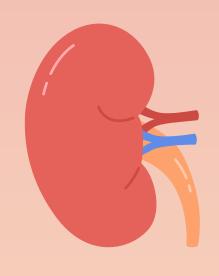
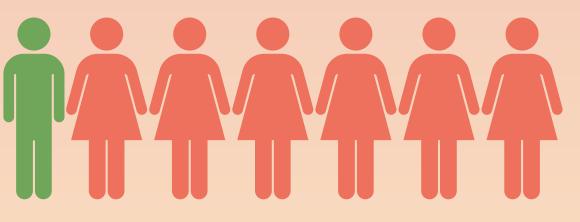
PARENTS' OF CHINESE CANADIAN PEDIATRIC PATIENTS WITH CHRONIC KIDNEY DISEASE: PERSPECTIVES ABOUT LIVING DONOR KIDNEY TRANSPLANTATION



Living donor kidney transplantation (LDKT) offers better health outcomes compared to deceased donor kidney transplantation (DDKT). Making decisions about transplantation can become complex when families' culturally-specific values and beliefs intermix with their experience in the Canadian healthcare system.





PARENTS DESCRIBED THE COMPLEXITIES OF:

SHARING ABOUT ILLNESS



Parents honoured cultural values of avoiding burden to others and sharing about poor health.

"... how can I tell my 83 years old parents that [my child] had a transplant? They wouldn't sleep... I don't want their worry."

ASKING FOR A LIVING DONOR



Parents weigh asking for a LDKT with the burden imposed on a donor and their family.

"If I have a relative here, and he [is] willing to do that [LDKT]... I would also take this... as a huge debt on myself."

MAKING A FAMILY DECISION



Parents prioritize the family unit in deciding between DDKT and LDKT.

"... it was a risk that we felt we couldn't take because of the extreme impact that [it] would have if either me or my wife were unable to work and had our own medical conditions to deal with."

"... sharing your health status... removes a bit of pride from the family... in my culture, there are situations where people don't like to propagate any negative attributes of their [family]."

"... each type of surgery, there's risks involved... I might potentially put them at risk... and their family will not be happy. So that's why... [this] is very hard for us to ask."

"... if I gave him one [LDKT] now... how do I know he's not going to be in a position to... get one as readily available later?"



Parents shared insight into why families may pursue DDKT for their child emphasizing respect for cultural values and all family members.

Parents may feel isolated within their communities. Enhanced support is needed for families within the Chinese Canadian community when making decisions about pediatric transplantation.





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