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Title	Health system barriers and facilitators to living donor kidney transplantation: a qualitative case study of British Columbia
Authors	Anna Horton MSc, Peter Nugus PhD, Marie-Chantal Fortin MD PhD, David Landsberg MD, Marcelo Cantarovich MD, Shaifali Sandal MD
Reviewer 1	Dr. Jason Y Lee
Institution	
General comments (author response in bold)	<p>The authors conducted an exploratory case study analysis of LDKT in the province of BC, which has demonstrated success and leadership in LDKT at the national level. The authors provided qualitative data on both facilitative factors as well as those that act as barriers based on analysis and sorting of interviewee answers to standardized questionnaires.</p> <p>Dear Dr. Lee. Thank you for taking the time to review our manuscript and for your helpful suggestions. Please find our response to each of your comments below. (N/A)</p> <p>1. There is some literature to suggest certain demographic groups (based on religion, immigrant-status, socio-economic status, etc) are more or less knowledgeable and more or less willing to proceed with living organ donation. Was this specific area explored? How do these demographics compare in BC to other provinces?</p> <p>Thank you for this comment. What you mention is indeed a very important barrier to LDKT and several patient-level barriers do exist. There is literature describing this. The goal of our qualitative case study was to explore that at the level of the health-system what facilitate and impedes LDKT and explore macro level factors. While patients are a central element to a health system, exploring whether these patient-level barriers exist differentially in BC when compared with other provinces is a part of our future work. (N/A)</p> <p>2. A similar exploratory case study in the province with the WORST LDKT performance data (not to point fingers, but to learn) would be valuable as follow-up to this study. Would allow for a better understanding as to which factors are more or less generalizable facilitative factors or barriers.</p> <p>Indeed, this is a very important part of our research program, and we are currently performing a similar case study in Quebec. Our preliminary work suggests that themes that we identified as being facilitators to LDKT in BC are emerging as barriers in QC. We hope to submit this work for peer-review and would be grateful if you would review that work as well. (N/A)</p> <p>QUESTIONS</p> <p>1. Based on your analysis, and the stakeholders involved, would you say this is granular enough to delineate the extent to which some factors are in fact facilitative? Interviewing those in management and leadership often doesn't capture what is actually happening "on the ground". Leadership may say "we have this policy in place" .. but in fact, most may not even be aware of the policy.</p> <p>Thank you for your feedback. We agree that the perspectives of leadership may indeed fail to represent practices on the ground. For this reason, we aimed to interview participants from the full 'organizational spectrum' of care in BC. Alongside participants in management in leadership, we</p>

interviewed social workers, nurses and nephrologists practicing at multiple clinics across different health authorities in BC. Our iterative approach to interviewing meant that policies brought up by leadership, or discovered through our document review, could be explored with care teams who are involved with patients, to better understand how these were being translated in practice (this iterative approach is now more fully described in section d.i. of 'Methods'). This form of verification was also an aspect of the analysis, as we compared regularities and divergences between different accounts. We believe that this approach was robust enough to support our categorisations of certain factors as facilitative and others as barriers. For example, we mention in-text that the first two themes cited as facilitators were supported by evidence from interviewees from the full organizational spectrum of care. Equally, divergences between accounts from leadership and from care teams are reflected in certain themes classed as barriers – eg. Disconnected care processes. This study presents a systemic perspective that is not often engaged. Although there may not necessarily be alignment between policy-making and frontline work, policymaking is an 'on-the-ground' of sorts. Policy-making and frontline work are linked interactionally and in influencing each other. (Table 1)

2. To what extent could there be selection bias, as those participating had to agree to the study? Also, were interviewees notified regarding the purpose of the study prior to agreeing to participate, or prior to interviews (Hawthorne effect)?

We appreciate your concerns about selection bias and the Hawthorne effect. Given the need for participants to agree to participate in the study, we acknowledge that there is some risk of self-selection bias and have included this in study limitations. However, given the range of professional roles, units and geographic location of our participants, we do not believe this risk to have significantly impacted our conclusions. Furthermore, this study was not an evaluative study per se. The study drew on a particular level of outcomes in a particular setting (BC) aimed at identifying systemic factors that shape service delivery. This was made clear to the participants and, we believe, reduced the incentive for seeking to affect the data.

We took measures to mitigate observer effect through a reflexive approach to recruitment and data collection. In our recruitment email we were careful to ensure that the study purpose was stated to focus on provincial systems, rather than on any individual behaviours. Our interview questions were reviewed by members of the research team and a patient partner to ensure that they were neutrally-framed (ie. open-ended and contained no language that could infer feedback or judgement on practice).

Our study design also did not involve direct observation in a naturalistic setting, the type of data collection that has been most noted to risk reactivity from research participants. Confidential interviews are likely to have lower risk of observer effect.

Given our reflexive approach to the tone of our recruitment email and the framing of our interview questions, as well as the stated confidentiality of the interview data, it seems to us unlikely that participants would have felt a need to significantly modify their responses. (page 14)

3. If interviewees provided very contrasting reports of infrastructure, resources,

	<p>processes, etc .. how was this rectified?</p> <p>As stated above, comparing accounts for similarities and divergences was a key component of our approach to data collection and analysis. Our iterative approach to data collection meant that attitudes and reports raised by participants could be discussed with other participants to better understand the root and context of contrasting reports.</p> <p>During data analysis differences in reports were considered in context: eg. unit, professional role, geographic location. Accounts were then compared to those of participants in similar contexts, to determine if this was a patterned response. Where contrasting reports were seen to be significant (ie. a pattern of contrasting reports), they contributed to themes. For example, the theme ‘Disconnected care processes’, categorized as a barrier, in part emerged from contrasts in accounts between participants from transplant centres vs. regional transplant clinics/kidney care clinics. (pages 7-8)</p>
Reviewer 2	Dr. Hassan Ibrahim Houston Methodist
Institution	
General comments (author response in bold)	<p>1. The patients are the main stakeholders but I feel they were very under-represented in your sample. Is it possible to include more?</p> <p>Thank you for this comment. The goal of our qualitative case study was to explore that at the level of the health-system what processes and attributes facilitate and impedes LDKT and explore macro level factors that determine the delivery of LDKT. While patients are a central element to a health system, we achieved data saturation and further patient interviews were not adding new information. (N/A)</p> <p>2. Your data makes me wonder whether expansion of Medicare in the US would be something to do.</p> <p>That is indeed a great comment and topic of much debate in the U.S. political system. We have limited expertise in the political sciences to make such a bold statement. But an international comparative case study analysis would indeed be of interest. (N/A)</p> <p>3. Is there a way to rank the contributions of the barriers and facilitators?</p> <p>As stated in the introduction to our results, themes were largely interdependent. Within the scope of this study, we do not believe we could reliably rank these contributions. However, we appreciate the aim to better understand the relative contributions of these themes towards improving practice. This case study forms one component of a larger, comparative case study in which we will compare three provinces with varying rates of LDKT: we believe that the cross-case comparison will enable us to more comprehensively understand the relative contributions of the themes discussed in this paper. We thank the reviewer for their comment and will certainly take this into account in future works resulting from the broader comparative study. (N/A)</p> <p>4. The methodology is not "mainstream" and therefore some basics would help the reader</p> <p>As recommended by the editor, we have included more fundamental background information about the approach and methods. (Pages 5-8)</p>

	<p>5. Are the rates of live donor transplants in the different provinces statistically different? The average LDKT rates in Canada from 2006-2018 is about 15 donors/million population [DMP]) and are highly variable across provinces (range 6-23 DMP). The cause of this interprovincial disparity is not well understood. BC has consistently outperformed other provinces with a living donor rate of ≥20 DMP. Also, 50-60% of all transplantations performed annually in BC are from living donors, which is much higher than, ON and QC, for example, where the percentages are 30-40% and <15% respectively. Thus, these rates are statistically different. (Page 4)</p> <p>6. What is a kidney care clinic nephrologist? We have clarified that these refer to the CKD clinics (Page 9)</p>
Reviewer 3	Dr. Patrick Fafard
Institution	Faculty of Social Sciences, University of Ottawa
General comments (author response in bold)	<p>General Comments</p> <p>This is a very interesting and important paper that provides insight into some of the organizational and systemic factors that have an impact on the performance of organ donation and transplantation systems. The case of living kidney transplantation in BC is a useful source of data and insight into these broader factors. I have no major issues or concerns with the overall approach and the methodology – they are quite well done. I agree with the authors that a case study is appropriate for this research question.</p> <p>Dear Dr. Fafard, Thank you for a very systematic approach to reviewing our paper and for your helpful comments. We have addressed your concerns related to the KPD program below. (N/A)</p> <p>First, the focus is resolutely on living kidney donation. However, for the factors under consideration – funding, accountability, training – there are significant similarities to other types of organ transplantation. Thus, it would best to situate the findings in this broader context.</p> <p>Second, the paper assumes that BC is a closed loop when it comes to living kidney donation. If this is the case, then this should be made clear. But I would expect that at least some of the living donors are not BC residents. If this is the case, more needs to be said about the implications of this, how and to what extent funding and matching issues are addressed, and the organizational and institutional factors that shape securing living donors out of province.</p> <p>Third, and this follows from the second point, I was surprised to see no reference to the Kidney Paired Donation Program operated by the Canadian Blood Service. What role, if any, does this Program play in the success of LDKT in British Columbia?</p> <p>We absolutely agree and this advice is well taken and will inform our future work in transplantation. The present work pertains to LDKT and since a big disparity exists amongst provinces, it provided us the perfect template to conduct a comparative case analysis following individual case studies. We hope that the template of learning health systems we create will help inform such work in the field of all organ transplants.</p> <p>Thank you for these comments and we will respond to these together. The aim of this present study is to conduct an independent case study of BC as to why it has the highest living donor rate per million population when</p>

compared with other provinces. Following this we will conduct independent case studies of QC and ON where we will use similar methods to identify facilitators and barriers to LDKT. QC has the lowest rate of living donors per million population while ON meets the national average and has the largest transplant volume. Findings of each individual study will then inform our comparative case analysis. Also, we will conduct focus groups with key national and provincial stakeholders from the fourth level of the health system, i.e., the “environment”. Herein, we will address national programs such as the paired kidney exchange to deepen and refine the themes regarding health system barriers and facilitators to LDKT.

For your first comment, none of our participants identified out of BC residents as being an issue. However, they did identify financial barriers for both recipients and donors. You have raised an interesting question and we will explore it in when we conduct our comparative case analysis

With respect to your second comment, we have data from the Canadian Blood Services that reports that BC and ON have relatively more pairs in each KPD match cycle when compared with the rest of the provinces. As we have discovered in our case study, BC has a very streamlined process of promoting LDKT and has more living donor and recipient pairs enrolled in the paired kidney exchange program. Thus, the success of BC lies in producing more recipient and donor pairs for the KPD program. The reason for this we have identified as facilitators to LDKT in our case study. We will be able to better contextualize the role of these national initiatives during the comparative case analysis where in we explore an important part of the health system, i.e., the environment. (N/A)

Minor

p. 12 line 22 “.. no study has learned a high-performing health system ..”

- I am not sure that ‘learned’ is the correct verb

Thank you for pointing this error and it is now rectified (page 13)