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

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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.

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, naive, 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.

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 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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