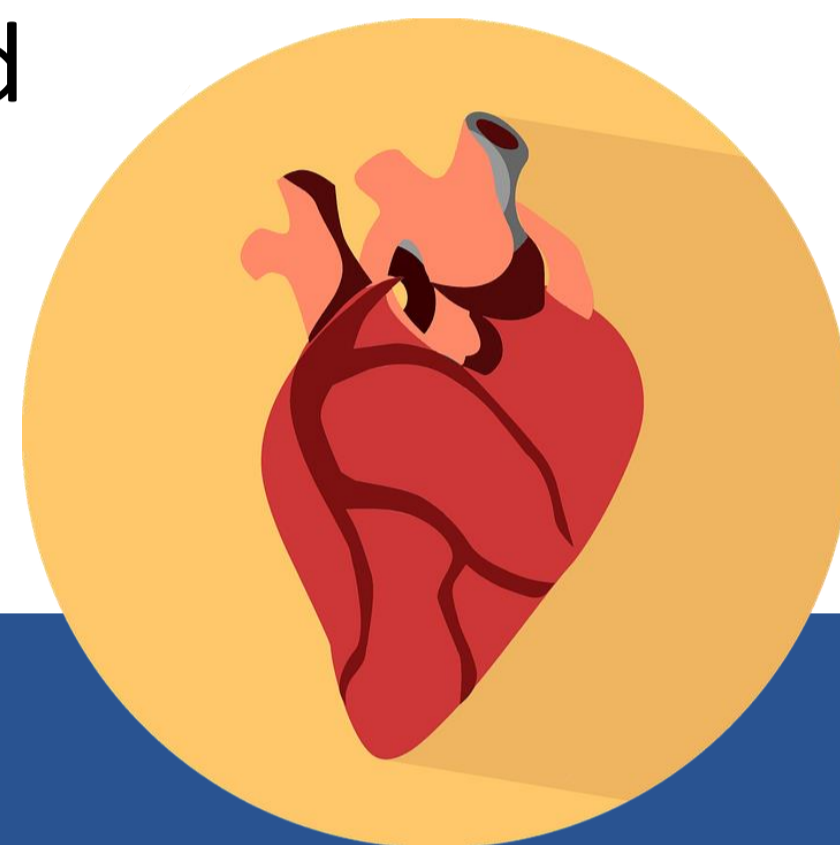
⁶Department of Pediatrics (Nephrology), University of British Columbia

⁷Multi-Organ Transplant Program, BC Children's Hospital

⁸Patient and Family Partner, BC Transplant

A Background for Direct Contact

- Non-anonymous direct contact began for adults in British Columbia in November 2019.
- This emerged from community self-advocacy.
- Whether children and adolescents should have the same opportunity is not discussed in the literature.
- Donor families can feel an unrecognized bond¹, while recipients often feel conflicting guilt and gratitude².

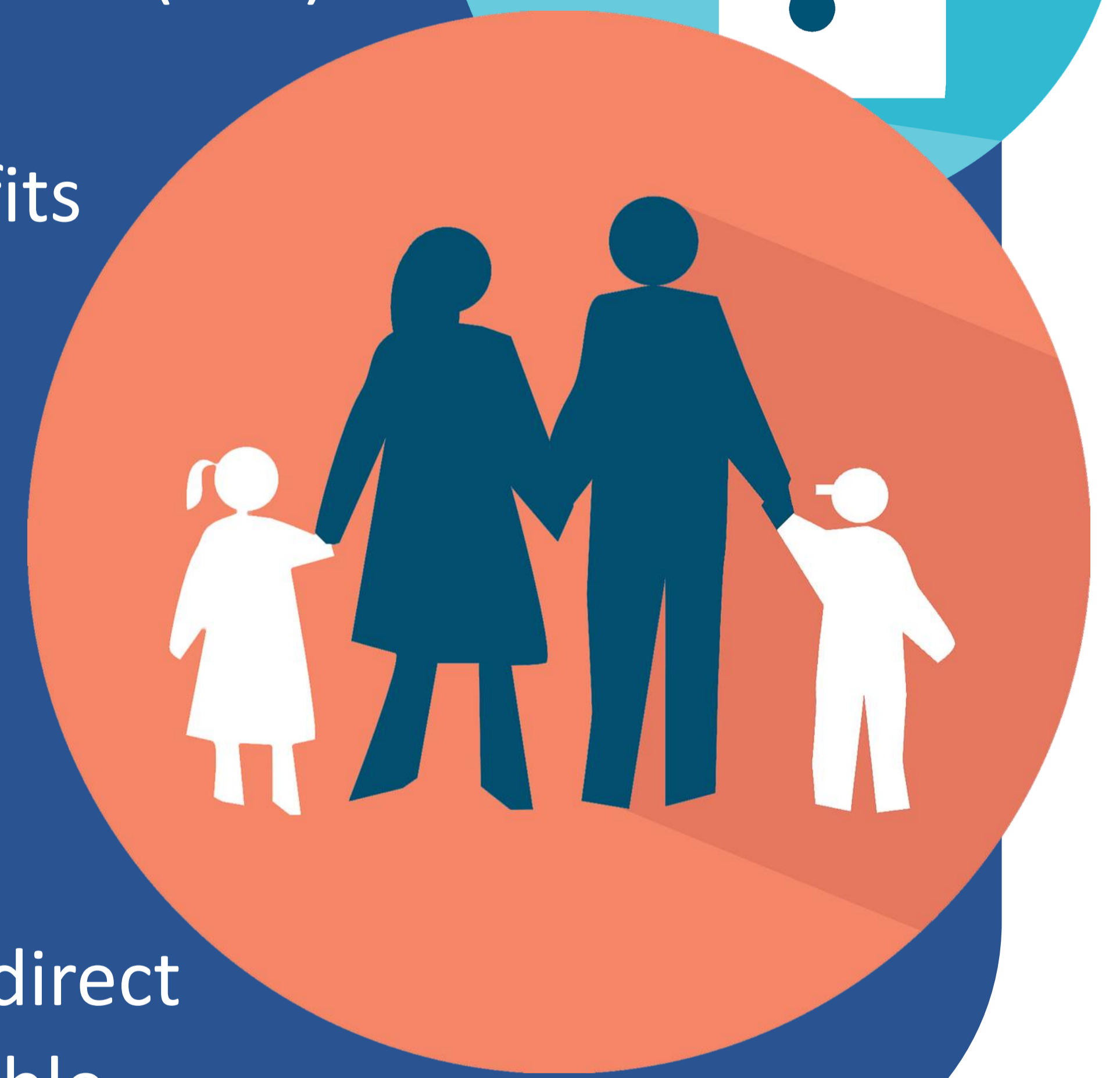


Our Research Questions

- Should children and adolescents have access to direct contact programs?
- Can we identify the harms and benefits of allowing (or not allowing) direct contact?
- Is it appropriate to have parents act as substitute decision-makers for direct contact?
- What supports do direct contact families require?

Main Results

- Two thirds of participants expressed wonder about their donor or the recipient. Eleven recipients had already found and met their donor (n=5) or learned significant personal information (n=6).
- Most participants believed there were significantly more benefits to direct contact than harms. Participants were also focused more on possible benefits and harms to the other family.
- The biggest discrepancy came from the responses about what age a child could consent for themselves. Parents and donors said 14-16 years of age, while current and adult recipients said 9-12 years of age.
- Almost all participants indicated families should be told about direct contact immediately and that supports should be readily available.



Methods

- Semi-structured, naïve, and collaborative interviews ranging 27-83 minutes in Spring and Summer 2021.
- Used both deductive and inductive coding. Interview questions gave our deductive codes and inductive codes emerged naturally from the transcripts.
- We had 29 participants: 13 graduated recipients, 11 current pediatric recipients, and 5 donor families.
- We included three organ groups: kidney, heart, liver.

Main Conclusions

- Pediatric direct contact programs should be offered as they appear to promote more benefits than harms to recipients, their families, and donor families alike.

Abridged References:

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2. Kaba, E., Thompson, D.R., Burnard, P., Edwards, D., and Theodosopoulou, E. (2005). Somebody else's heart inside me: A descriptive study of psychological problems after a heart transplantation. *Issues in Mental Health Nursing* 26(6): 611-625. doi: 10.1080/01612840590959452.

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