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The Lived Experience of "Being Evaluated" for Organ Donation

Focus Groups with Living Kidney Donors

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Abstract

Background and objectives Comprehensive evaluations are required to safeguard voluntarism and minimize harm to living kidney donors. This process is lengthy, invasive, and emotionally challenging, with up to one fifth of potential donors opting out. We aimed to describe donors' experiences of the evaluation process.

Design, setting, participants, & measurements We conducted 14 focus groups involving 123 kidney donors who completed donation from three transplant centers (Australia and Canada). Transcripts were analyzed thematically.

Results We identified six themes reflecting donors' experiences of evaluation. The themes that related to perseverance included emotional investment (prioritizing the recipient's health, desperation for a normal life, protecting eligibility, shame of disappointing others, and overcoming opposition), undeterred by low risks (medical confidence and protection, worthwhile gamble, inherent invincibility, and normalizing risks), and mental preparation (avoiding regret, resolving decisional ambivalence, and managing expectations of recovery). The challenges included underlying fears for health (processing alarming information, unsettling uncertainty, and preoperative panic), system shortfalls (self-advocacy in driving the process, stressful urgency, inconsistent framing of safety, unnerving bodily scrutiny, questioning risk information, and draining finances); and lifestyle interference (living in limbo, onerous lifestyle disruption, and valuing flexibility).

Conclusions Previous donors described an emotional investment in donating and determination to protect their eligibility, despite having concerns for their health, financial and lifestyle disruption, and opposition from their family or community. Our findings suggest the need to prepare donors for surgery and recovery, minimize anxiety and lifestyle burdens, ensure that donors feel comfortable expressing their fears and concerns, reduce unnecessary delays, and make explicit the responsibilities of donors in their assessment process.

kidney donation | evaluation | assessment | focus groups | qualitative research | Panic | Shame | Uncertainty | Focus Groups | Investments | Emotions | Living Donors | Risk | Fear | Tissue and Organ Procurement | Anxiety | Life Style | Australia | Canada

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