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3 **Health System Barriers and Facilitators to Living Donor Kidney Transplantation: A Case Study of British**
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5 **Columbia**
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Confidential

Abstract

Background: In patients with kidney failure, living donor kidney transplantation (LDKT) is the best treatment option; yet LDKT rates have stagnated in Canada and vary widely across provinces. Over the past decade, the province of BC has consistently outperformed others in LDKT. We aimed to learn the functions of this high-performing health system to identify barriers and facilitators to LDKT.

Methods: This study was conducted using an exploratory case study approach. The “case” was comprised of the people and organizations that are involved with enabling LDKT. Data collection entailed document review and semi-structured interviews with key stakeholders recruited via purposive sampling and snowballing technique. Thematic analysis was used to generate themes.

Results: We identified the following themes as facilitators to LDKT: a centralized infrastructure, a mandate for timely intervention, an equitable funding model, a commitment to collaboration, and cultivating distributed expertise. Specifically, the relationship between two provincial organizations (BC Transplant and BC Renal) was identified as key to enabling the mandate and processes for LDKT. Barriers arose from silos between provincial organizations, which manifested as inconsistencies in coordinating LDKT along the spectrum of care. These were divided accountability structures, disconnected care processes, missed training opportunities, inequitable access by region, and financial burden for donors and recipients.

Interpretation: We demonstrate strong links between provincial infrastructure and the processes that facilitate or impede timely intervention and referral of patients for LDKT. Our findings have important implications for policymakers and provide opportunities for cross-jurisdictional comparative analyses and the development of Learning Health Systems.

Introduction

Patients with kidney failure experience significantly higher morbidity and mortality than the general population and need high-cost treatment options. (1-7) In these patients, living donor kidney transplantation (LDKT) is the best therapeutic option, especially when done pre-emptively (patient never receives dialysis). (3, 8-14) Yet, the living donor rate in Canada has stayed the same since 2010 (~15 donors/million population) and varies significantly across provinces (ranging from 6-23 donors/million population). (3, 15-17) The provision of transplantation is at the provincial level and there is a lack of national legislation and policy frameworks to guide provincial transplant programs. (3, 18) BC is recognized to be a high-performing health system as their living donor rate has been consistently ≥ 20 donors/million population. (15, 17, 19) Also, the fraction of LDKT to all kidney transplantations performed annually is 50-60%. This is much higher than QC and ON, for example, where this fraction is <15% and 30-40%, respectively. (15) To understand the potential reasons for this, we previously conducted an interpretive descriptive study of health professionals in these three provinces. (4, 20) Our work suggested that there are differences in health system processes and attributes that may explain BC's high performance in living donation.

Learning from the function of high-performing health systems to address priority policy and practice questions in a timely way is being increasingly called upon. (21, 22) Developing Learning Health Systems (LHSs) is a strategic priority of the CIHR Institute of Health Services and Policy Research to collaboratively drive efficient and effective health systems. (22) LHSs are accountable healthcare organizations that can use data in an intelligent fashion to improve care and guide system-level changes in a dynamic way. (21, 22) Thus, we aimed to conduct an exploratory case study of a high-performing health system and to learn barriers and facilitators to LDKT.

Methods

Approach

This study was conducted using a qualitative case study approach. Case studies are useful when studying complex phenomena within their environmental context, (23) and are the preferred methodology for examining high-performing health systems. (24) Given a shortage of evidence regarding the whole-system function of LDKT, we adopted an exploratory approach to our research aim. This approach was designed to produce inductively derived themes and explanations, (25, 26) about how structural arrangements and patterns of behaviour are linked with the provision of LDKT in BC. We followed the COREQ guidelines to ensure rigor in our study. (27)

Case Selection

The “case” was comprised of the people and organizations that are involved with enabling LDKT in BC. Following a Complex Adaptive Systems approach to health systems as multi-level and interconnected networks, (28) we mapped out the organization spectrum for LDKT in BC (Figure 1). The two main organizations involved in facilitating LDKT are BC Renal (provides all kidney care services) and BC Transplant (oversees all aspects of organ donation and transplant), and since 2009, they have partnered together. (29) Kidney Foundation of Canada is a charity with provincial branches that provides funding for research and patient services.

Data Collection

Data were collected using semi-structured interviews and document review. The purpose of document review was to better understand the operational framework and resources for LDKT and served as means of triangulation with interview data. (30) Documents for review were identified in consultation with our collaborators in BC, during interviews, and using web searches (Supplementary Table 1). Interview guides were formed with the combined expertise of our research team, preliminary document review, and in consultation with our patient partner. Purposive sampling and snowballing techniques were used to invite

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3 key stakeholders for interviews. (25, 31) Of the 45 individuals contacted for an interview by email, 22 agreed
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5 to participate (Table 1). Interviews were conducted until data saturation was achieved. Semi-structured
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7 interviews were conducted via Video call and lasted on average 52 minutes (range 32-77 minutes). The
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9 purpose of the interviews was to understand the system for LDKT in BC and to glean stakeholder
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11 perspectives about organizational structures, processes, and care. Interviews were conducted, digitally
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13 audio-recorded, and transcribed by A.H who is experienced in conducting qualitative research and was
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15 previously unknown to interview participants.
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21 **Analysis**

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23 Data were coded inductively by A.H., following a thematic analysis approach. (25) NVivo (QSR International)
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25 software was used to manage the data. Interview data were organized into codes that emerged iteratively
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27 from the data set. Codes were then compared across the dataset for regularities and divergences and
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29 modified accordingly. Through this process of inductive analysis, patterned responses developed into
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31 themes, which retained strong links with the original dataset. (32) Data from documents were reviewed and
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33 clustered thematically. Document and interview analyses were then compared for regularities and
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35 variations. Coding and emergent themes were independently reviewed by P.N. to ensure consistency and
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37 reliability in the analysis.
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43 **Findings**

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47 Findings are organized into themes that are categorized as facilitators or barriers to LDKT in BC (Figure 2).
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49 Themes are organized and presented separately for clarity but were largely interdependent. Selected quotes
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51 that illustrate each theme are presented in Tables 2 and 3.
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56 **Facilitators to LDKT**

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59 *A Centralized Infrastructure:*
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3 A centralized infrastructure was deemed to be important for coordinating service delivery between regional
4 clinics and transplant centres. The tight formal relationship between the BC Transplant and BC Renal enabled
5 the efficient circulation of the mandate for LDKT as the first treatment choice for patients with kidney failure
6 throughout the province. A joint ongoing initiative, called Transplant First, helped to further the mandate for
7 pre-emptive LDKT by standardizing early intervention and referral of patients from the Kidney Care Clinics
8 (KCCs). In addition, BC Transplant and BC Renal are united in joint efforts for accountability and performance
9 monitoring. This includes granulated indicators regarding transplant activity throughout the province. There
10 are consistent efforts for performance improvement. Both share a centralized provincial database through
11 which kidney transplant referrals are coordinated. Interview participants from all along the organizational
12 spectrum of LDKT affirmed strong and supportive leadership from BC Transplant and BC Renal as vital for
13 consistent and efficient care.
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30 *A Mandate for Timely Intervention*

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32 To advance pre-emptive, LDKT province-wide, BC Transplant and BC Renal have mandated provision of
33 information about LDKT to patients as the preferred treatment modality for kidney failure when GFR is ≤ 25 .
34 This intervention generally occurs in regional KCCs. The importance of early intervention was cited by
35 stakeholders along the full organizational spectrum of LDKT. Recent efforts to strengthen early intervention
36 can be seen in separating a single education session about modalities for treatment into separate sessions.
37 Transplantation, with emphasis on LDKT, is the focus of the first session. These efforts also go some way to
38 alleviate overwhelming patients with information about treatment options, which was cited as a concern by
39 many stakeholders.
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52 *An Equitable Funding Model*

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54 BC Transplant uses an activity-based funding model. This means that funding for transplant activity follows
55 the patient as they move through the system and enables the decentralization of transplant-specialized
56 services. BC Transplant funds eight specialized pre-transplant clinics that are linked to KCCs around the
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3 province. Following each patient through the healthcare system, including in regional areas, incentivizes
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5 dedicated roles for transplant activity and coordination across various services. This also reduces
6
7 competition for funds among services and assists in mandating early intervention for LDKT.
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10 11 12 *A Commitment to Collaboration*

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14 High value is placed on facilitating connectivity through collaborative associations in and between local
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16 health authorities and organizations. Furthermore, at a less formal level, working groups, committees, and
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18 cross-provincial events in BC have created strong “communities of practice”. (33) Such collaborative
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20 activities are multi-disciplinary, include transplant and non-transplant professionals and patient
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22 representatives, and span health authorities across the province. This has supported the consistent
23
24 implementation of the mandate for LDKT, and system-wide sharing of lessons from local innovations.
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26 Collaborative networks were also credited for the development and circulation of educational resources
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28 about LDKT for healthcare professionals, patients, and donors, that are used throughout the province.
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34 35 *Cultivating Distributed Expertise*

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37 The full range of interview participants conveyed an awareness of and knowledge about LDKT. The
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39 Transplant First initiative delivered training about LDKT in KCCs throughout the province. This was credited
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41 by KCC service providers as developing expertise about LDKT in regional clinics and fostering a culture of
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43 awareness of the benefits of LDKT as the primary treatment modality for kidney failure. Service providers in
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45 KCCs felt equipped to either discuss LDKT with patients or to refer them to a colleague. Since 2018, BC
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47 Transplant has funded dedicated roles for pre-transplant work-up, either within KCCs, or an adjoining pre-
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49 transplant clinic. This was cited as helping to facilitate early intervention and smoother coordination
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51 between KCCs and transplant centres for LDKT. Recent efforts are also being made to cultivate champions
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53 for transplantation in KCCs.
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59 **Barriers to LDKT in BC**

Divided Accountability Structures

Whilst the partnership between BC Transplant and BC Renal Agency was generally perceived to be strong, some divisions were cited in identifying what organization was responsible for what work, particularly during the recipient pre-transplant work-up. Some challenges to the consistent delivery of LDKT existed in having two provincial organizations trying to coordinate the “spectrum of care” (Unit 1d). Complications occasionally arose from having distinct financial pools and separate leadership. Some perceived barriers to care processes being fully patient centred arose from the distinct purposes and accountabilities of the two organizations.

Disconnected Care Processes

Although the relationship between regional clinics and transplant centres was largely reported as being positive, some silos existed and the processes for facilitating LDKT were characterised by some as “clunky” (Unit 1c). The separation of services sometimes manifested in poor communication between transplant centres and regional clinics. Whilst this was mostly discussed with regards to the recipient pre-transplant work-up, “donor fatigue” from the testing process was also cited as a concern (Unit 2c). Interview participants from regional clinics also reported inconsistent communication and guidelines between transplant centres, which could result in inconsistent care delivery. There were some calls for national guidelines for donor and recipient testing to be reviewed to ensure they are evidence-based and to better standardize the care process.

Missed Training Opportunities

Professional training was inconsistent, and largely “on-the-job” (Unit 3b). Some participants were concerned that a lack of consistency in professional training for LDKT undermined the quality of care. Similarly, variations in training were cited as a barrier to consistent realization of the mandate for pre-emptive LDKT across BC. The training and educational resources provided by BC Transplant and BC Renal Agency were

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3 highly rated, but many healthcare professionals felt they would benefit from more formalized training. The
4
5 need for more culturally sensitive educational resources for patients was also highlighted by many.
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10 *Inequitable Access by Region*

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12 Despite significant efforts to standardize care across the province, inequitable access to LDKT between
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14 regions exists. Expertise and resources for transplantation are centralized in Vancouver, the site of the two
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16 transplant centres. The size of the BC and Yukon territories that these two centres serve and the remoteness
17
18 of many communities creates challenges in accessing the transplant centres for donors and recipients who
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20 live further away from Vancouver. Whilst some aid is available for travel and accommodation through the
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22 Kidney Foundation, many interview participants noted that this did not fully offset the geographical
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24 disadvantages.
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30 *Financial Burden for Donors and Recipients*

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32 The financial burden on donors and recipients was cited as a significant barrier to LDKT along the full
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34 organizational spectrum. Current reimbursement schemes do not adequately cover costs either for donors
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36 or recipients. Financial burden was cited as a barrier for potential recipients to consider LDKT, both in terms
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38 of their own losses and for those of potential donors. Many interview participants called for more
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40 comprehensive efforts to neutralize costs for donors and provide better financial support for recipients.
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46 **Interpretation:**

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50 In this exploratory case study of the best performing health system in Canada, we have identified elements
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52 within the organizational spectrum that facilitate LDKT and those that act as barriers. Data analysis
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54 demonstrated strong links between provincial infrastructure and the processes that facilitate LDKT.
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56 Specifically, the relationship between BC Transplant and BC Renal was identified as key to enabling the
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58 mandate and processes for LDKT to be distributed consistently across the province, and for timely
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3 intervention and referral for LDKT. Barriers arose from silos between these organizations, which manifested
4 as inconsistencies in coordinating LDKT along the spectrum of care. To our knowledge, this is the first
5 exploratory case study to derive detailed knowledge of how a Canadian health system governs LDKT.
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13 Previous work on increasing LDKT has focused mainly on interventions that address patient-level level
14 barriers, which are resource intensive and only modestly effective. (34, 35) Some work on health
15 professional-level barriers have pointed to system-level variabilities and inefficiencies. (20, 36, 37) Outside of
16 Canada, others have analyzed how system- and center-level factors contribute to inequities in access to
17 LDKT. (38-41) However, no study has learned a high-performing health system and shed insight into its
18 successful features, i.e., facilitators, and areas for growth and improvement, i.e., barriers. We demonstrate
19 that BC is able to address patient-and health professional-level barriers via a holistic organizational approach
20 that may explain its consistent success with LDKT.
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33 Building LHSs to inform practice and policy is a research priority for the CIHR; (22) however, a systematic
34 review of 57 studies, pointed to the absence of a consistent definition of what constitutes a high-performing
35 health system. (42) Our case study has identified what facilitates LDKT in BC, and support the seven
36 attributes of a high-performing system, as summarized by the Canadian Health Services Research
37 Foundation. (43) This knowledge makes practical contributions towards system competencies for LDKT. Our
38 qualitative approach to studying the whole-system function of LDKT may also serve as a template for
39 understanding the dynamic health ecosystems that premise LHSs. (44) Our multidisciplinary team
40 exemplifies the leadership and partnership needed to drive mutual learning. (22, 43)
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53 Strengths of our study are the qualitative approach adopted and the multidisciplinary team involved, that
54 includes a patient partner. Interviews were conducted by a qualitative researcher with limited background in
55 transplantation reducing the potential for moderator bias. The organization of our findings responds to the
56 dual purpose of this exploratory case study: both staying true to perceptions of services in BC, but also
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3 rendering them transferrable as barriers and facilitators for LDKT. The following limitations, however, need
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5 to be acknowledged. We did not perform member-checking, i.e., respondent validation, although this has
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7 been criticized for jeopardizing the internal validity of the study given the risk of participants changing their
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9 perspective following the interview. (45, 46) Also, our findings in BC may have limited applicability in other
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11 provinces, however, the present study provides a framework to conduct such an analysis in other provinces,
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13 and to allow cross-jurisdictional comparative analyses.
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19 In conclusion, using an exploratory case study method, we have identified barriers and facilitators to LDKT in
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21 a high-performing health system in Canada. There are several elements to the organizational spectrum of a
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23 health system that facilitates LDKT. Our findings have important implications for policy makers and
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25 practitioners and provides opportunities for cross-jurisdictional comparative analyses and the development
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27 of LHS competencies.
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Table 1: Individuals interviewed for data collection within each level of the organization spectrum

<p>Organization (n=5)</p> <ul style="list-style-type: none"> • Representative from BC Transplant • Representative from BC Renal • Representative from the Kidney Foundation
<p>Care-Teams - Transplant Centre (n=7)</p> <ul style="list-style-type: none"> • Nephrologist • Social worker • Nurse
<p>Care-Teams - Regional units (n=8)</p> <ul style="list-style-type: none"> • Pre-transplant clinic nurse • Kidney care clinic nephrologist • Kidney care clinic nurse • Kidney care clinic social worker • Dialysis centre social worker
<p>Patients (n=2)</p> <ul style="list-style-type: none"> • Donor • Recipients

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Table 2: Selected quotes that illustrate each theme identified as a facilitator to living donor kidney transplantation in BC

Theme	Illustrative Quotes
A Centralized Infrastructure	<p><i>'In BC, there is one provincial health authority, which funds BC Renal and BC Transplant through MOH [Ministry of Health] dollars and has the mandate to enable provincial services. The centralization of funding and clarity of mandate; helps break down the silos to some extent' (Unit 1c)</i></p> <p><i>'I think that's a huge strength in BC, is the communication with the kidney care clinics and the provincial renal agency as well as BC Transplant. We are lucky that it's one big program here. And that the communication is the same and that we work and have the same messaging across centres and sites' (Unit 2c)</i></p> <p><i>'We have the provincial renal agency, which does a lot and they promote a lot. And we have our database and we have – they are always working on new teaching and patient materials and DVDs and stuff' (Unit 3e)</i></p>
A Mandate for Timely Intervention	<p><i>'So generally speaking, the kidney care clinics in our province try to refer people that are transplant suitable, are eligible, when their GFR is around 20-25. So the thinking is that gives us enough time to be assessing them and helping them find a donor in time' (Unit 2e)</i></p> <p><i>'We're seeing that recipients are being referred a little bit earlier for their transplant assessments, but conversations are also starting earlier about living donation. So we will see and hear from living donors much earlier in the process so that they have time to work through it prior, ideally, prior to their recipient needing to start dialysis. So we're really trying to support pre-emptive living donor transplant where we can' (Unit 2c)</i></p> <p><i>'It was just going so perfectly down the road as things went along. And it was sort of nice maybe, not to be flooded with all the information, too.' (Unit 1d)</i></p>
An Equitable Funding Model	<p><i>'So in B.C., we use let's call it an activity-based funding model, meaning you get a certain bundle of funding per patient year of services. And what's built into that is all the activities that are assumed to take place through the year. And so, yeah, that's when they added a lift to specifically say that one of the items, once people got down to a certain GFR, is that they would be assessed for transplant. It's relevant because even though it's just a small amount for each patient, in aggregate, it can become a large amount. And that's what, it actually let some places – like, for example, where I work in xxxx, it let us set up a dedicated, we have a couple of dedicated nurses, who specifically do this transplant work' (Unit 1d)</i></p> <p><i>'It's a lot easier to lobby a transplant organization to give you funding for transplant than it is to lobby a hospital, who has to support everything' (Unit 1a)</i></p>
A Commitment to Collaboration	<p><i>'I think everybody in the renal world is pretty well-connected to ask questions or provide good care and figure out how we can make things work better. We are always kind of asking that question' (Unit 3g)</i></p> <p><i>'there's a large working group that includes nurses, patients, doctors, transplanters and social workers. And they've come up with a work plan [for Transplant First] and they've come up with tools' (Unit 1c)</i></p> <p><i>'That's, I think, the key piece of it. Working together, working collaboratively,</i></p>

	<i>bringing in the regions, working with the kidney care clinics' (Unit 3a)</i>
Cultivating Distributed Expertise	<p><i>'So there is an initiative, a pre-transplant initiative, training all our CKD nurses in terms of recognizing patients that would benefit from pre-emptive transplant and beginning the whole work-up. So the nephrologists are aware of this as well. But this comes from the ground up. So when I walk in to see a patient for clinic, my nurse might say, hey, so-and-so has a donor. I was talking to her about transplant. Can we refer her? So it's not only got the nephrologists thinking about it, but we've also got our nurses prompting us' (Unit 3d)</i></p> <p><i>'Everyone's open to talking about it – all of our team members are open to talking about transplant and feel, you know, some comfort level in doing that' (Unit 3f)</i></p>

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Table 3: Selected quotes that illustrate each theme identified as a barrier to living donor kidney transplantation in BC

Theme	Illustrative Quotes
Divided Accountability Structures	<p><i>'When [BC Transplant and BC Renal] are different groups... there can be a predisposition to, kind of silo things. Which is trying to break apart, whose dollar is it that's paid for which task, as opposed to just say, well, it's a patient, it needs to get done and just get on with it.'</i> (Unit 1d)</p> <p><i>'There are processes at B.C.T over which we at B.C Renal, do not have authority. But some of the processes are a little bit inefficient, but part of that is because they don't have the funding. But I can't give them the funding because that's not how it works'</i> (Unit 1c)</p>
Disconnected Care Processes	<p><i>'... a big challenge for us is – from the recipient side – is making sure that all the tasks that need to be done for them to get approved, worked up and approved, get done. It's challenging just making sure that it's clear who's doing what, because the way it works here, a lot of it is done regionally and then they get referred to the transplant centre downtown. Sometimes there is a bit of confusion of who's doing what and when things are being done. You're sitting around waiting for tests and nobody knows if it's done or not'</i> (Unit 1d)</p> <p><i>'[the pre-transplant process] can be very disjointed and pieces go missing'</i> (Unit 3h)</p> <p><i>'There is a lack of consistency between VGH and St. Paul's, in terms of multiple areas actually, which is a problem'</i> (Unit 3d)</p>
Missed Training Opportunities	<p><i>'I see other social workers that are new to the area who don't understand because they just haven't been through it, they haven't learned about it. They don't understand the transplant process and therefore they can't support patients with that transplant process.'</i> (Unit 3h)</p> <p><i>I'm just frustrated that the people that are actually in the positions, aren't trained in the positions. And the fact that administration seems to think that, well, everything works, so we'll just continue on as it is. You know, we'll bring one person in and we'll train them and then we'll bring another one and we'll train them. And it doesn't work. I mean, we can see it doesn't work.'</i> (Unit 3b)</p>
Inequitable Access by Region	<p><i>'The bad thing is if you live not within driving range of Vancouver, your incentive to get a living donor is potentially marred by the by the notion, a. you've got to be away from home for three months, b. your donor has to come from a way'</i> (Unit 1c)</p> <p><i>'[KCCs in Vancouver] have access to all that knowledge and education and processes, whereas in the regions it's a bit different. We don't have immediate access to that'</i> (Unit 3a)</p>
Financial Burden on Donors and Recipients	<p><i>'I mean, I think everybody understands the financial benefits of living donor transplant. So, you know, this is a resource we are getting for free. So let's put some money into it, for God's sakes. It's ridiculous.'</i> (Unit 2b)</p> <p><i>'But the hardest part for [my donor] was all of that time off and just the financial end of it, you know. Like she doesn't have a husband, like I say, and two kids, and she has to pay rent and – or mortgage, I guess – and it was very hard on her.'</i> (Unit 2b)</p> <p><i>'My challenge is always that we don't – the health care system and, you know, the clinicians, everybody who works to do transplant, we don't want transplant, or finances to be a barrier to transplant. But the reality is, is that it is.'</i> (Unit 3g)</p>

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8 Figure 1. The organization spectrum of living donor kidney transplantation in BC: Based on a Complex

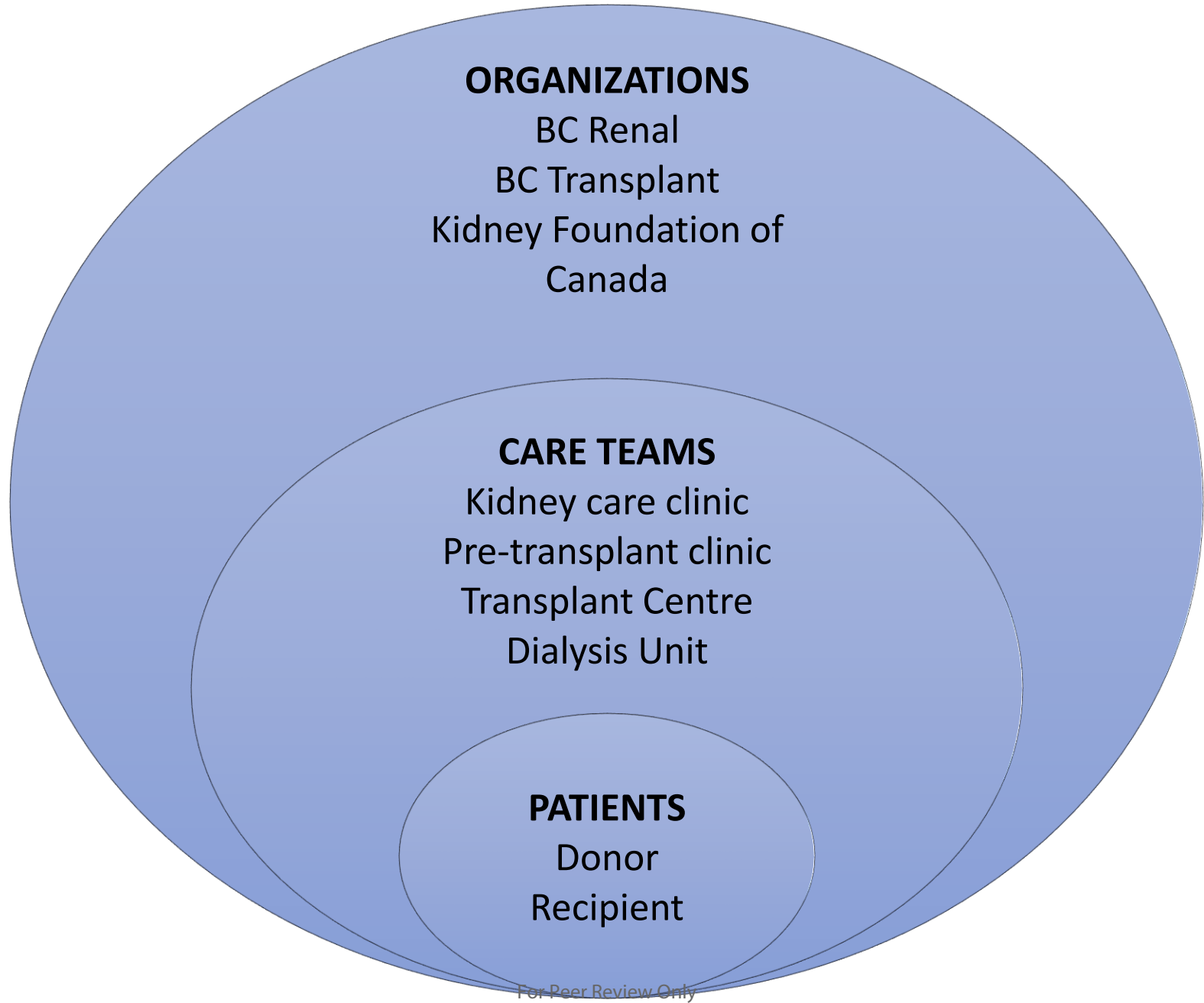
9 Adaptive Systems approach to health systems as multi-level and interconnected networks
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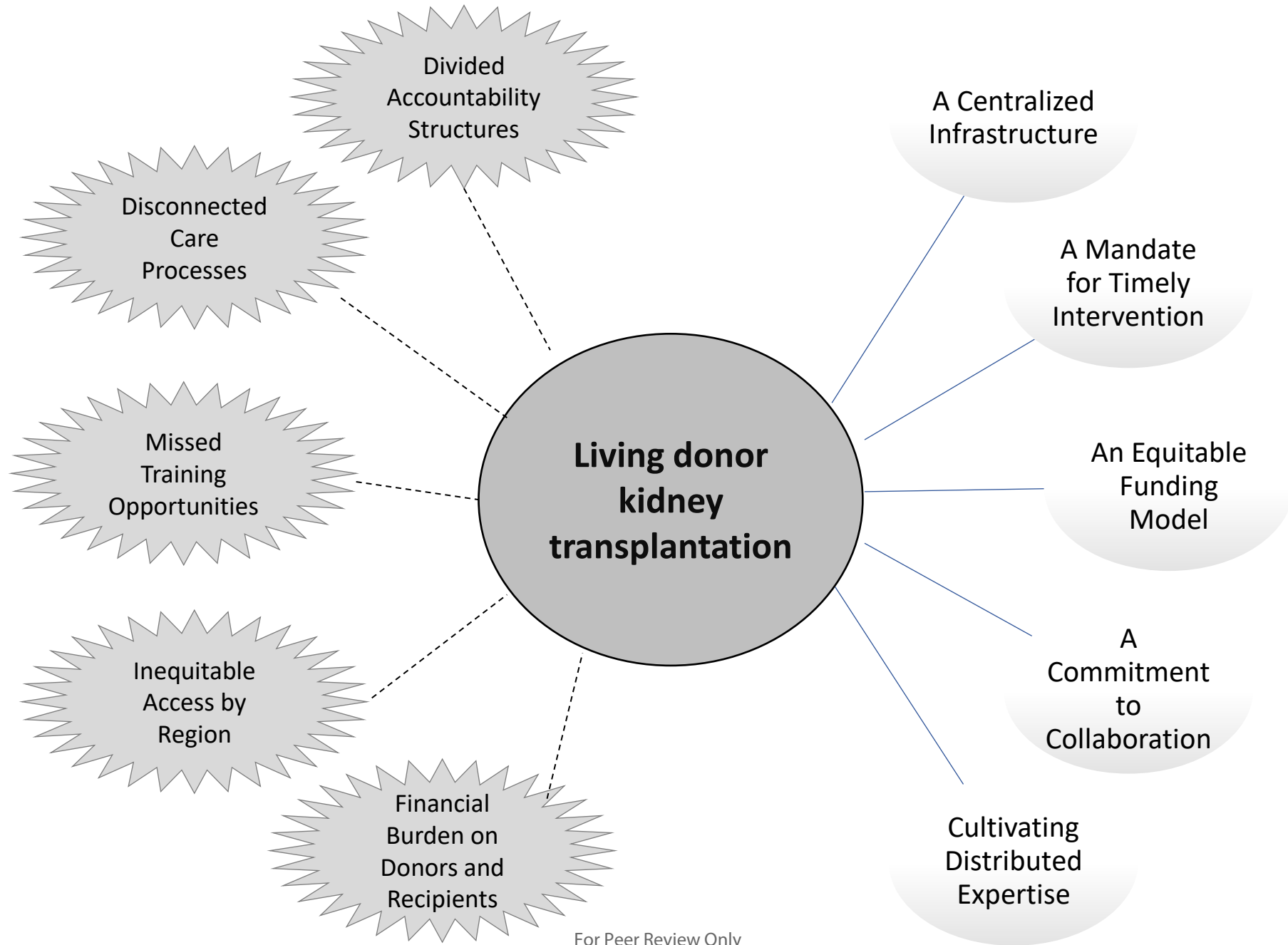
14 Figure 2: Health system barriers and facilitators to living donor kidney transplantation in a high-performing

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