




# “Weighing the Pros and Cons of Everything”: A Qualitative Descriptive Study Exploring Perspectives About Living Donor Kidney Transplantation From Parents of Chinese Canadian Pediatric Patients With Chronic Kidney Disease

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Sarah J. Pol<sup>1</sup>, Enid K. Selkirk<sup>1</sup>, Alameen Damer<sup>1</sup>, Istvan Mucsi<sup>2,3</sup>, Susan Abbey<sup>2,4,5</sup>, Beth Edwards<sup>2</sup>, Kenneth Fung<sup>6</sup>, Jagbir Gill<sup>7,8</sup>, Paula Neves<sup>2</sup>, Suk Yin Ng<sup>2</sup>, Rulan S. Parekh<sup>1,9,10</sup>, Linda Wright<sup>11</sup>, Minglin Wu<sup>2</sup>, and Samantha J. Anthony<sup>1,12</sup> 

## Abstract

**Background:** As of 2021, more than 6000 children and youth in Canada were living with end-stage kidney disease (ESKD), for which kidney transplantation is considered the preferred treatment by health professionals. Research shows that living donor kidney transplantation (LDKT) has superior allograft and recipient survival compared to deceased donor kidney transplantation (DDKT). However, in a pediatric setting, the choice of LDKT or DDKT is a summative consideration of factors weighed carefully by the patient’s family, health care team, and patient. Decision-making surrounding transplantation may be more complex for racial and ethnic minorities as culturally specific values and beliefs are interwoven within dominant understandings and concepts of health and accepted models of health care. For example, Chinese Canadians have an increased risk of ESKD, yet reduced access to LDKT compared to White patients, despite being the largest visible minority population in Canada.

**Objective:** The objective of this qualitative study is to deepen our understandings of the decision-making process surrounding DDKT versus LDKT among parents of Chinese Canadian pediatric patients with chronic kidney disease (CKD).

**Design:** Qualitative descriptive study design.

**Setting:** The Nephrology Program at The Hospital for Sick Children in Toronto, Canada.

<sup>1</sup>Child Health Evaluative Sciences, Peter Gilgan Centre for Research and Learning, The Hospital for Sick Children, Toronto, ON, Canada

<sup>2</sup>Ajmera Transplant Centre, University Health Network, Toronto, ON, Canada

<sup>3</sup>Division of Nephrology, University of Toronto, ON, Canada

<sup>4</sup>Centre for Mental Health, University Health Network, Toronto, ON, Canada

<sup>5</sup>Temerty Faculty of Medicine, University of Toronto, ON, Canada

<sup>6</sup>Department of Psychiatry, University of Toronto, ON, Canada

<sup>7</sup>Division of Nephrology, Faculty of Medicine, The University of British Columbia, Vancouver, Canada

<sup>8</sup>Kidney Transplant Program, St. Paul’s Hospital, Vancouver, BC, Canada

<sup>9</sup>Department of Medicine, Women’s College Hospital, Toronto, ON, Canada

<sup>10</sup>Department of Paediatrics, The Hospital for Sick Children, Toronto, ON, Canada

<sup>11</sup>Department of Surgery, University of Toronto, ON, Canada

<sup>12</sup>Factor-Inwentash Faculty of Social Work, University of Toronto, ON, Canada

## Corresponding Author:

Samantha J. Anthony, Child Health Evaluative Sciences, Peter Gilgan Centre for Research and Learning, The Hospital for Sick Children, 555 University Avenue, Toronto, ON M5G 1X8, Canada.

Email: samantha.anthony@sickkids.ca



**Participants:** Caregivers of Chinese Canadian patients with CKD, 18 years of age or older, and who spoke English, Cantonese, or Mandarin.

**Methods:** One-on-one, semistructured interviews were conducted virtually, by a member of the research team and were audio-recorded and transcribed verbatim. Thematic analysis was used to explore participants' shared experience.

**Results:** Seven interviews were conducted with 6 mothers and 1 father of 6 Chinese Canadian pediatric patients with CKD: 4 patients had undergone a kidney transplant, and 2 were not yet listed for transplant. Analysis of data highlighted that cultural influences affected whether parents shared with others about their child's illness and experience. The cultural understanding that it is inappropriate to burden others contributed to the creation of an isolating experience for participants. Cultural influences also impacted whether parents asked others to be a living donor as participants articulated this would place a physical burden on the living donor (e.g., potential risk to their health) and an emotional burden on the participant as they would be indebted to a willing donor. Ultimately, parents' decision to choose DDKT or LDKT for their patient-child was a result of evaluating both options carefully and within an understanding that the ideal treatment choice reflected what was best for all family members.

**Limitations:** Findings reflect experiences of a small sample from a single recruitment site which may limit transferability.

**Conclusions:** Parents in this study felt that they had access to the necessary evidence-based information to make an informed decision about the choice of DDKT versus LDKT for their child. Participant narratives described feeling isolated within cultural communities of family and friends and participants' suggestion of benefiting from increased support may guide future research directions. Practitioners can offer direct and indirect support to families, with recognition of the importance of cultural values and family-centered care on decision-making within families. Opportunities are needed for accessible, virtual social support platforms to increase parental feelings of culturally mediated peer support from parents who share similar experiences.

## **Abrégé**

**Contexte:** En 2021, plus de 6000 enfants et jeunes au Canada vivaient avec une insuffisance rénale terminale (IRT), une affection pour laquelle la transplantation rénale est considérée comme le traitement préférentiel par les professionnels de la santé. La recherche montre que la transplantation d'un rein de donneur vivant (TRDV) présente des taux de survie du greffon et du receveur supérieurs à ceux de la transplantation d'un rein de donneur décédé (TRDD). En contexte pédiatrique, le choix entre la TRDV et la TRDD fait l'objet d'une évaluation sommative de facteurs soigneusement pesés par le patient, sa famille et l'équipe de soins. La prise de décision entourant la transplantation peut s'avérer encore plus complexe pour les personnes issues des minorités raciales et ethniques, car des valeurs et croyances spécifiques à la culture sont imbriquées dans les conceptions et concepts dominants de la santé et les modèles de soins acceptés. Les Canadiens d'origine chinoise, par exemple, présentent un risque accru d'IRT, mais leur accès à la TRDV est réduit par rapport aux patients d'origine caucasienne, bien qu'ils constituent la plus importante minorité visible dans la population Canadienne.

**Objectif:** L'objectif de cette étude qualitative est d'approfondir notre compréhension du processus décisionnel entourant le choix entre la TRDD et la TRDV chez les parents de patients pédiatriques d'origine chinoise atteints d'insuffisance rénale chronique (IRC).

**Conception:** Étude qualitative et descriptive.

**Cadre:** Le program de néphrologie de l'Hospital for Sick Children de Toronto (Canada).

**Sujets:** Des adultes proches aidants de patients Canadiens d'origine chinoise atteints d'IRC et parlant anglais, cantonais ou mandarin.

**Méthodologie:** Des entrevues individuelles semi-structurées ont été menées en mode virtuel par un membre de l'équipe de recherche; les entrevues ont été enregistrées (audio) et transcrites textuellement. L'analyse thématique a été utilisée pour explorer l'expérience commune des participants.

**Résultats:** Sept entrevues ont été menées auprès des parents (6 mères et un père) de 6 patients pédiatriques Canadiens d'origine chinoise atteints d'IRC: quatre avaient subi une greffe rénale, les deux autres n'étaient pas encore inscrits sur la liste pour une transplantation. L'analyse des données a révélé que les influences culturelles affectaient la façon dont les parents parlent de la maladie et de l'expérience de leur enfant avec d'autres personnes. La conception d'origine culturelle selon laquelle il n'est pas approprié d'accabler les autres a contribué à créer de l'isolement chez les participants. Les influences culturelles ont également interféré dans le fait de demander ou non à d'autres personnes d'être donneurs vivants; les participants ont expliqué que le don vivant imposait un fardeau physique au donneur vivant (p. ex., un risque pour sa santé) et un fardeau émotionnel au participant, car ceux-ci seraient redevables au donneur consentant. La décision des parents de choisir la TRDD ou la TRDV pour leur enfant aura finalement été le résultat d'une évaluation minutieuse des deux options, avec la perspective que le choix de traitement idéal reflétait ce qui était le mieux pour tous les membres de la famille.

**Limites:** Ces résultats reflètent les expériences d'un faible échantillon de sujets provenant d'un seul centre, ce qui peut limiter la transférabilité.

**Conclusion:** Les parents interrogés pour cette étude estimaient avoir eu accès aux informations factuelles nécessaires pour prendre une décision éclairée dans leur choix entre la TRDD et la TRDV pour leur enfant. Les récits des participants ont décrit leur sentiment d'isolement au sein des communautés culturelles de la famille et des amis; la suggestion des participants de bénéficier d'un soutien accru pourrait guider les orientations futures de la recherche. Les praticiens peuvent offrir un soutien direct et indirect aux familles en reconnaissant l'importance des valeurs culturelles et des soins centrés sur la famille dans la prise de décisions par les familles. Il est nécessaire de créer des plateformes de soutien social virtuelles et accessibles, afin que les parents aient le sentiment de bénéficier davantage du soutien culturel d'autres parents qui partagent des expériences similaires.

### Keywords

living kidney donation, parent support, pediatric kidney transplant, chronic kidney disease (CKD)

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### Introduction

As of 2021, more than 6000 children and youth in Canada were living with end-stage kidney disease (ESKD).<sup>1</sup> This represents the final stage of chronic kidney disease (CKD)<sup>2</sup> for which kidney transplantation is considered the preferred kidney replacement treatment by health professionals.<sup>3-9</sup> Excluding Quebec, there were 60 pediatric kidney transplant recipients in Canada in 2021.<sup>1</sup> While pediatric patients who receive a kidney transplant can expect an increased lifespan, most will require a subsequent kidney transplantation between 12 and 15 years after their first transplant, the average half-life of a kidney transplant.<sup>3,5,6,9-12</sup>

Living donor kidney transplantation (LDKT) offers superior recipient and graft survival compared to deceased donor kidney transplantation (DDKT).<sup>3,5,6,9,10,13</sup> In addition, LDKT is often associated with pre-emptive transplantation, which can avoid dialysis-related medical and psychosocial complications, contributing to improved kidney transplant outcomes and less financial cost to the health care system.<sup>3,6,7,10,11</sup> However, the choice of LDKT or DDKT for a pediatric patient is not a simple cost-benefit analysis, as it is a summative consideration of factors weighed carefully by the patient's family, health care team, and patient.<sup>9</sup> Barriers to LDKT may include concerns about the health of a potential donor, and social or environmental factors related to the child and family.<sup>3,8-10,14</sup> Furthermore, research suggests that decision-making surrounding transplantation may be more complex for visible minorities as culturally specific values and beliefs are interwoven within dominant understandings and concepts of health and accepted models of health care.<sup>15</sup>

Differences in access to LDKT across cultures have been described both globally and within the Canadian context.<sup>16-18</sup> For example, Chinese Canadians are the largest visible minority population in Canada, with an increased risk of ESKD, yet have markedly lower access to LDKT compared to Caucasians.<sup>19,20</sup> Furthermore, East Asians (primarily Chinese) have a 73% lower likelihood of receiving a LDKT compared to Caucasians, even after adjusting for sociodemographic and clinical variables.<sup>19,21</sup> In light of these disparities, there is a need for research to elucidate ethnocultural differences to provide a foundation for strategic action.<sup>22</sup>

The objective of this qualitative study is to deepen our understanding of the decision-making process surrounding DDKT versus LDKT among parents of Chinese Canadian pediatric patients with CKD. Through an exploratory approach, we aim to inform clinical care to improve access to LDKT in ways that honor cultural beliefs and values of Chinese Canadian families.

### Methods

#### Study Design and Methods

A qualitative descriptive study design was selected as an exploratory method to elicit a rich description of our participants' values, beliefs, and perceptions.<sup>23,24</sup> An exploratory approach is preferred since, to our knowledge, this study is the first examination of ethnocultural perceptions and experiences of LDKT in the Chinese Canadian community. Exploring social and cultural beliefs toward organ donation and transplantation are an important aspect of understanding the experience of LDKT in the Chinese Canadian community.<sup>25-29</sup> The study was approved by the Institutional Research Ethics Board (REB) at The Hospital for Sick Children (SickKids) (REB number: 1000073203).

#### Participant Recruitment

Within our exploratory research design, we engaged both convenience and snowball sampling approaches to recruit participants from the Nephrology Program at SickKids in Toronto, Canada. All caregivers of Chinese Canadian patients with CKD at SickKids were eligible if they were 18 years of age or older and spoke English, Cantonese, or Mandarin. Eligible participants were invited by a member of the pediatric patient's health care team to participate in the study. Recruitment took place between March 2021 and July 2021. If interested, the potential participant gave their permission for the research team to contact them. Participants provided written informed consent prior to study involvement. Consenting research participants were asked following interviews if additional family members would like to participate.

## Data Collection

Upon recruitment, participants completed a self-reported sociodemographic questionnaire. One-on-one, semistructured interviews were conducted virtually by a member of the research team (SJP) trained in qualitative methods. The interview guide was informed by clinical experience and a review of the literature. Questions were developed to explore participants' perceptions and experiences with CKD and transplantation and allowed for additional probes to facilitate a depth of understanding within participant responses. Examples of questions include: "What were some of the first things that came to your mind about kidney disease when your child was first diagnosed?"; "Do other members of your family know about your child's diagnosis? What was their reaction?"; and, "When you/your family were thinking about treatment options for your child, do you think you had access to all of the available information and resources you needed to make your decision?". All interviews were audio-recorded, transcribed verbatim, and de-identified to protect participant confidentiality.

## Data Analysis

Research team members experienced in qualitative methods (SJP, AD, SJA) used thematic analysis to explore emergent themes.<sup>23,30</sup> This approach identifies similar words, phrases, patterns, and concepts as analysis moves from a detailed descriptive level to a broad thematic level. Similar codes were analyzed comparatively, and discrepancies were resolved to develop a coding structure and codebook. NVivo 12 was used for qualitative data management.<sup>31</sup> To maintain rigor and credibility during analysis, the research team engaged in critical reflexivity around their positionality as (primarily) non-Chinese Canadian researchers. This included reflecting on personal assumptions around the study population, power dynamics inherent in the research process, and exploring alternative ideas and explanations in the data. Interpretations were presented to Chinese Canadian patient partners for member checking.

## Results

### Participants

A total of 8 families comprising Chinese Canadian pediatric patients with CKD were identified as eligible and approached. Parents from 6 of the families agreed to participate and 7 individual interviews were conducted between August 2021 and January 2022: 2 participants were a husband-and-wife dyad caring for the same patient. Six participants were mothers and 1 was a father. Six interviews were conducted in English, of approximately 85 minutes in length, and 1 interview was conducted in Cantonese with the assistance of an interpreter from a company on contract to SickKids. Five

participants were first-generation immigrants and 2 were second-generation immigrants to Canada. Participants identified as Chinese Canadian (n = 4), Chinese (n = 1), Vietnamese Canadian (n = 1; husband identified as Chinese Canadian) and Malaysian Irish (n = 1; husband identified as Chinese Canadian). The 6 child patients of the participants ranged from 4 to 17 years of age (n = 3 female). Of the 6 patients, 4 had received a kidney transplant, and 2 were not yet listed for transplant at the time of the interview. There were no differing demographic characteristics collected which defined the participant who had received a LDKT or DDKT for their child. Table 1 reports additional demographic information.

### Thematic Findings

Our findings present the experience of 7 parents of Chinese Canadian pediatric patients with CKD. While our sample was predominately mothers, we will use the term "parents" to describe our findings that include the perspective of one father. Our analysis is the first to explore experiences within this population and an experienced interviewer facilitated the generation of rich qualitative data. Overall, cultural influences contributed to the creation of an isolating experience for parents of Chinese Canadian pediatric patients with CKD when making decisions about LDKT. These influences indirectly contributed to whether the parents of a patient-child would: (1) share about their child's illness and experience with other family members and close friends and (2) ask family members to be a living donor for their child. The decision to select a DDKT versus LDKT for their patient-child appeared most influenced by what was collectively best for the family unit.

*Cultural influences affecting whether parents shared about their child's illness and experience.* Parents described cultural values about not imposing burden (麻煩) on others and how this contributed to their decision to not share information about their child's illness. In this sense, parents felt that it was burdensome to cause unnecessary worry for family members by sharing information about a child being sick, particularly with elderly family members, such as grandparents. As one participant questioned, ". . . how I can tell my 83 years old parents that she had a transplant? They wouldn't sleep. . . . And I don't want their worry" (P-6).

Parents also described how it was perceived as socially undesirable from a cultural perspective to share information about one's family that was not considered "positive," including a family member's experience of illness. Participants described how the cultural perception of "illness as negative" was interwoven with the social expectation, particularly of grandparents, to ideally only share positive information about one's family to others outside of the family. One parent described:

**Table 1.** Participant Demographics.

Participant gender (self-identified), n (%)	
Woman	6 (86)
Man	1 (14)
Patient-child sex, n (%)	
Female	3 (50)
Male	3 (50)
Patient-child type of organ transplantation received, n (%) (four patient-children had received a kidney transplant at the time of the interview)	
Deceased donor kidney transplantation	3 (75)
Living donor kidney transplantation	1 (25)
Number of children in addition to the patient, n (%)	
Zero	1 (14)
One	2 (29)
Two or three	4 (57)
Highest degree received, n (%)	
Diploma or certificate from Community College	1 (14)
Bachelor's degree	2 (29)
Master's degree or higher	3 (43)
Information not available	1 (14)
Employment type <sup>a</sup> , n (%)	
Part-time	1 (14)
Full-time	4 (57)
Homemaker	1 (14)
Information not available	1 (14)
Household income, n (%)	
\$40-59 999	1 (14)
≥\$100 000	4 (57)
Information not available	2 (29)
Language spoken most often at home, n (%)	
English	5 (72)
Mandarin	1 (14)
Cantonese	1 (14)
Language of Interview, n (%)	
English	6 (86)
Cantonese (with assistance of medical interpreter)	1 (14)

<sup>a</sup>Percentages may not add to 100 due to rounding.

... by sharing your health status, it kind of removes a bit of pride from the family ... in my culture, there are situations where people don't like to, you know, propagate any negative attributes of their children or their grandchildren. (P-3)

Another parent shared how grandparents told them they were not allowed to share that the patient required a transplant because "if you tell someone that your grandchild has—has issue, it just doesn't look good on you" (P-5).

Overall, the cultural understandings that it is inappropriate to burden others or share negative family experiences contributed to feelings of isolation among Chinese Canadian parents of children with CKD. One parent highlighted: "... I don't feel like I have enough support emotionally ... I need

to share with someone [in my family]" (P-5). Another parent described "finally" telling their extended family about their child's illness despite cultural expectations, emphasizing wanting more support without hiding information or isolating themselves:

... we finally started ... letting people know ... it wasn't until maybe a year ... before his transplant ... I didn't want to hide it from my family members ... I wanted to have the extra support so that people understood ... because we felt we had to kind of isolate ourselves from people that we're close to. (P-3)

*Cultural influences affecting whether parents asked others to be a living donor.* Participants identified the risks of being a living donor as a reason why it was unacceptable to ask others to be a donor for their child, which further illustrates the concept of taking care not to burden others in Chinese culture. One participant described how the simple act of asking something from someone—the request for help—was considered imposing burden on that individual:

I guess a lot of Asians do find, they don't like to ask ... it's not like they wouldn't be able to—[that] they wouldn't want to help—[it] is just now you're burdening another family or somebody else. (P-1)

Burdens identified by participants included the health risks assumed by the donor and also the risk of impact to the donor's caregiver and other immediate family members. The burden of risk that was extended to the donor and the donor's family was one of the key reasons why parents felt hesitant to approach others to be a living donor. One participant described the risk as inherent in any kind of surgery:

... each type of surgery, there's - there's risks involved ... I might potentially put them at risk. And ... as such, their family will not be happy. So that's why even ... for ourself, is very hard for us to ask. (P-5)

This is consistent with the Chinese proverb 不怕一万, 只怕万一, which advocates one to be cautious and literally translates to, "we're not afraid of the 10,000 times when things turn out as expected, but we are afraid of the 1 in 10,000 occurrence of the unexpected".

Another participant emphasized their concern about the future health risk imposed on a family member as a potential donor:

there is the risk there and ... say ... my cousin decides to donate ... to my child ... even though there's a small chance that, that everything is going to be fine, but does that mean my cousin is going to have a harder life? (P-3)

Participants clearly described that asking a family member to be a donor would be an emotional burden on themselves as they would be indebted to a willing donor. One parent expressed:

If I have a relative here, and he willing to do that . . . I would also take this one as a huge debt on myself. Whenever he sick, I would be the first person to go [and help him] . . . (P-6)

Another parent explained how this sense of indebtedness could not easily be repaid: “I don’t think anything shorter than actually trading an organ would be suffice” (P-4). One parent even described how a grandparent intervened to prevent the patient-child’s uncle from screening for eligibility given the potential risks:

. . . my brother did come forward and say that, “Oh, I’m not sure I’m eligible, but I can go for a test,” but my mom right away stop him . . . She [grandmother] said [to brother] “Why would you want to do that? This is gonna to significantly affect your health. And you don’t want to do that—and what would happen to your future?” Because my brother is also her son, right [laughs]? Her pride [laughs]! (P-5)

Overall, the experiences of participants reflected culturally patterned considerations, which affected whether a parent would ask someone else to be a living donor for their patient-child. For these reasons, participants described how a patient-child’s parent was the primary—or in most cases, the only option considered as a potential living donor.

*Making a family decision about DDKT versus LDKT.* Parents’ decision to choose LDKT or DDKT for their patient-child was a result of evaluating both options carefully. One parent stated: “. . . I will say that decision that we’ve made, is - is kind of balance” (P-6). Another parent described the decision-making process: “when it came down to the decision of what to do, it was sort of weighing the pros and cons of everything” (P-1). Parents primarily discussed the mother or father as a potential living donor. Parents’ narrative often reflected what was best for the family unit during a parent’s recovery period or if complications presented after surgery. If a patient-child’s parent was not being considered as a living donor, then DDKT appeared to be the most likely option for families. Many participants described that they [mother and father] were considering LDKT and DDKT, but if the decision was urgent—relative to the health status of the patient-child—it might change their’s or others’ immediate decision to pursue live donation. One mother stated:

If my daughter . . . [if] something was going to happen to her, like, you know, within a week and she was that desperate—it’s not saying no family or member would, or friend would come forward and say, “oh, what can I do to help?” (P-1)

This careful decision-making process took time. Some, parents’ also described that while they were still considering their options, their patient-child was listed, and when a DDKT became available, the transplantation proceeded. In one case, a parent described how they were able to facilitate dialysis at home, terming this “Cadillac dialysis” (P-1),

which offered them more time to decide about transplant options, eliminating the sense of urgency for a decision.

Most families were deciding on the best transplant option knowing that all family members would be impacted. According to one participant, the mother and father made their decision about DDKT versus LDKT before either parent was tested as a potential donor. This parent-couple did not want the results to influence their decision about what was best for the whole family. A few parents highlighted how they also included their patient-child in the decision-making process. One parent described how the patient-child did not want a family member to assume the risk of being a living donor if another option was available: “. . . it’s based on that—the whole family’s benefit . . . so eventually, we discussed and she [patient-child] didn’t - she didn’t even want to do that as well” (P-6).

It is important to note that, even though several participants in this study agreed to a DDKT for their child, participants did not overtly express a nonpreference for a LDKT. For example, in some cases, the parents of the patient-child expressed that they would prefer to be a living donor for their child’s second transplant, if it was needed when the patient-child was older—a time when the child may not be prioritized on a waiting list for DDKT. One parent questioned: “if I gave him one now . . . how do I know he’s not going to be in a position to—to get one [DDKT] as readily available later?” (P-3).

Overall, participants felt well-informed about their options regarding DDKT versus LDKT. Parents did not describe any concerns with accessing information about LDKT or DDKT in relation to the process of decision-making. Improved medical interpretation services were noted by one participant as having the potential to increase support to Chinese Canadian parents as the participant identified that there were many different cultural nuances to the use of Chinese language beyond literal interpretation. They also suggested that access to additional interpretation services may allow for parents to receive an opinion from a second medical specialist if it was desired. It was evident that most participants had an understanding of the medical information they had received because they were able to retell their learning about CKD. In retelling, participants could express their knowledge using appropriate physiological and anatomical terms related to the cause and treatment of their child’s experience with CKD. While many participants felt that they had received adequate information from different sources (Table 2), a few noted benefits if the medical team played a role in providing education to older family members (e.g., grandparents). These participants described how cultural values concerning respect for elders and their hierarchical position in the family unit made it difficult for younger generation parents to assume an educator role for older family members about their child’s kidney disease. One participant described how having a nurse who spoke the same language as the family made a difference in their

**Table 2.** Participant Cited Kidney Disease Information Sources.

Kidney disease information sources, n (participants reported all sources that they accessed)

Total participants n = 7

Patient's transplant team	7
Independent internet research	7
Other families of children with chronic kidney disease	2
Family members in the medical field	1
Scientific literature	1

experience, particularly because it increased the knowledge transfer available to the patient-child's grandparents.

Parents described themselves as being a generation who valued Western medicine, scientific information, and research when making decisions about their child's health. As described by one participant: "I'm from the newer generations. I'm more into Canadian culture, more into science" (P-5). A respect for elders and family members who practiced traditional medicine was acknowledged, but it was not a primary consideration in their child's care. One parent emphasized, "... traditional medications, or Chinese medications or anything like that ... we wouldn't unless there's kind of more scientific basis around certain treatments ... ." (P-3). Parents also understood that there were benefits associated with choosing a LDKT. For example, one parent shared that LDKT was associated with lower risks because of the ability to schedule the process: "... with the living donor, because it's more planned, then it was a little bit better option ... if it's planned, then you can kind of schedule everything. So then the risks seemed a bit lower" (P-1). Another parent described LDKT as the better option because evidence suggests it has a lower chance of rejection, compared to DDKT:

... from what I understand, there's a higher chance of things going well, with a live donor ... it's a lower chance of rejection from a live donor ... And also, the chances of rejection are lower on a live donor rather than a deceased donor. (P-4)

Parents felt that because of the known advantages of having a LDKT, the health care team unanimously believed that a LDKT was the best option for their patient-child and family. One parent related their conversations with health care providers pre-transplant:

... when it came to the medical staff, it was ... kind of independent of the external factors—like what would be the best situation—and it was very much focused on—on the live donor option. (P-3)

Another parent shared: "... they encouraged us to go the living donor" (P-6).

Yet, despite the perceived preference by the health care team for a LDKT, parents saw advantages for their family

to choose a DDKT. Many participants described how health care providers overlooked the importance of variables associated with a family-centered approach to decision-making, which was central to their final decision. For example, participants described the importance of considering family duties and caregiving responsibilities for siblings if a parent was a living organ donor. One parent emphasized: "... I have two children ... if I went for surgery and my child went for surgery, then who's gonna take care of the rest of the family?" (P-7). Some parents talked about financial responsibility and the potential negative impact financially on their family if a parent was a live donor, experienced complications, and then was unable to work. One parent described:

... it was a risk that we felt we couldn't take because of the extreme impact that would have if either me or my wife were unable to work and had our own medical conditions to deal with, in addition to two small kids, plus another—three small kids but two healthy kids and one child with an abundance of special needs. (P-3)

Another parent stated,

... at the moment, we have to at least keep one job my husband's job, right? So that our family will be able to sustain otherwise we probably on welfare, and that's also affected the quality of [patient's] life too. (P-5)

Additional concerns were expressed regarding the anticipated stress on a family when a parent is a live donor: "... I just can't afford one more person gets sick in the family. That's my situation, that's gonna be—it's gonna be a disaster" (P-6). In the perspectives of some, choosing a LDKT meant incurring additional risk within a family unit that was already experiencing an exceptional amount of stress due to their patient-child's health journey. Given the health care team's perceived preference for LDKT, many parents described questioning their choice and not feeling supported when they decided to pursue a DDKT. One parent described: "... when we made the decision to say, we want to go deceased donor ... we kind of weighed the pros and cons around making that decision ... Are we terrible parents for making this decision?" (P-3). Another parent emphasized:

Some of the physician might make an assumption of if you have a choice of family donor, you will have to go for it. Why not? Like, how could you not? I think one of her comment is 'how could you not decided to save your child?' ... the physician trying to force us that you need to do a family donor (P-5)

Overall, through listening to the shared experiences of participants, it appeared that families described a very weighted decision-making experience within the isolation of not having ideal systems of familial support and few

options to consider for living organ donors. This occurred simultaneous to knowing that their patient-child's health care team had a strong preference of LDKT as the primary plan of care.

## Discussion

The interplay of varied Chinese Canadian cultural values and ways of thinking, among other factors, contributed toward parents feeling isolated in their journey with a child with CKD. Furthermore, asking family or friends to be a living donor for their child was difficult to consider as an acceptable treatment option. This created a conflict between what parents knew was evidence-based and medically recommended and what they felt was possible within their own network of family and friends. This decision-making process, which often led patients away from deciding in favor of LDKT, also included the consideration of logistical factors that parents deemed as important to family responsibility and functioning. Overall, parents considered the decision-making process concerning DDKT versus LDKT as representing the need to make the best decision for their family as a whole. It was also an experience shaped by cultural influences. These findings are similar to adult literature that highlight how culture affects the decision-making process surrounding transplantation and organ donation, such as the decision to donate, be listed, or accept an organ.<sup>32,33</sup>

The unique contribution of this study was its focus on pediatric kidney transplantation within the cultural context of the experience of Chinese Canadian parents. This created a novel space to explore the cultural influence of relationships between extended family members, particularly grandparents, parents, and a patient-child. The intergenerational-relationship dynamics that surrounded the experience of deciding between LDKT and DDKT provided increased understanding about how the process of selecting a treatment option for a child with CKD unfolds within a family unit when at least one patient-child parent is Chinese Canadian. Within our findings, descriptions of cultural traditions that value displaying and maintaining a respect for grandparents' wishes and well-being given their esteemed elder role<sup>34</sup> offered insight into how the Chinese cultural concept of filial piety was represented in the participants' lived experience.

Within Chinese culture, the concept of filial piety as a cultural value, includes respecting, obeying, and not dishonoring one's parents,<sup>34,35</sup> "harmonizing" the family,<sup>35,36</sup> taking good care of parents and being mindful of their well-being, and behaving in a way that brings one's parents respect and honor within the community.<sup>35,37</sup> This traditional cultural understanding of intergenerational hierarchy extends into adulthood as adult children act and behave in ways that support their parents' well-being.<sup>35,38</sup> The expectation of this

family-centered cultural construction is that adult children have a responsibility to sacrifice their own interests (e.g., physical, financial, and social) for the well-being of their parents or family.<sup>34,35</sup>

The concept of filial piety was described by participants through multiple examples, and it was clear from the interviews with participants that this cultural influence affected their decision-making process surrounding DDKT versus LDKT and their overall experience of having a child with CKD. Showing respect and protecting the well-being of elders was exemplified through actions, such as ensuring that their choices did not invite grandparents to worry. As previously described, this was evident when participants described purposively not sharing information with grandparents to prevent unnecessary worry about the patient-child. In many cases, the concept of filial piety provides context for improved understanding to participants' descriptions of honoring requests or expectations of grandparents. This includes not sharing information with others about the patient-child's health condition to protect the perception of the family within the community and honoring a grandparent's wishes that their child (i.e., the patient-child's uncle) not be an organ donor due to the potential risks of organ donation. These examples highlight the importance of cultural considerations that must be understood and considered by the health care teams incorporating an inclusive family-centered care approach when working with Canadian-Chinese families.

Parents in this study felt that they had access to the necessary evidence-based information to make an informed decision about the choice of DDKT versus LDKT for their patient-child. It was not indicated that making a different decision—or changing their minds—in choosing DDKT or LDKT would be influenced by having additional information or information provided in another form. Information received from different sources was assimilated and understood within the context of what it meant to the family as a whole. Decisions were then made including the consideration of best evidence and the health care team's recommendations; however, the decision to choose DDKT versus LDKT was not based solely on these parameters. Parents seemed acutely aware that their patient-child may need more than one transplant in their life, and this influenced their thoughts regarding when it might be ideal for a parent to be a living donor if possible. However, it was also evident through parent narratives that they felt a responsibility to the family as a whole to make a decision aligned in the best interest of all family members. This element of the decision-making process is pragmatic and logistical; through a cultural lens, it also highlights the value given to family duty and responsibility in Chinese communities.<sup>36</sup>

Improved information transfer and knowledge translation was not highlighted as essential to affecting the participants'



decision-making process; only one parent in this study required an interpreter to participate, suggesting a strong command of the English language among research participants. Since recruitment involved self-selection for participation, this may have contributed to participants consenting who were confident in their communication skills, either with or without an interpreter. This needs to be considered within our finding that enhanced information transfer was not emphasized as required to aid decision-making in this population. Notably, improved interpretation services, increased language options, and more interaction with health care professionals, such as nurses, who spoke multiple languages were mentioned as means to increase support to parents of Chinese Canadian patients with CKD. In particular, the latter may be an overlooked and culturally acceptable, opportunity to aid understanding in elders or others within the family unit. Overall, given the intergenerational influences of cultural tradition and values, the shared lived experience of study participants describes how familial and community support may differ from other parents with children with CKD. As a result, it is concerning that the parent participants described not feeling supported or understood by the health care team if their final decision was to pursue DDKT versus LDKT, particularly when they felt the decision was made in an informed manner and in the best interest of their family.

This single site study is limited by its small sample size ( $n = 7$ ), yet the sociodemographic data of participants suggests diversity within our target population. We made several attempts to employ snowball sampling to increase the number and diversity of participants (e.g., recruiting participants' spouses or parents); however, we were unable to increase our sample. We acknowledge that this has implications for the transferability of study findings and also that study participants' experiences are not representative of all parents, in particular fathers, of Chinese Canadian pediatric patients with CKD. Our analysis ensured a reflexive and authentic presentation of collective experiences observed across the study's research participants. Our reflection on why LDKT may be accessed less by East Asian communities in Canada was to offer an informed understanding that can help to increase opportunities for treatment. There was no intention to compare donation rates between cultural communities in a way that suggests relative altruistic behavior. Our challenges with recruitment may parallel the narrative of our findings in that family elders might not be comfortable talking about the family experience with CKD. It is unclear why the spouses of participants declined invitations to participate. The health care team approached most eligible families in clinic (2 families were invited by email), and it is possible that more mothers than fathers agreed to participate because mothers are often the caregiver who attends the child's health care appointments.

## Conclusions

The goal of this study was to help improve understanding of the decision-making process surrounding DDKT versus LDKT among parents of Chinese Canadian pediatric patients with CKD. Health care teams have an imperative role in enhancing the social support experienced by parents of Chinese Canadian pediatric patients with CKD. For example, health care professionals can offer communication and education support to immediate and extended family members, recognizing the importance of cultural values that affect communication and decision-making within families. Social workers, in particular, can optimize the availability of key resources at all timepoints of the CKD journey, including diagnosis and at times of transition between treatments. Online resources may provide increased options for support across various languages. Proactively accessing and arranging for necessary resources and care may help to alleviate familial concerns about increased care needs for potential donors and recipients post-transplantation. Given our findings, the understanding that parents may feel isolated within cultural communities of family and friends emphasizes an essential need for health care teams to demonstrate decision-making support for families that is impartial to DDKT versus LDKT, reflecting awareness of the value placed on family-centered decisions within this population. Importantly, participants' suggestion of benefiting from increased support also may guide future research directions. Opportunities are needed for accessible, virtual social support platforms to increase parental feelings of culturally mediated peer support from parents who share similar experiences.

## List of Abbreviations

CKD, chronic kidney disease; DDKT, deceased donor kidney transplantation; ESKD, end-stage kidney disease; LDKT, living donor kidney transplantation.

## Ethics Approval and Consent to Participate

The study was approved by the Institutional Research Ethics Board (REB) at The Hospital for Sick Children (SickKids) (REB number: 1000073203). Participants provided written informed consent prior to study involvement.

## Consent for Publication

Not applicable.

## Availability of Data and Materials

The qualitative data (i.e., interview transcripts) cannot be shared.

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## ORCID iD

Samantha J. Anthony  <https://orcid.org/0000-0002-1800-2333>

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