



# Patient, Caregiver, and Provider Perspectives on Improving Provider-Patient Interactions in Hemodialysis: A Qualitative Study

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## Abstract

**Background:** Improving interactions between people receiving hemodialysis and health care providers of facility-based hemodialysis care is a top priority for patients, caregivers, and health care providers.

**Objective:** To identify challenges for high-quality clinical interactions in facility-based hemodialysis care as well as potential solutions.

**Design:** Multicentre qualitative study using focus groups and semi-structured interviews to elicit the perspectives of patients, caregivers, and health care providers.

**Setting:** Five Canadian facility-based hemodialysis centers.

**Participants:** English-speaking adults receiving facility-based hemodialysis for longer than 6 months, their caregivers, and hemodialysis health care providers.

**Methods:** Between May 2017 and August 2018, focus groups and interviews with patients and their caregivers subsequently informed semi-structured interviews with providers. Data were analyzed using inductive thematic analysis with application of a grounded theory approach.

**Results:** A total of 8 focus groups and 44 interviews were completed. Participants included 64 people receiving hemodialysis, 18 caregivers, and 31 health care providers. Communication between health care providers and patients was often characterized as *intersections* of care (unidirectional) rather than *interactions* (bidirectional). Challenges were grouped into 4 main themes as follows: (1) culture of care provision; (2) mistrust between patients and health care providers; (3) time constraints for clinical interactions, and (4) lack of collaboration and care coordination among health care team. Potential solutions were identified for each challenge.

**Limitations:** Findings were limited to Canadian context, English-speaking adults, and individuals receiving facility-based hemodialysis in urban centers.

**Conclusions:** Interactions between health care providers and people receiving dialysis are often unidirectional, where the patient is a passive recipient of ideas and information from the health care provider. To promote improved bidirectional interactions, team-based care that includes better tools to improve information transfer, better information regarding roles, and identity of health care team members and opportunities for all members of the health care team, including the people receiving dialysis, to provide input on care plans is required.

**Trial Registration:** Not applicable.

## Abrégé

**Contexte:** Dans les unités d'hémodialyse en centre hospitalier, l'amélioration des interactions entre les patients sous hémodialyse et les prestataires de soins est une priorité absolue pour les patients, le personnel soignant et les prestataires de soins de santé.



**Objectif:** Identifier les obstacles qui limitent les interactions cliniques de haute qualité dans le contexte des soins d'hémodialyse en centre, et fournir des pistes de solution.

**Type d'étude:** Étude qualitative multicentrique utilisant des groupes de discussion et des interviews semi-structurées pour obtenir les perspectives des patients, du personnel soignant et des prestataires de soins de santé.

**Cadre:** Cinq unités d'hémodialyse en centre hospitalier du Canada.

**Personnes participantes:** Des adultes anglophones recevant des traitements d'hémodialyse en centre hospitalier depuis au moins six mois, leurs soignants et des prestataires de soins d'hémodialyse.

**Méthodologie:** Des interviews et des groupes de discussion menés auprès des patients et leurs soignants entre mai 2017 et août 2018 ont permis de recueillir des données qui ont par la suite guidé des interviews semi-structurées avec les prestataires de soins. Les données ont été traitées par analyse thématique inductive en appliquant une approche de théorisation ancrée.

**Résultats:** En tout, 8 groupes de discussion et 44 interviews ont été réalisés auprès de 64 patients, 18 soignants et 31 prestataires de soins. La communication entre les prestataires de soins et les patients a été plus souvent caractérisée de *point d'intersection* pour les soins (unidirectionnelle) que d'*interaction* (bidirectionnelle). Les obstacles ont été regroupés sous quatre thèmes principaux: 1) culture de la prestation de soins; 2) méfiance entre les patients et les prestataires de soins; 3) contraintes de temps pour les interactions cliniques et 4) manque de collaboration et de coordination des soins au sein de l'équipe soignante. Des pistes de solution ont été proposées pour chacun.

**Limites:** Les résultats se limitent au contexte canadien et aux adultes anglophones recevant des traitements d'hémodialyse en centre hospitalier urbain.

**Conclusion:** La communication entre les prestataires de soins et les personnes sous hémodialyse est souvent unidirectionnelle, les patients étant les destinataires passifs de l'information fournie par leurs prestataires de soins. Pour encourager les interactions bidirectionnelles, il est nécessaire d'instaurer une stratégie de prestation de soins en équipe qui prévoirait des outils pour améliorer le transfert de l'information, de meilleures informations sur l'identité et le rôle des membres de l'équipe soignante, et la possibilité pour tous les membres de l'équipe, y compris les personnes sous hémodialyse, de contribuer aux plans de soins.

## Keywords

hemodialysis, quality of care, qualitative research, patient-centered care, patient engagement

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## Introduction

A gradual shift toward more patient-centered chronic disease management<sup>1</sup> has empowered patients to become shared decision-makers in their care.<sup>2</sup> Research demonstrates that interactions, defined as a mutual or reciprocal action or influence, between health care providers and patients in various health care settings are critical to knowledge translation, empowerment, and better health outcomes.<sup>3,4</sup> Such interactions are particularly important for people with kidney failure requiring hemodialysis, who are often faced with

complex decisions regarding their treatment based on their individual health and social circumstances. People with end-stage renal failure receiving hemodialysis often face multiple comorbidities requiring complex care<sup>5</sup> from multiple specialists, adding an additional layer of complexity to their care provision.

In 2016, the Can-SOLVE CKD (Canadians Seeking Solutions to Overcome Chronic Kidney Disease) Network was established as part of Canada's Strategy for Patient-Oriented Research (SPOR) with a mandate to meaningfully engage patients as co-researchers in the field of kidney health

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research with the objective of improving health outcomes for kidney patients.<sup>6</sup> The Can-SOLVE CKD Triple I project was a multisite Canada-wide mixed-methods study (active from 2016 to 2024) that brought together researchers, nephrologists, clinicians, and patient partners to work collaboratively to advance the quality of care and health outcomes for individuals receiving facility-based hemodialysis.<sup>7</sup> The original framework for the Triple I study was co-developed with patient partners and multiple stakeholders, including researchers and clinicians with the broad aim to identify the key challenges to address to improve facility-based hemodialysis care.<sup>7</sup> The resulting guiding framework in the Triple I study was to improve facility-based hemodialysis care by addressing the 3 identified key challenges to: *interactions* with health providers, *information* provided to patients about their health and health care, and *individualization* of care in facility-based hemodialysis.<sup>7</sup>

The objective of this article is to describe the challenges and proposed solutions to improving *interactions* between health care providers and patients undergoing facility-based hemodialysis as identified by people receiving hemodialysis, their caregivers, and health care providers.

## Methods

In this qualitative study, we conducted focus groups and interviews with individuals receiving facility-based hemodialysis, their caregivers, and health care providers in 5 urban dialysis units across Canada (Calgary, Edmonton, Winnipeg, Ottawa, and Halifax) between May 2017 and August 2018. See supplementary material for focus group and interview guides. In phase 1 of the Triple I project, the researchers utilized qualitative description and content analysis to summarize and organize the data into the Triple I categories (Information, Individualization, Interaction).<sup>8</sup> In 2020, two of the researchers who were part of the original parent study conducted a secondary systematic analysis of the data using a grounded theory approach to identify emergent patterns and themes.<sup>9</sup> The results of this secondary analysis are described in this article. A more detailed description of the methodology, participant selection, and data collection are described in previous publications.<sup>7-9</sup>

## Ethical Approvals and Considerations

For this multisite study, ethics approval was granted by the University of Manitoba Health Research Ethics Board, University of Calgary Conjoint Health Research Ethics Board, University of Alberta Human Research Ethics Board, University of Ottawa Health Sciences and Sciences Research Ethics Board, and Nova Scotia Health Research Ethics Board. All participants provided written informed consent. The COREQ consolidated criteria checklist for reporting qualitative research was followed.<sup>10</sup>

## Patient Engagement

A patient advisory group comprising 4 people with lived experience with kidney disease, who acted as partners in research, formed an integral part of the research team. Since the project's inception, patient partners provided input at all stages of the project, including proposal development, study design, interview and focus group guide development, data analysis, and interpretation.<sup>7-9,11</sup> Two of the patient partners are also members of the Can-SOLVE CKD Indigenous Peoples' Engagement and Research Council (IPERC), promoting cultural sensitivity and awareness in the project and helping to identify relevant issues and solutions for Indigenous peoples.<sup>12</sup> In Canada, Indigenous people are 2 to 3 times more likely to be affected by chronic kidney disease than the average population<sup>13</sup>; therefore, it is integral to ensure that Indigenous voices are represented and considered in the research for relevance and cultural safety. For individuals receiving facility-based hemodialysis, there are unique challenges, disruptions, and constraints that they must contend with. These include time spent dialyzing (often 3 times/week, 2.5-5 hours per time)<sup>13</sup> that interferes with the ability to work, many individuals must move to urban centers from rural and remote areas in order to receive hemodialysis treatment, and they must attend multiple appointments to see care providers for comorbid conditions. By engaging with patient partners with the lived experience related to the unique challenges facing this group, we ensure that the research is relevant for those for whom it matters most.

## Participant Selection

Selection criteria for patient study participants included English-speaking adults ( $\geq 18$  years old) receiving facility-based hemodialysis for  $>6$  months who were able to provide written informed consent. Health care study participants included: 31 health care providers, including 13 nephrologists, 8 nurses, 7 allied health professionals, and 3 managers with experience working in facility-based hemodialysis. We recruited health care providers in-person or via email and recruited people receiving hemodialysis and their caregivers through an information letter posted at hemodialysis clinics. Participants were recruited using both purposive and snowball sampling techniques in order to reach participants that fit the recruitment criteria, including health care providers who work in clinical kidney care, and patients and their caregivers who have experience with hemodialysis. For the purposes of this study, *caregiver* refers to the family member, spouse, or friend of an individual receiving hemodialysis who is aware of their illness and assists with care provision. During recruitment, people receiving hemodialysis were asked if they have a caregiver who might be interested in participating and if so, these individuals were also approached for recruitment.

## Data Collection

Focus groups and interviews were conducted in-person with individuals receiving hemodialysis and caregivers to elicit challenges in hemodialysis care and potential solutions to address these challenges. Patient partners provided input into the development of focus group guides and interview questions. In addition, the Ottawa Hospital Research Institute's needs assessment guidelines and the existing literature guided the development of these guides and questions.<sup>14</sup> The challenges and solutions that were identified during the focus groups with patients further informed the development of the interview guide for semi-structured interviews conducted with health care providers. Data analysis and data collection occurred in succession and concurrently, allowing for refinement of the interview questions based on the results of the focus groups by employing an iterative reflection process. In the interviews, providers were asked to elaborate on the barriers and solutions to hemodialysis discussed in the focus groups.

Focus groups were conducted with patients and caregivers for 90 to 120 minutes and interviews with health care providers ranged from 30 to 60 minutes. Moderation of the focus groups and interviews was conducted by 2 members of the study team with training and experience in qualitative research methods and no pre-existing relationships with participants (K.S., research assistant and J.F., senior study team member). All interviews and focus groups were conducted in-person, audio-recorded, transcribed verbatim, deidentified, and supplemented with field notes taken by the interviewer and/or study team members. The credibility and reliability of the data was ensured by the built-in redundancy of having 2 note-takers present at each focus group and interview.

## Data Analysis

In phase 1 of the Triple I study, we utilized qualitative description and content analysis to sort the data into the 3 Triple I categories (Information, Individualization, and Interaction).<sup>7,8</sup> Transcripts were analyzed according to the participant group, that is, data from people receiving hemodialysis and their caregivers were analyzed separately from those of the health care providers. These 2 perspectives presented in this article are abbreviated as "patients" representing both people living with kidney disease and their caregivers and "providers" representing health care providers.

For this secondary analysis, we conducted a more in-depth analysis of the data related to interaction, employing grounded theory as a methodological approach to inductively develop insights and identify key emerging patterns within the data.<sup>9,15</sup> Grounded theory allows for the data to inform new concepts and theories, rather than working with an existing theoretical framework.<sup>16,17</sup> Two researchers with training

and expertise in qualitative research methods (M.D.T. and P.F.S.) worked closely together and employed open coding to highlight overarching themes within interactions between people receiving facility-based hemodialysis and health care providers. When reading through the transcripts, the researchers wrote memos to capture their thoughts and insights, and noted key recurrent themes in the data.<sup>16,18</sup> The researchers reflected on how these ideas were interrelated in order to extract larger common themes across the narratives. Through an iterative process, themes and sub-themes began to emerge, and it became possible to identify how the themes intersected between the 2 perspectives of patients and providers (Figure 1). We achieved theoretical saturation once the 2 researchers identified no new themes in the data and determined that existing themes were clearly defined.<sup>17</sup> Themes were reviewed and agreed upon by the larger research team, including patient partners. In a previous publication, we identified overarching themes, challenges, and potential solutions related to information using this methodology.<sup>9</sup> This article addresses the findings underpinning interactions between patients and health care providers in hemodialysis care.

## Results

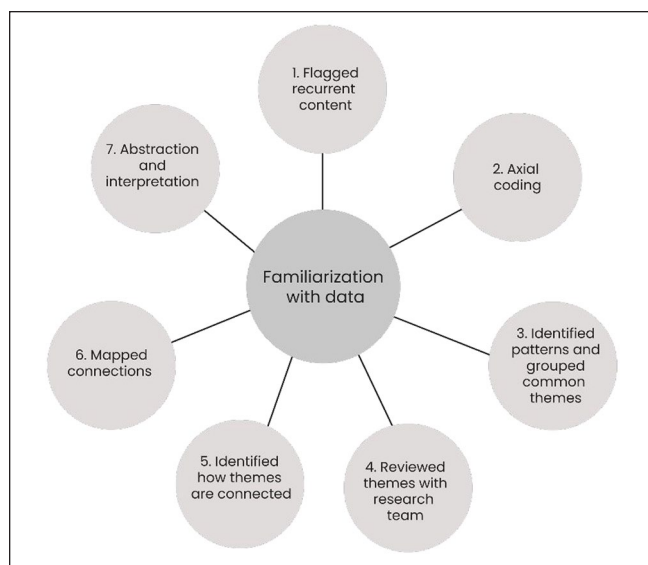
### Participant Demographics

A total of 113 individuals participated in 44 interviews and 8 focus groups. See Table 1 for detailed demographic characteristics of participants. Forty-seven patients and 18 caregivers participated in focus groups in 4 urban centers (Winnipeg, Halifax, Ottawa, and Edmonton). An additional 17 interviews with patients in Calgary (n = 13) and Edmonton (n = 4) were completed. Patients and caregivers had a median age of 60 years (interquartile range [IQR] = 51, 74) and 65 years (IQR = 56, 68), respectively. Health care providers (n = 31) were 77% female and had been in practice for a median of 13 years (IQR = 6, 16). Thirty-three percent of patients and 72% of caregivers were female. The median length of time since initiating hemodialysis for patients was 3 years (IQR = 1, 6).

### Thematic Results

The overarching theme was that communication between health care providers and patients was often characterized as unilateral (from health care provider to person receiving hemodialysis) *intersections* of care rather than *interactions*. In addition, several common themes were identified across both participant groups: (1) existing culture of care provision, (2) mistrust between health care providers and patients, (3) time constraints faced by health care providers, and (4) a lack of collaboration/communication among the health care team (Figure 2). Potential solutions to mediate these challenges as indicated by both participant groups were also identified and are described below.





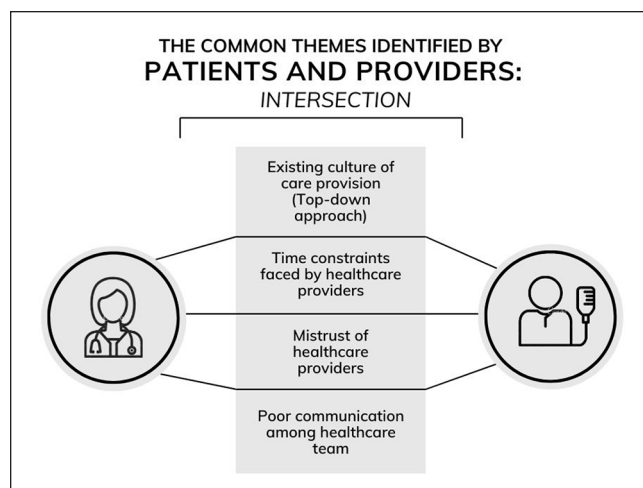
**Figure 1.** Analytic process.

**Table 1.** Participant Demographic Characteristics (n = 113).

	Patients	Caregivers	Health care providers
Overall participation, n (%)	64 (57)	18 (16)	31 (27)
Sex			
Female	21 (33)	13 (72)	24 (77)
Male	43 (67)	5 (28)	7 (23)
Age (y)			
Median (IQR)	60 (51, 74)	65 (56, 68)	—
Location, n (%)			
Calgary	13 (20)	0 (0)	8 (26)
Edmonton	14 (22)	3 (17)	3 (10)
Winnipeg	22 (34)	7 (39)	13 (42)
Ottawa	3 (5)	1 (6)	3 (10)
Halifax	12 (19)	7 (39)	4 (13)
Time since initiating facility-based hemodialysis (y)			
Median (IQR)	3 (1, 6)	—	—
Years in clinical practice			
Median (IQR)	—	—	13 (6, 16)

#### Culture of care—"top-down approach."

**Challenges.** Patients, caregivers, and providers spoke to the less visible aspects of interactions, such as the hierarchy that exists within a culture of care that places providers at the top and the patients beneath. From a patient perspective, interactions generally have a single-pointed focus, which is determined by the nephrologist, "there is one particular doctor that makes his rounds that I always find he's kind of singularly focused on, 'take more fluid off, take more fluid off'" (ID P1). Providers recognized that interactions with patients often fall into a top-down approach, "I think there's a lot of



**Figure 2.** Thematic schema.

telling people what to do and nattering at people and lecturing them . . . it's not a collaborative kind of, iterative process, where we work with our patients" (ID HCP8).

There was a shared perception that patients cannot raise multiple concerns or take up too much time during doctor visits and their questions are often deflected to their primary care providers, "I know they can't stick around and talk to me for an hour, but the only time I have problems, I would like them to help me instead of, 'See your family physician'" (ID P3). Patients described feeling reluctant to ask questions despite receiving encouragement from the health care team to acquire self-management skills, "They don't want us to ask questions, but they want us to take an active role" (ID P85).

**Solutions.** Patients wanted to feel reassured by providers during interactions, "It would be nice if they could just, I don't know, listen to me more" (ID P102). Patients wanted more frequent, scheduled, one-on-one appointments with nephrologists and also expressed the need for a greater sense of community in the unit with more opportunities to get to know providers. For example, handing out a book with pictures and role descriptions of the health care team would be a helpful way to gain a sense of familiarity and know who to direct questions to. Both patients and providers agreed that a mobile application (app) would be an effective way to communicate with each other. A provider suggested an app with multiple categories to reach multiple providers correspondingly, ". . . these are issues that relate to a specific medical problem that I have or, these are issues that I require reassurance about, or these are issues that I require education about" (ID HCP28).

Providers expressed an interest in care approaches that foster relationship building with patients. A provider shared an approach that focuses on problem-solving,

I try and use a motivational interviewing approach with patients . . . When someone has high weight gain, I try and figure it out . . . If it's because they are thirsty, I try and get to the root cause of why they are thirsty. Is their diabetes out of control? (ID HCP8)

Another provider drew attention to the need for greater empathy and collaboration as people with kidney disease experience many hardships through their lives,

I think we need to pay attention to this burden that people have and you know, call them the night before and say that we need to review your medications and could you bring them in, and we will go through them together. (ID HCP8)

### *Mistrust between patients and health care providers*

**Challenges.** Patients overwhelmingly stated that providers were not listening to their needs and concerns. This perceived lack of empathy from providers left patients with a lingering feeling that they are being dismissed by their health care team,

There may be the occasional doctor who has some bit of a heart, but for the most part they are very textbook oriented and they don't realize you have emotions and there's a lot that's on the line here for us, it's our life and we are just like another number to them is what it feels like a lot of the time . . . (ID P67)

At the same time, nephrologists noted that patients withhold important medical information from them when rounding. A provider depicted the following interaction,

Some days you say to a patient, "How are you?" And they say, "Fine, no problems," and then the nurse will tell you that last week they were in the hospital and they've got an . . . infection in their foot . . . (ID HCP11)

On one hand, patients experience a pattern of invalidation by their health care team, and on the other hand, providers are frustrated that patients fail to disclose crucial information regarding their care.

The reluctance to trust providers has led patients to follow what they believe is right for themselves, "At some points if I didn't listen to myself . . . I probably could have passed . . . I honestly felt that way" (ID P39). Some patients pointed out they were unable to relax during dialysis treatments because they did not trust providers, "I had issues with the nurses who would actually come sneaking over to turn [the pump speed] up while I was sleeping and when I opened my eyes and caught her doing it" (ID P19) and "I sit and watch TV all afternoon. I'm watching, because I don't know what they are trying to give me" (ID P72). Patients also raised concerns about undergoing procedures and/or taking medications they did not fully consent to, "[the medical staff] knew I wasn't going to argue so they pretty much did it and each time I protested they basically ignored me . . . leaving an unnecessary scar on my arm" (ID P15).

**Solutions.** Patients expressed a sense of urgency to have more time with providers and wanted their health care team to take the time to be more familiar with their charts. A patient shared, "The nurses need to read your chart and I've caught them three or four dozen times, they do not read your charts" (ID P34). From a caregiver's perspective,

if you can have an appointment with one of the doctors, every six weeks even for 15 minutes, just to discuss your loved one's situation and they can clear up some questions and then you move on with power and you know what's going on . . . (ID P15)

For patients and caregivers, feeling heard, validated, and fully informed by providers is a pathway to regaining trust. When trust is broken or compromised, several patients pointed out that mechanisms and procedures to direct complaints and concerns, such as patient advocacy groups and/or access to a unit manager, would be helpful.

Providers highlighted the power of language and the importance of reframing questions in a way that is open and inviting of the patient's voice. A provider demonstrated how reframing a question can shift the conversation,

Everybody appears rushed and dismissive—any concerns for the doctor? Nope. And that doesn't go any further. But trying to articulate . . . What are your goals? What are the three most important things you want to work on right now? (ID HCP8)

### *Time constraints during patient visits*

**Challenges.** Patients and caregivers emphasized that providers are constantly in a rush and do not have the time to direct the adequate attention to patients. A patient described their experience, "they get so many people to see that they give you 30 seconds at best sometimes" (ID P52). Another patient acknowledged there are systemic issues impacting the ability of providers to take the time to truly interact with patients and drew attention to the nurse scheduling problem, "We are all here before [the nurses] are, and then they show up and have to set everything up. It's very rushed for them. It's at the cost of their sanity and the patients' care" (ID P21). Time constraints further contribute to feelings of dismissal, "They have so many patients that you're thinking that they're listening but they are doing other things . . ." (ID P54). The lack of time in provider–patient interactions was identified as a main barrier to forming trusting relationships.

Providers drew attention to the lack of provincial standards for provider-to-patient ratios in hemodialysis units, and that nurses and doctors are overloaded with responsibilities. Nephrologists identified logistic issues when accessing patients' medical records, such as having to constantly log on to a computer when rounding while already pressed for time. As a result, nephrologists often do not know the details of what each individual patient is going through, "because often times you say, 'oh you look good today,' and then you realize they've just been diagnosed with cancer five days ago and

the patients are thinking, ‘how did you not know this?’” (HCP ID12).

**Solutions.** Due to existing time constraints faced by health care providers and the complexity of care required for patients undergoing hemodialysis, providers suggested the development of an “active issue list.” This tool would include the patient’s key areas of concerns to be discussed and addressed during rounds. Providers acknowledged that keeping such a list updated would require coordinated effort but that it is a way to centre the patient’s voice while utilizing time effectively. A patient indicated they would like to see trainees in the unit to increase the frequency of doctor-patient interactions, “to me this is a great opportunity for a med student to come in and do these things, and we don’t see any med students at all” (ID P131). Patients also suggested that nurses take a break between dialysis sessions to familiarize themselves with the next group of patients.

#### *Lack of collaboration among health care team*

**Challenges.** Both patients and providers talked about communication problems among the health care team in the context of providers being overloaded with responsibilities. One patient said, “we could have a little bit better communication, because I know the doctors are super busy, and the nurses—and they are doing the best they can—I think with the amount of patients that they have and stuff” (ID P61). Uncoordinated care undermines the confidence of patients in the health care team, “You bring something up and no one knows about it, it seems to be endemic in the system, communication problems” (ID P64). Furthermore, a lack of communication ultimately leaves room for medical errors and poorer health outcomes, “the doctor one weekend made a recommendation that I reduce the amount of my pills, but nobody told me, and then a month later I find out, oh you were supposed to reduce your pills, well nobody told me” (ID P26).

Another patient highlighted the frustration involved in speaking with multiple providers about their conditions, “It shouldn’t be like [the film] ‘Groundhog Day’ either, right, just repeat yourself every treatment” (ID P62). The lack of mechanisms to maintain an open line of communication among providers can cause confusion for patients: “I come in for my dialysis, and they are telling me something different. You know I’m just one person, I don’t need six people telling me six different things to try to adjust to” (ID P48). Having multiple health care providers requires a certain level of collaboration to ensure patients are not having to repeat themselves nor having to discern between numerous recommendations for treatments.

**Solutions.** Patients suggested receiving a binder containing pictures and role descriptions of the providers working in and with the dialysis unit, “you get 12 nephrologists, and all of these nurses, and five different dieticians, why don’t they

give us a book of pictures of who’s, who? What doctor does what?” (ID P135). Being able to identify the different staff and knowing who to direct questions to would leave patients feeling better situated in their care.

The value of holistic team-based care is explained by a nephrologist,

Nephrologists, we don’t understand all the issues with respect to some of the general screening practices or, you know, other aspects of care, so I really think it’s important that they also maintain connections with their family doctors and so if that was clearly indicated, . . . it would help them to understand that. (ID HCP 16)

Some challenges could be alleviated if patients were informed about their team of care providers and which issues to raise with which providers.

Nephrologists highlighted the importance of team-based care and made practical suggestions to ensure continuity of care, “there are some units where the charge nurse will come around and round with you . . . ’cause then the charge nurse can say, yeah this is an issue that they’ve had that’s being looked into by their family doctor” (ID HCP11). Adding tools to the unit to improve information transfer such as a checklist system, an app, computers that are already logged in, and rounding tools such as a binder or other style of notebook were identified as effective. One provider explained,

I was wondering about using iPads or something, or just something that is more portable than that big computer on a big system that you have to drag around. So, something that was more functional, maybe dropdown menus or tick boxes. (ID HCP 16)

Using a smaller device to access the patient’s medical record holds the potential to be effective and efficient, but providers pointed out the challenges of operationalizing such a tool, “You have to have a [provincial health authority] approved device—they are usually clunky. You have to double authenticate everything. It becomes so cumbersome that a lot of the things that could make care more efficient are not usable” (ID HCP19).

## **Discussion**

Our findings suggest that interactions between providers and patients were typically unidirectional and often influenced by (1) the culture of care provision, (2) mistrust between patients and providers, (3) time constraints, and (4) a lack of collaboration among the health care team.

Interactions between health care providers and patients are a critical component to care provision. Not only do these interactions facilitate a transfer of information, they also serve to develop a rapport, relationship, and trust on both sides. In determining how successful an interaction is, one

must first identify what constitutes an interaction? Lexically, “interaction” is defined as “a reciprocal action or influence.”<sup>4</sup> With this concept in mind, it is important to consider that for an interaction to be successful, it must have a certain condition which permits and promotes a sense of mutuality. Within the hemodialysis setting, our findings suggest that the interaction between health care provider and patient resembles an *intersection* more closely than an *interaction*. At the interface of these *intersections* of care, the patient becomes a passive recipient of an injection of ideas from the health care provider. In a study by Lederer et al,<sup>19</sup> patients perceived themselves in a subservient role as “listener” in relation to the medical doctor. A key finding in the study by Lederer et al<sup>19</sup> was that a lower level of knowledge about chronic kidney disease inhibited the ability of patients to communicate with their doctors. However, the participants in our study highlighted the desire to actively engage in their care and hold meaningful interactions with providers.

## A Way Forward

*Moving from existing culture to patient/person-centered care.* Previous studies have identified power dynamics within renal programs where providers are positioned as the sole experts and patients become recipients of care.<sup>2,20,21</sup> Patients in our study echoed a common concern that their autonomy was undermined in the existing model of care. Bear and Stockie attributed this behavior pattern to medical education, which traditionally has taken on a top-down approach of “‘doing to’ and ‘doing for’” instead of “‘doing with’” and taking time to incorporate patient expertise on their condition and experiences.<sup>2</sup> Similarly, in a study by Havas et al,<sup>22</sup> patients expressed that they wanted to receive more than just factual information about chronic kidney disease from providers and that they wanted providers to also convey a sense of support and encouragement during interactions. In this cross-sectional study, patients rated the aspects of self-management they wanted more support with and the area that received the highest rating was “keeping a positive attitude and taking care of mental and physical health” (22:3). Morton and Sellars emphasized the need to move from patient-centered care (a focus on a patient’s health care needs) to person-centered care, which looks at an individual beyond the clinical setting.<sup>21</sup> The principles underpinning person-centered care promote the recognition of a person’s values, individual preferences, and overall personhood, and bring a stronger sense of mutuality in the relationship between service providers and users.<sup>21</sup> Recent focus on more person-centered care may ameliorate these dynamics in the future as current trainees move into practice.

One way to promote a more person-centered care approach is to offer communication training for health care providers. NephroTalk is a communications skills workshop to guide nephrologists on how to navigate difficult conversations with patients who are terminally ill.<sup>23</sup> The training workshop

focuses on teaching nephrologists to respond to patients with empathy in 2 specific situations, delivering bad news and establishing goals of care. In a study by Cohen et al<sup>24</sup> in 2021 exploring acceptability and utility of NephroTalk, 108 fellows rated the multimodal curriculum very highly. Although the NephroTalk curriculum focuses on a specific dialysis population undergoing conservative care, it holds some promise to improve communication skills between providers and patients.

One-sided care dynamics have been improving over recent years as Canadian medical organizations and health research funders have been calling for the implementation of person-centered care and patient engagement in research.<sup>2</sup> The downstream effects of engaging patients in all aspects of their health care, including decision-making, care provision, care delivery, and health research, may become more apparent as the paradigm shifts toward empowering patients and promoting a person-centered health care system.

*Building trust and effective communication.* For communication to be effective, patients need to trust their providers and providers need to trust their patients. There must be time and openness to facilitate an exchange of information that is listened to and heard from both sides. Communication between care provider and patient must be regarded as an authentic transmission of information for both parties to feel trust.<sup>25</sup> According to Arnason, the practice of authenticity, which is “based on mutual trust and responsibility, would enhance common decision-making and overcome the alienation between patients and professionals” (25:227). Authenticity in the patient-provider relationship would establish ethical decision-making and enable patients to gain a greater sense of autonomy.

In a study examining communication between renal dietitians and patients with chronic kidney disease, Morris et al<sup>26</sup> found communication to be “helpful” or “unhelpful.” If the renal dietitian takes an approach that could be described as “paternalistic,” patients are less likely to follow the information provided and the transactional engagement is rendered ineffective or “unhelpful.” In contrast, if the communication style is of a patient-centered approach, the engagement and communication becomes “helpful.”<sup>26</sup>

Indigenous peoples in Canada and globally are disproportionately affected by chronic kidney disease.<sup>13,27</sup> Cultural safety training provides a means to foster respect and integrity in interactions between Indigenous people on hemodialysis and non-Indigenous providers.<sup>28</sup> One-time cultural safety training does not effectively address communication barriers<sup>29</sup> and needs to be followed up with real efforts to “look beyond the patient-provider interface and challenge the structural and systemic causes of racial oppression” (29:3). Establishing trusting relationships is a key element of cultural safety and enhances interactions between patients and providers.<sup>28</sup> A study examining the experiences of Aboriginal people receiving hemodialysis care in Australia



suggested that more informal initiatives to support meaningful conversations between patients and providers are needed.<sup>30</sup> The authors suggested that a “tea room” may be an effective pathway for patients and providers to talk, connect, and get to know each other beyond a rigid medical setting.<sup>30</sup>

Communication challenges may also have been exacerbated by the COVID-19 pandemic and related restrictions (2020-2022 in Canada), such as mask-wearing, social distancing measures, and a shift to remote/virtual care, all of which may have hindered fostering relationships between patients and providers in facility-based hemodialysis.<sup>31</sup>

**Alleviate time constraints through collaboration.** Health care providers in hemodialysis care face enormous time constraints in their capacity to spend time with patients, given their volume of patients, high patient-to-provider ratio, and ever-increasing patient load. These constraints place pressure on providers to make the interaction as efficient as possible in order to best address the patient’s health concern within the shortest time available. In one review article, the authors point out that despite the goal of personalizing patient care, “it is just not possible to spend 10 min per patient when 50 or more patients are treated during a 4- or 5-[hour] shift” (33:786). The authors suggested the use of continuous quality improvement (CQI) processes to evaluate quality of care in hemodialysis facilities and improve patient outcomes. Although CQI is an effective way of measuring and standardizing health care quality at a system level, rigid protocols can diminish the autonomy of health care providers.<sup>32</sup> The nuances of communication and individualized care could be further compromised, thus impinging on meaningful interactions between health care providers and patients.

Our findings reveal that *interactions* in the hemodialysis care setting offer opportunities for improvement with key areas to address. Although interactions are a multifaceted concept, the overarching themes are centered on communication and trust. Building trust and improving communication strategies both between patients and providers, and among providers can optimize patient care in hemodialysis care. By integrating person-centered care into training programs, health care providers will build capacity for effective communication, noting that it requires time, authenticity, respect, and trust.<sup>22</sup> Establishing collaborative team-based care and adopting technological tools and innovations may alleviate existing time constraints faced by providers.<sup>33,34</sup>

Currently, we are testing a selection of prioritized solutions to address some of the key challenges identified in this project.<sup>20</sup> We recently conducted a cross-sectional national survey to assess the interest in bringing health care providers who normally provide care outside of the hemodialysis unit into the unit to improve quality of care and communication. Of 331 respondents, including people receiving hemodialysis, their caregivers, and hemodialysis health care providers,

most respondents indicated that they support this approach. Based on the results of this survey, the Hubs of Care project is currently ongoing in 5 Canadian centers and will assess the effect of bringing the top 3 health care providers that were identified (including mental health, diabetes, and foot care specialists) into the hemodialysis unit on patient satisfaction and quality of care.<sup>35</sup>

## Strengths and Limitations

A strength of our study is meaningful engagement with patient partners throughout all stages of the study.<sup>7-9</sup> Our study team includes 1 Indigenous researcher and 2 Indigenous patient partners, further strengthening the study by ensuring there is a culturally safe lens to the research. In addition, our study is strengthened by gathering diverse perspectives using a pan-Canadian participant sampling approach. Possible limitations to this study include a relatively long length of time (median 3 years) that participants received hemodialysis, participants were English-speaking, and results only represent urban facility-based hemodialysis experiences in Canada. Data were collected prior to the COVID-19 pandemic; therefore, it is unknown if COVID-19 pandemic restrictions further exacerbated patient and provider interactions.

## Conclusions

In conclusion, communication between health care providers and patients may be negatively characterized as an *intersection* of care rather than an *interaction*. Interactions allow knowledge to flow in both directions in a bilateral exchange of ideas, whereas an intersection refers to the knowledge being imparted unilaterally. Providers could seek to build a rapport through mutual respect, cultural sensitivity, and taking time to build a relationship and trust, thus encouraging questions, knowledge sharing, and self-care management. Training and capacity-building for health care providers to improve authentic communication could help to ensure information is transferred bidirectionally and understood by patients. Promoting and expanding the concept of a multidisciplinary health care team within the hemodialysis unit could help alleviate time constraints and improve continuity of care and health outcomes.

## Ethics Approval and Consent to Participate

For this multisite study, ethics approval was granted by the University of Manitoba Health Research Ethics Board, University of Calgary Conjoint Health Research Ethics Board, University of Alberta Human Research Ethics Board, University of Ottawa Health Sciences and Sciences Research Ethics Board, and Nova Scotia Health Research Ethics Board. All participants provided written informed consent.

## Consent for Publication

Not applicable.

## Availability of Data and Materials

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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## Supplemental Material

Supplemental material for this article is available online.

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