



An Exploratory Study of Person-Centered Care in a Large Urban Hemodialysis Program in Canada Using a Qualitative Case-Study Methodology

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Abstract

Background: Person-centered care (PCC) can benefit patients, clinical staff, and health care organizations, but has not yet been widely adopted into practice. Hemodialysis is a unique care environment in which clinical staff can be involved with patients for protracted periods of time each week and often over a number of years. While kidney care is arguably more holistic than other chronic condition management programs, most patients requiring hemodialysis do not receive care that is optimally person-centered.

Objective: The purpose of this research was to explore how care is experienced and provided in a large urban hemodialysis program in western Canada in relation to key principles of PCC. In addition, we wanted to understand what factors at an individual, unit, and organizational level facilitate or inhibit PCC in this environment.

Methods: We used a qualitative case-study approach to explore multiple perspectives of care provision using a number of data sources including semi-structured interviews with patients, family members, clinical staff, and administrative staff, as well as observing patterns of clinical practice in local hemodialysis units.

Findings: In our study of a single hemodialysis program, we found limited evidence of PCC. Overall, patients reported that their care was good and they had positive relationships with their care team. However, they did not feel involved in decisions regarding their care or consider it to be individualized. In general, providers acknowledged the potential benefits of PCC but were constrained in their practice by a number of factors, including individual perceptions of their role, a prescriptive care environment, and an organizational focus on managing demand.

Conclusions: Evidence of PCC within hemodialysis services was limited, with a number of individual, unit level, and organizational barriers mitigating against its adoption and spread.

Abrégé

Contexte: Les soins axés sur le patient sont bénéfiques pour les patients eux-mêmes, mais également pour le personnel clinique et les établissements de santé. Néanmoins, ils demeurent peu adoptés en pratique. L'hémodialyse constitue un contexte de soins unique où le personnel clinique est impliqué auprès des patients pendant de longues périodes chaque semaine et souvent, pendant plusieurs années. Les soins en néphrologie sont probablement plus holistiques que les autres programmes de prise en charge des maladies chroniques, mais la plupart des patients qui nécessitent des traitements d'hémodialyse ne reçoivent toujours pas des soins individualisés.

Objectif: Cette étude visait à examiner, du point de vue des principes clés de la prestation de soins individualisés, la façon dont les soins sont prodigués et reçus dans un vaste program d'hémodialyse en milieu urbain dans l'Ouest canadien. Nous souhaitons également connaître les facteurs au niveau de l'individu, de l'unité de soins et de l'établissement de santé, qui facilitent ou entravent la pratique de soins davantage axés sur le patient dans un tel environnement.

Méthodologie: Nous avons adopté une approche des études de cas qualitative pour examiner un certain nombre de modèles de prestation de soins en utilisant plusieurs sources de données, notamment des entretiens semi-structurés avec les patients, leurs proches et des membres du personnel clinique et administratif, et l'observation des modèles de pratique clinique dans les unités locales d'hémodialyse.

Résultats: Dans notre étude, menée dans un seul program d'hémodialyse, nous avons recueilli peu de preuves d'une prestation de soins personnalisée. Dans l'ensemble, les patients ont indiqué recevoir de bons soins et entretenir de bonnes relations avec le personnel soignant; tout en ajoutant ne pas se sentir impliqués dans les décisions relatives à leurs soins,



ni considérer que ces derniers étaient personnalisés. De leur côté, les fournisseurs de soins reconnaissent les avantages potentiels des soins personnalisés, mais se disaient limités dans leur pratique par un certain nombre de facteurs, notamment la perception individuelle de leur rôle, un environnement de soins normatif et une orientation organisationnelle axée sur la gestion de la demande.

Conclusion: Les données probantes attestant d'un program de soins individualisé dans le contexte de l'hémodialyse se sont avérées limitées; et un certain nombre d'obstacles, tant sur le plan individuel, de l'unité de soins que de l'établissement de santé, ont atténué l'adoption et la propagation de ces soins.

Keywords

hemodialysis, person-centered care, research, nephrology, service delivery, organizational support

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What was known before

Person-centered care is increasingly cited as a key component of high-quality health care and yet its adoption into practice is limited. Patients requiring maintenance hemodialysis often have a high illness and treatment burden and are likely benefit from care that is individualized and enabling. Although there is evidence that person-centered care can improve outcomes for patients, providers, and organizations, its optimization in practice is limited.

What this adds

This research identified a complex mix of interdependent factors that influence how care is provided within a hemodialysis program, including factors that inhibit and/or facilitate person-centered care. The findings are important if we are to improve patient experiences of health care and make more effective use of health care resources.

Introduction

Patients treated with maintenance dialysis have a high illness and treatment burden and their care often requires considerable health care resources.¹ The burden experienced by patients can be accentuated by care delivery systems that are disease specific, episodic, process focused, and fragmented. Hemodialysis is a unique care environment in which clinical staff can be involved with patients for protracted periods of time each week and often over a number of years. While kidney care is arguably more holistic than other chronic condition management programs, most patients requiring

hemodialysis do not receive care that is optimally person-centered.²

Person-centered care (PCC) is individualized, personalized, and enabling and requires patients be treated with compassion and respect.³ Person-centered care represents a shift away from traditional systems of care that are often organized for the convenience of providers⁴ toward those that focus on the needs and preferences of individual patients. Person-centered care has several potential benefits which include improved health outcomes,⁵ increased patient satisfaction,⁶ and reduced demand on health services. Despite this, contemporary care within hemodialysis services tends not to be based on principles of PCC, but instead is typically (1) organized to suit providers,⁴ (2) mainly disease specific,⁷ and (3) focused on dialysis delivery and optimizing metabolic and dialysis-related targets.⁸ Patients requiring maintenance hemodialysis often have complex health needs and meeting these can be challenging. Many are multimorbid, require polypharmacy, and often have conditions associated with advancing age, including reduced mobility, cognitive impairment, and frailty.⁹⁻¹¹ Accordingly, patients who require hemodialysis are typically managed by multiple providers, which can lead to fragmentation of care.

Addressing patient and system-level complexities is challenging. It requires an interdisciplinary approach through which the patient's beliefs, values, and expectations regarding their wellbeing and care are fully explored, understood, and documented. These should then be shared through ongoing dialogue between the patient, significant others, and members of the dialysis team.¹² Although PCC has been widely accepted as a philosophy of care, its adoption in practice is limited.¹³

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The purpose of this study was to explore how care in a contemporary, large, urban hemodialysis program in western Canada is delivered and experienced in relation to some key principles of PCC.

Methods

Case study¹⁴ is useful when studying complex phenomena in naturalistic settings.¹⁵ It typically involves a small number of cases, usually only one, and this allows the case/cases to be studied in depth (see Appendix A). This exploratory approach was aimed primarily at improving our understanding of care in the sampled dialysis facilities, from the perspectives of those who use and provide these services. Rather than being able to generalize from the findings, case study provides “working hypotheses” from which understanding other cases (transferability) may be possible depending on the similarities between the source case and the target cases.¹⁶ The “case” and unit of analysis is care provision within hemodialysis.

Participant Selection and Recruitment

We conducted the study over 30 separate days between April and December 2017 in 3 hemodialysis units: 1 in-hospital and 2 satellite units affiliated with a large hemodialysis program in western Canada. The study sites include in-hospital and in-center conventional hemodialysis as well as in-center nocturnal and home hemodialysis. These areas were purposively selected to determine whether care provision varied across different sites. Patient and family—we included patients enrolled in a maintenance dialysis program and family members who were 18 years of age or older and who spoke English.

Patient and Family Members

Nurses on the unit approached patients who were not confused or acutely unwell and asked whether they were interested in speaking to a researcher about their experiences of care. The researcher provided an information sheet and obtained written informed consent (CHREB ID REB16-2115). Patients were encouraged to share the information with family members and to inform the researcher if any wanted to participate in the study. Most patient participants and family members chose to be interviewed during dialysis/at the dialysis facility; others chose a private office or a coffee shop.

Health care Providers

The director of the dialysis program informed health care providers of the study, and unit managers gave permission to approach individual members of staff on the hemodialysis units. Some staff chose to be interviewed at work and others off-site. The principal investigator on this study (a nephrologist) sent an electronic invitation to medical staff who were interviewed in a place of their choosing.

Table 1. Participants (n=49).

Interviewees (n=49)	
Characteristic	Frequency (%)
Patients	20(41)
Family members	6(13)
Nurses	9(18)
Nephrologists	6(12)
Social workers	3(6)
Managers	5(10)

Table 2. Demographic characteristics of patients (n=20).

Patients (N=20)	
Characteristic	Frequency (%)
% Female	7(35)
Age (years)	
<50	4(20)
51-64	7(35)
>65	9(45)
Marital status	
Single	5(25)
Married	13(65)
Other	2(10)
Employment	
Full/part-time	2(10)
Retired	11(55)
Unemployed	7(35)

Table 3. Demographic characteristics of healthcare providers.

Healthcare providers (N=23)*	
Characteristic	Frequency (%)
% Female	17(74)
Age (years)	
29-34	5(22)
35-44	11(48)
>45	7(30)
Years in current role	
<5	6(26)
6-10	12(52)
>10	5(22)

*Healthcare provider characteristics are aggregated to protect confidentiality

Participant Characteristics

A total of 49 people were interviewed: 20 patients, 6 family members, 9 nurses, 6 physicians, 5 managers, and 3 social workers. See Tables 1, 2, and 3 for characteristics of participants. Some categories of participant characteristics (particularly providers) were aggregated to maintain confidentiality (at their request) (see Table 4).

Table 4. Individual-, Unit-, and Organizational-Level Barriers to Person-Centred Care.

Barriers to person-centered care		
Individual	Unit/facility	Organization
Professional practices: role perception, beliefs, and values	Stressful work environment, limited support from leadership, management	Resource allocation, increasing demand on services
Workload, time constraints	Limited opportunities for team working/ collaborative practices, limited evidence of integrated working both clinically and managerially Focus on dialysis delivery, task oriented, routinized, prescriptive work practices	Structure of care, lack of opportunities for clinical staff to influence/be involved in organization of care

Data Collection

The first author (R.L.) digitally recorded interviews that were guided by a set of semi-structured questions (Appendix B); R.L. is a nurse practitioner in nephrology and a post-doctoral fellow who is familiar with the field but not practicing in any of the clinical areas. While PCC is diversely interpreted in the literature, for the purposes of this research, the questions for providers focused on how care is delivered and the challenges to providing the care that they wanted to. Interviews with patients and family members explored how their illness impacted on their life, their experiences of care, and the extent to which they were involved in planning and evaluating it. Interviews and written fieldnotes were transcribed verbatim. Day-to-day activities within the dialysis areas were observed (R.L.) over 30 hours and at various times of the day. These observations included interactions between patients, family members, and health care providers, as well as physician rounding. Fieldnotes handwritten during observation periods and interviews were another data source used to support or clarify situations and interview data.

Analysis

There is no consensus on the definition of PCC or agreement on its constituent parts: “terminology changes over time and over successive central administrations, so the evidence base is confused and confusing.”^{17(p4)} Many definitions have evolved from the Institute of Medicine’s 6 principles (or domains) of PCC that include care that is responsive to, and respectful of, individual patient preferences, needs and values, and ensuring that clinical decisions are based on these values.¹⁸ For the purposes of this research, care was identified from the interview and fieldnote transcripts by the researcher (R.L.) as person-centered if it reflected *principles* of PCC such as personalized, coordinated, and enabling. Similarly, *activities* were considered person-centered if they facilitated PCC, that is, through shared decision making, supported self-management, and/or collaborative/team based care.¹⁷

Data were inductively coded by one researcher (R.L.) and categorized into emergent themes using NVivo® to manage the data. These themes were generated from different participant group perspectives and the researcher’s (R.L.) observations of clinical encounters. Dominant and sub-dominant themes were identified, those not directly linked to care provision or experience of hemodialysis care, and were excluded from the ongoing analysis, such as, patient transport. This was mainly to circumscribe the volume of data and to allow more in-depth analyses of the remaining themes. Two other researchers independently reviewed a number of transcripts to confirm themes and consistency in data analyses. Similarly, respondent validation¹⁹ was undertaken with a number of participants reviewing the findings and checking the researcher’s interpretation and whether their experiences resonated with the described care.¹⁴

Findings

Findings are organized under 3 broad headings individual, unit/facility, and organization (Table 5). These represent care contexts that varyingly influence the delivery of activities. The categories are not mutually exclusive and are largely interdependent but are useful in identifying where certain drivers of practice reside and where intervention is necessary if change is to occur. For logistical reasons, the research focuses on care at the individual patient/clinician level, although the other 2 levels are alluded to. To preserve the identities of individual participants, we report the findings collectively.

The prominence of themes varied in degrees across the service areas. For instance, while time was a constraint for all care providers, it was more evident in the in-center unit where patient acuity, dependency, and instability were higher than the satellite units. The results from all the service areas were reported together. See Appendix C for a summary of themes.

Individual, Clinician-Patient Level

In general, patients were very satisfied with their care and they liked and respected the nurses and nephrologists. Patients believed the nurses knew them and were knowledgeable

Table 5. Themes and Selected Quotations/Observations.

Theme	Selected quotations/observations
<p>Individual Patients' and nurses' perspectives</p>	<p>You can have a doctor one week who changes an order and then a different one the next week who changes it again, you might not see either doctor again for 6 months and then another doctor comes and says, why did they make these changes. I'm like, don't ask me . . . they don't ask you what the problem is, they just like to change things [. . .] my own doctor is not like that but she isn't able to come very often. (Satellite patient 15)</p> <p>He doesn't know me, he's telling the nurses to drop my weight, I'm trying to tell him that we tried that and I was unwell, and he's like rushing on to the next person [. . .] I wish they [the doctors] would just listen. (In-center, patient 14)</p> <p>[Primary nephrologist] he's so wonderful. You know, he's gone above and beyond you know . . . but I don't see him enough. (Home patient 1)</p> <p>I think he's a great physician. I really like him, I think he's a good nephrologist. I again, would probably get down to that wishing that maybe there was more communication or just even caring about some of the things that I suggest alternatively. (Nocturnal patient 11)</p> <p>The relationships that we are able to build with our patients are a tremendous draw [. . .] it's tremendously rewarding. (nurse 8)</p> <p>[I]t was so awful when they died, I was so upset . . . I had known him for about 10 years, I knew all about his family . . . he was funny, he used to make us all laugh" (Nurse 6).</p>
<p>Professional practices, role perception, beliefs, and values</p>	<p>You only need three things in order to be a great dialysis nurse: are you able to justify your fluid loss; are you able to justify your electrolyte prescription based upon your bloodwork; is your access working ok or do you need to address it to the doctor? (Nurse 3)</p> <p>Primarily in here our focus is dialysis, right. It's the same thing as, I don't even know if it's even an implacable question that if you bring someone to ultrasound, do you really have to have all the history of the patient in order to treat them? (Nurse 3)</p> <p>We also have doctors that, when they go in there [dialysis unit] they're like, just do the same thing as before even though they haven't really assessed the patient that well. (Nurse 3)</p> <p>I mean the argument is often given as though, we don't have time for that. And maybe you don't have time for a 100% of that every encounter every time, but if that's your fundamental belief of how you perform care, you have time to treat people with respect. You have time to speak to people and understand their preferences and manifest them in the ways that you can. (Nurse 6)</p>
<p>Unit/facility Stressful work environment, limited support from leadership, management</p>	<p>I've been in the hemo unit with people who don't have good attitude and I just roll my eyes and thinking, go home if you don't want to be here. Don't take it out on the nurses, they're doing the best they can. Don't be a dick go home. They're keeping you alive for crying out loud. (Nocturnal patient 8)</p> <p>Am I trusting myself to a leadership team that knows what they are about or not? And, because we don't have really any communication and the answer to that is somewhat unclear to me. (Nurse 7)</p> <p>So some of the phrases attributed to the leadership are, "the morale in this place is not my problem." (Nurse 7).</p>
<p>Limited opportunities for team working/collaborative practices, limited evidence of integrated working both clinically and managerially</p>	<p>[Researcher] Do you have meetings where you can share information and concerns you may have about a patient?</p> <p>No, I just tell the nurse clinician or the doctor if I see them. (Nurse, 5)</p> <p>There's many barriers to good multidisciplinary care [. . .] trying to get a team to participate in working together to care for the patients is very difficult. (Nephrologist 6)</p> <p>Myself and another physician have tried to participate in these operations meetings, but there is no updates on what's going on. So, it's very difficult and intense relationship with the operations. I feel like the management doesn't have a lot of mentorship and the management style is very controlling . . . it's just a very difficult culture and I think the physicians have been trying really hard to improve nurse moral but the managers and nursing staff need to take some responsibility and help with that because I personally think that nurse morale is very low. (Nephrologist 6)</p>

(continued)

Table 5. (continued)

Theme	Selected quotations/observations
Task-orientated, prescriptive work practices	<p>There's all these checklists that have been developed, things need to get done and they have this culture of blitzing, so we are going to do this blitz this week, this blitz week, this blitz this . . . instead of looking at the person as a whole [. . .] they [the nurses] should be getting to know the patient as a person instead of just doing these checklists and trying to compartmentalize care. (Nephrologist 6)</p> <p>Medically wise, what their current issue is in the unit, you have to do it yourself and you have to find out, but now again because of the rounds we are doing we are trying to focus on that, which can be hard too because you are swamped at times already and you are trying to learn this patient. (Nurse 2)</p> <p>Their [the management] clear preference is people who know and complete the policies unquestioningly and who place an emphasis on the biomedical, optimizing the biomedical and the timetable, if you demonstrate a critical voice, that will be marked against you. (Nurse 7)</p> <p>Like every patient is different however we follow the same routine for everybody, like this patient, I know he is very stable with his BP and everything, why [do] I still have to check every half hour and have to document every half hour. We are writing stuff nobody is going to read. (Nurse 8).</p> <p>You know it is all routine . . . why not . . . like I use this time a lot to educate patient, to discuss with specific patient what's your concerns what can I do what can the team can do to make you feel better, to make you feel more comfortable. It's just routine, routine, routine. I worry I may get in trouble if I don't follow the routine, if I help the patient first and not the routine, I will get in trouble, I protect myself. After routine I do as much as I can to make it better for the patient. (Nurse 8).</p> <p>[Fieldnote] Nurse crying during interview. Nurse non-Canadian graduate, had worked in native country as manager in dialysis prior to working in this unit. Has been here 10 years. Feels frustrated, micromanaged, not allowed to use professional judgment.</p> <p>No the management are not supportive of this more integrated approach I look at this whole dialysis thing and it is very task focused and we have a lot of dialysis patients and so it doesn't really foster the nurses being able to deal with some of these psychological stressors that the pts may be dealing that probably need to be dealt with at that moment . . . you know the patient is distressed and maybe needs to speak to the nurse more before they move onto the task, but you know there are several factors which works against the nurse being able to do that. (Social worker, 3)</p> <p>When you're on the ward for 2 weeks you can admit patients, see other patients, wrap up their issues and have them wrapped up with before the next person comes on and so there's been some talk of is this the best way to have some continuity in the dialysis unit to make those rotations two weeks back to back as well . . . it doesn't give you overall continuity, but is a good first step. (Nephrologist 1)</p> <p>So, it might be me rounding this week and then [another physician] rounding the next week, and so on and so on, so I think the continuity of care becomes a bit problematic, and I think when there's 52 handovers on patients in a year there is a lot of [. . .] potential for missed information." (Nephrologist 1)</p> <p>So I think the continuity of care becomes a bit problematic and I think when there's 52 handovers on patients in a year there is a lot of potential for missed information and for maybe things that have been ordered to not be followed up on. (Nephrologist 1)</p> <p>I think if there could potentially be a system where there was more consistency in the physician who was rounding on the unit then that creates somewhat better individualized care. (Nephrologist 1)</p> <p>So, sometimes it's hard in that situation cause even though you are the case manager there's all this management that is happening that you are not aware of until usually something major happens or people want to clarify something. Sometimes I feel like in terms of case management, as soon as people get onto dialysis they are less well cased managed then they were before they were on dialysis. (Nephrologist 2)</p>

(continued)

Table 5. (continued)

Theme	Selected quotations/observations
	<p>I mean we all take turns rounding on the units. You know depending on somebody's clinical service, they will do more or less dialysis rounds . . . each nephrologist will usually try to go to every single dialysis unit at least once a year. (Nephrologist 2)</p> <p>With the satellite dialysis units to travel back and forth between multiple satellite dialysis units that are geographically located or multiple sites that are geographically located you know, 20 or 30 km apart within the city and the traffic and all that other stuff then yeah, for sure it impedes your ability to deliver individualized patient care to an extent because you have to round on that dialysis unit. (Nephrologist 5).</p> <p>There is a huge gap in terms of continuity or follow-up of issues. That is a huge challenge and they are only here one day a week. It used to be three times a week at least they would round right so that they could follow-up with an issue on Monday, evaluate it, see how it went. (Unit manager, 1).</p> <p>The same patient is not on the same spot [hemodialysis space], might be the same spot but it's always a different nurse. (Nurse 3)</p> <p>[Researcher] And how do you keep up with all of those [hemodialysis] patients?</p> <p>MD: I can't, I try and so I think it comes down to our local practice pattern. (Nephrologist 4).</p> <p>Every five days you've got a new nephrologist and there is someone else of the weekend and it's kind of piecemeal try to care of the patient, I'm not saying my colleagues aren't competent, caring physicians, it's just that a lot of those things happen at bedside and the information is not always transmitted or shared. (Nephrologist, 4)</p> <p>[[It's just that logistical stuff impedes your ability to spend enough time with the patients because you physically have to round and move on. You know, to get all of that done in a morning and to do a good job of it and give individualized patient care to the you know, 40 plus patients you might see that morning, like that's damn near impossible. (Nephrologist 5)</p>
Stressful environment to work	<p>They are not happy, so some patients they yell. They treat other people sometimes with no respect, which is understandable. So, yeah, so I think the system, the culture and it should be supportive [of the nurses]. (Nurse 6)</p> <p>Because a lot of these new nurses will come to me and say, oh so and so is not nice to me and I tell them, don't feel too special because they aren't nice to everyone. (Nurse 3)</p> <p>It's a really tense environment and staff are very stressed and I think that there is not a good way to bring people together and talk about the patient and try and come up with plans . . . (Nephrologist 6)</p> <p>I think it's challenging for them. I think there is a huge time constraint. I don't think they have enough time to do that individualized care. Even though we say anemia protocol and INR [International Normalized Ratio] nomogram, they are protocols, you follow it. Sometimes what you see with errors is that lack of individualizing it. (Manager 1)</p> <p>Primarily in here our focus is dialysis, right. It's the same thing as, I don't even know if it's even an implacable question that if you bring someone to ultrasound, do you really have to have all the history of the patient in order to treat them? (Nurse 3)</p> <p>It's not about me it's about their routine [. . .] they have to get things done, I get asked the same questions [. . .] 4 times a week, "any nausea, diarrhea, vomiting . . ." [. . .] a couple of weeks ago I did have diarrhea and vomiting, but the nurse just went "okay" and that was it, nothing was different." (Patient 8, nocturnal program)</p>
<p>Organization</p> <p>Resource allocation, increasing demand on services</p> <p>Structure of care, lack of opportunities for clinical staff to influence/be involved in organization of care</p>	<p>[Fieldnote] Nurses perceived increase in workload but with no additional resources.</p> <p>It's just like an "us or them" kind of structure [. . .] It's not a partnership and part of it is the structure of the program [. . .] there's no transparency, we have tried to promote interdisciplinary working but there is little consistent feedback on what's going on. (Nephrologist 6)</p> <p>[Fieldnote] The organization of the rounding rota does not (obviously) account for nephrologists' workload or patients/service needs.</p>

about their treatment and care, particularly in the nocturnal and home programs:

[t]he nurses are fantastic, if I have a problem I can just ring them up' (patient 12, home dialysis program), "[i]f it wasn't for the nurses I wouldn't come, they are the only thing that keeps it bearable." (Patient 19, satellite unit)

While patients considered their care to be very good, they did not feel their care was individualized and, for the most part, were not involved in decisions regarding it. They observed that clinical staff, and nephrologists in particular, were very busy and did not always have the time to listen to their concerns. Health care providers acknowledged PCC as "a good thing" and a number of staff members, particularly nephrologists, described their practice as such. While there were examples of PCC, these were typically limited to individual and episodic encounters. Care was largely focused on the process of dialysis, the collection and recording of related data, and addressing immediate clinical concerns.

Professional Practices

At an individual level, the beliefs and values of health care providers influenced the perception of their role and consequent practice. This was particularly evident in those who worked more autonomously such as social workers, nephrologists, and nurse practitioners. Nurses were the primary care providers in this environment and described themselves as "dialysis nurses" (as opposed to nurses working in dialysis) and did not always consider care beyond dialysis delivery, as part of their role:

You only need three things in order to be a great dialysis nurse: are you able to justify your fluid loss; are you able to justify your electrolyte prescription based upon your bloodwork; is your access working ok or do you need to address it to the doctor? (Nurse 3)

When asked their reasons for working in hemodialysis, nurses typically fell into 2 groups: those who liked the close relationships that developed with patients and their families and those who cited the practical aspects of the dialysis environment (ie, better shift patterns, care predictability, and less lifting). Some preferred the (perceived) circumscribed role of working in hemodialysis and the limited responsibility. Others liked the familiarity of the same patients and found the inherent complexity challenging, but rewarding. Nurses described the close relationships that developed with some of their patients:

the relationships that we are able to build with our patients are a tremendous draw [. . .] it's tremendously rewarding" (nurse 8). "[I]t was so awful when he died, I was so upset . . . I had known

him for about 10 years, I knew all about his family . . . he was funny, he used to make us all laugh. (Nurse 6)

Nurses were generally aware that their role could include more individualized and holistic care, but stated that this was not always possible due to the prescriptive nature of their work, which is focused on specific clinical activities. Care continuity was often an issue as pertinent information relating to individual patients was not always shared or easy to find [O Observation /I interview]. This situation was accentuated by the lack of consistency in nurses' schedules and assignment of patients, which varied each dialysis session [O/I]. Although nephrologist practices were typically more autonomous, in the absence of an agreed guide to the content and format of rounding, there was wide variation in what aspects of care were addressed [O/I]. For some nephrologists, care was limited to the management of acute issues, while others sought a more pragmatic approach drawing on the patient's concerns and the knowledge of the wider care team [O/I].

Despite this more holistic approach in some instances, medical staff were also constrained by how their time and workload were scheduled. While all the nephrologists interviewed described their practices as person-centered, the sheer number of patients and the time available often limited them to addressing acute issues [O/I]:

[I]t's just that logistical stuff impedes your ability to spend enough time with the patients because you physically have to round and move on. You know, to get all of that done in a morning and to do a good job of it and give individualized patient care to the you know, 40 plus patients you might see that morning, like that's damn near impossible. (Nephrologist 5)

Patients were generally satisfied with their care but felt that the nephrologists did not always listen to them. They were often frustrated if they felt unwell as they thought some of the nephrologists did not have time for them and there was little continuity of care:

He doesn't know me, he's telling the nurses to drop my weight, I'm trying to tell him that we tried that and I was unwell, and he's like rushing on to the next person [. . .] I wish they [the doctors] would just listen. (In-centre, patient 14)

You can have a doctor one week who changes an order and then a different one the next week who changes it again, you might not see either doctor again for 6 months and then another doctor comes and says, why did they make these changes. I'm like, don't ask me . . . they don't ask you what the problem is, they just like to change things [. . .] my own doctor is not like that but she isn't able to come very often. (Satellite patient 15)

Therapeutic relationships and care continuity were difficult to initiate and sustain due to staff scheduling, workload, and the time available [O/I].

The Dominance of Hemodialysis

There has been a significant increase in demand for hemodialysis services in the province in recent years and a key health service priority is accommodating this demand. Clinical staff experienced a tension between meeting demand and practicing holistically:

There's all these checklists that have been developed, things need to get done and they have this culture of blitzing, so we are going to do this blitz this week, this blitz week, this blitz this . . . instead of looking at the person as a whole [. . .] they [the nurses] should be getting to know the patient as a person instead of just doing these checklists and trying to compartmentalize care. (Nephrologist 6)

It's a routine [. . .] I worry I may get in trouble if I don't follow the routine, if I help the patient first and not the routine, I will get in trouble, I protect myself. After routine, I do as much as I can to make it better for the patient. (Nurse 8)

Patients also referred to the clinical focus on routines like “. . . a military operation” (Patient 14):

It's not about me it's about their routine [. . .] they have to get things done, I get asked the same questions [. . .] 4 times a week, “any nausea, diarrhea, vomiting . . .” [. . .] a couple of weeks ago I did have diarrhea and vomiting, but the nurse just went “okay” and that was it, nothing was different.” (Patient 8, nocturnal program)

Prescriptive Practices

Hemodialysis treatment necessarily involves a number of repetitive activities and care was largely routinized around these, and the recording of them. Clinical staff described a number of required activities that did not add any value to care:

[L]ike every patient is different however we follow the same routine for everybody, like this patient, I know he is very stable with his BP and everything, why [do] I still have to check every half hour and have to document every half hour. We are writing stuff nobody is going to read. (Nurse 8)

The nurses' time was spent mainly delivering dialysis and monitoring and recording biomedical and technical data related to the treatment. They perceived that they had few opportunities to think critically or apply their skills to provide individualized care.

Facility/Unit

An important facilitator of PCC is a supportive and enabling context or environment. Hemodialysis facilities are unique care environments and can be a challenging context within which to work, particularly in-hospital units [O/I]. Nurses

talked about their attachment to particular patients and their grief and sadness when these patients became acutely ill or died. They described a stressful environment and times when they felt frightened and hurt when working with abusive and/or aggressive patients. Nurses alluded to a hierarchical and constraining work culture and talked about the pressure to conform to accepted practices and ways of working that perpetuated informal hierarchies and micromanaging. Some nurses felt bullied.

Nursing leadership was considered variable and absent in some areas. Challenging or questioning these ways of working, or seeking support from colleagues, was discouraged and participants believed likely to attract scrutiny and criticism:

You very frequently see “new to the unit” or “new to train,” nurses being questioned on why they are speaking to their colleagues. It creates a culture of fear that you have to know everything on your own all the time [. . .]. There's kind of a hostility towards folks who are more knowledgeable who are independent thinkers. (Nurse 7)

[T]he nurses here are mean [. . .] and they eat their young [. . .], there is a bit of bullying happening around [. . .] a lot of these nurses that [are] new will come to me and say, oh so and so is not nice to me and I tell them, don't feel too special because they aren't nice to everyone. (Nurse 3)

The acuity and complexity of patient needs may contribute to an already stressful work environment for nurses and rounding nephrologists. An additional stressor was locating information and the absence of effective mechanisms through which to systematically record and share it:

So, it might be me rounding this week and then [another physician] rounding the next week, and so on and so on, so I think the continuity of care becomes a bit problematic, and I think when there's 52 handovers on patients in a year there is a lot of [. . .] potential for missed information.” (Nephrologist 1)

There were few formalized inter-professional interactions between different clinical disciplines or between the clinical and managerial workforce [O/I]. Nephrologist 6 shared, “There's many barriers to good multidisciplinary care [. . .] trying to get a team to participate in working together to care for the patients is very difficult.”

Organizational Level

At an organizational level, participants cited a number of factors influencing PCC including resource allocation and structural factors such as staffing levels, care policies, and processes. Decisions regarding these factors were often external to the hemodialysis environment and therefore not explored in any depth. While the staff reported increasing workloads, resource allocation was perceived as static and may have been reflected by lower nurse to patient ratios.

Similarly, shift schedules were extended to accommodate the increased number of patients. Nephrologists and nurses both reported having little or no involvement in decisions regarding how care was organized:

It's just like an "us or them" kind of structure [. . .] It's not a partnership and part of it is the structure of the program [. . .] there's no transparency, we have tried to promote interdisciplinary working but there is little consistent feedback on what's going on. (Nephrologist 6)

Nephrologists were more involved in the organization of care in the home and nocturnal programs with higher levels of care continuity perceived in these areas. Managers explained this in terms of the smaller groups of patients and lower turnover of staff and patients. In the nocturnal program, patients and nephrologists described good nursing leadership and written management plans that facilitated continuity of care between the nursing and medical staff. Another factor contributing to care continuity may have been the relative wellness and stability of these patients, who were typically younger, more independent, and with less complex health needs than patients treated with other hemodialysis modalities.

The organization of care was an important determinant of how clinicians practiced and most were adept at modifying the scope of their activities to fit into the time available. Many would have liked to have worked differently but felt they had limited opportunities to be involved in care outside their immediate clinical role [O/I]. Social Worker 1 stated, "the management are not supportive of this more integrated approach. I look at this whole dialysis thing and it is very task focused."

It's a really tense environment and staff are very stressed and I think that there is not a good way to bring people together and talk about the patient and try and come up with plans . . . (Nephrologist 6)

These aspects of culture and practice were particularly evident in the in-center unit where nurses tended to defer treatment decisions to nephrologists. However, there were limited opportunities for clinical staff to contribute collectively to improving care practices. To some extent, managers recognized that dialysis units could be a challenging place to work and that problems could arise from not allowing nurses to work to the scope of their knowledge and experience:

I think it's challenging for them. I think there is a huge time constraint. I don't think they have enough time to do that individualized care. Even though we say anemia protocol and INR [International Normalized Ratio] nomogram, they are protocols, you follow it. Sometimes what you see with errors is that lack of individualizing it. (Manager 1)

All the managers were involved in supporting staff, but had huge workloads covering a number of dialysis services. This limited the time that they were available to support individual members of staff.

Discussion

This research used a case-study approach to explore how contemporary hemodialysis care is provided and to identify practices that inhibited or facilitated PCC in a large renal program based in western Canada. Care in general was considered to be very good by patients, who liked and respected their nurses and nephrologists. However, a complex interplay of individual-, unit-, and organizational-level factors²⁰ were found to inhibit the practice of PCC. Person-centered care requires a number of pre-requisites including empowered patients and staff, enabling and supportive processes, and a facilitative environment.²¹ The organization and practice of care within the dialysis units, in particular, made it difficult to develop and sustain the therapeutic relationships and care continuity central to PCC. The heavy workload of all the providers was perceived by them to be an important factor in this respect.

Individual Clinician-Patient Level

Person-centered care requires patients to engage with providers to jointly develop and evaluate a program of ongoing care. Despite the extended time spent with patients during dialysis, the opportunity for providers (both nurses and nephrologists) to develop ongoing therapeutic relationships with patients was limited. This was mainly attributed to scheduling, daily patient assignments, prescriptive and routinized working practices and lack of time. Previous research in this area reported very little social interaction between patients and clinicians, despite prolonged treatment times,²² with dialogue and shared decision making, key to PCC, often missing. Similar to Aasen's research, patients in this study reported that their physicians, in particular, were always in a hurry and did not have the time to listen to their concerns. The primary providers of care in this setting, nurses, described being unable to work to their full scope of practice and did not feel enabled or empowered. The focus on routinized tasks in nursing was a predominant feature of nursing in the 1980s and was found to undermine the nurses' ability to individualize care and to work holistically.²³ Time and workload are commonly cited constraints on practice in health care. Flynn's research advocates a multidisciplinary review of practice activities within hemodialysis to determine they are appropriately assigned.²⁴ Reassignment of activities can free nurses and nephrologists to focus on those aspects of care where they can add the most value. With no generally accepted script of core responsibilities, the content and style of patient care rounds varied according to the practices of individual nephrologists. All participating nephrologists described their practice as person-centered. However, during rounds, the time available to individual patients was often limited due to their workload. Research in this area indicates that the focus of clinical discussions in hemodialysis facilities are typically determined by clinician priorities²² and that

perceptions of what should be addressed during consults varies among nephrologists.²⁵ The prevailing power and dominance of physicians in health care environments have been identified by researchers as a major barrier to PCC, and to change in general.²⁶ The scheduling of nephrologists on a weekly rounding rotation and the assignment of patients to nurses prior to each dialysis session was a source of frustration for participants, particularly the patients. This proved a major barrier to the development of therapeutic relationships and PCC. Researchers in the United Kingdom also found that allocating patient assignments on a shift basis was detrimental to care continuity and professional accountability.²³

Unit/Facility Level

At the unit level, there was little support for PCC. The barriers included (1) prioritization of prescriptive activities relating to dialysis delivery, (2) lack of integrated working, and (3) limited opportunities for clinical staff to be involved in deciding how care should be organized. There is some evidence, albeit in a non-dialysis health care setting, that organizational priorities of managing demand and maximizing efficiency can conflict with professional values and that without appropriate organization it will not be possible to deliver PCC or its associated emphasis on psychosocial factors.²⁷ Hemodialysis care is increasingly conflated with dialysis delivery, with much of the clinical activity organized to promote efficient and effective dialysis. This focus on the treatment is a feature of other research in this area. Bennett and Niell²⁸ described dialysis as a “technically dominated”^(p149) area in which patient care can be limited to the technical aspects of the treatment. Similarly, Bevan’s research describes the technical “primacy of dialysis”^(p732) whereby the increasing demand for dialysis has led to a “production line” of treatment through which nurses become technically skilled, but often to the detriment of caring.^{29,30} Commenting on care for people who require dialysis, Finkelstein^{12(p158)} describes an “obsessive documentation of laboratory values” and a check box culture driven by standardized prompts in computer programs. In this environment, care is uniquely routinized around discrete tasks that may improve efficiency and patient flow but contribute to fragmentation of care and dissatisfaction among the clinical staff.³¹ A care environment that is supportive and enabling of PCC is key to operationalization of PCC in practice. Important characteristics of hemodialysis facilities in this regard include staff input into policies and decisions and competent managers who are supportive.²⁴ Our findings suggest that key to this is ensuring a supportive environment within which nurses have some influence over their own practice, including determining care priorities for individual patients. Other research specific to hemodialysis found that while nurses need to have control over their practice, this

was often not appreciated or supported by the managers or the organization.³² While not widely researched, a study by Gardner and Walton³² reported that nurses working within hemodialysis settings struggled to be heard and recognized. They stated that nurses felt professionally marginalized, with little opportunity to be involved in planning patient care, advocating for patients in team meetings, or contributing to the day-to-day organization of the service. Reviewing and reallocating certain activities (to less skilled workers), facilitating more integrated working, and encouraging more autonomous practices are likely to release time for clinicians to focus more on individual patient needs. Although this would require additional resources to implement, supportive care environments facilitate high-quality care as well as promoting more positive nurse outcomes such as increased job satisfaction.

A key strength of this research is its inclusion of a diverse range of key participants who receive or provide care across a hemodialysis program. Its qualitative approach allows issues to be explored in depth and at length, and large amounts of rich, descriptive data were collected. For practical reasons, the scope of the data analysis was limited to factors informing, inhibiting, and/or facilitating PCC and the analysis was focused at the individual and unit level. While organizational factors are also important drivers of practice, these were not explored in any depth in the current research.

Limitations

The findings of this research are not necessarily generalizable to all hemodialysis programs. However, many of the determinants of care delivery identified in this case study are supported by other research in this area. Further research is needed to explore the effects of organizational systems and processes that restrict clinicians, and nurses’ in particular, freedom to practice.

Conclusions

Person-centred care is widely considered to be beneficial to patients, practitioners, and health care organizations. Despite this, there was limited evidence of PCC in contemporary hemodialysis care in the case studied. A number of barriers observed at the individual, unit, and organization level were identified. In particular, how professionals practiced was often constrained by prescriptive tasks and care processes that focused on managing demand—leading to fewer perceived opportunities for nurses to use their skills and judgment, and to participate in interdisciplinary collaborations and team work. At the organizational level, supporting clinical staff to be involved in the wider aspects of care organization is likely to enable and empower individuals to work collectively and productively with better outcomes for their patients.

Appendix A

Case Study and Interpretive Description

While case study is an umbrella term and includes a diverse range of qualitative methodologies, we draw mainly on the epistemological perspective of Stake,¹⁴ which suggests knowledge is largely constructed as opposed to discovered. Within case-study research, multiple perspectives or views of a case exist and while researchers endeavor to present a comprehensive and representative report, “. . . there is no way to establish, beyond contention, the best view.”^{33(p108)} Interpretive description^{34(p1)} “is an inductive analytic approach designed to create ways of understanding clinical phenomena that yield applications implications.” It reflects an evolution of qualitative methodology within the discipline of nursing and philosophically aligns with interpretive naturalistic orientations. Interpretive description recognizes that experiences are constructed and contextually dependent at the same time as acknowledging multiple realities. Using inductive logic, the researcher’s analyses focus on identifying patterns and trends across multiple individual perspectives, providing an interpretive description aimed at informing clinical practice. Similar to Stake theory of case-study research in which credibility or “validity” of the findings are confirmed by the extent to which they resonate with the intended reader, good interpretive descriptions^{34(p8)} will pass the “thoughtful clinician test.” This describes experts with knowledge of the phenomenon under study who “find that claims are plausible and confirmatory”^(p8) while highlighting new linkages and understandings.

Appendix B

Interview Guide

Interview guide for patients semi-structured

- Can you tell me a little bit about your illness?
- How does this illness impact on your everyday life?
- What is being on dialysis like?
- How does the treatment impact your life day to day?

- Who provides you with information about your condition/treatment?
- Who is in-charge of your care?
- Are you involved in decisions regarding your care?
- Do you think the nurses have enough time to address any worries or concerns you may have?
- When do you see a kidney doctor?
- When do you see your own kidney doctor?
- Is this often enough?
- Do you think your dialysis care is individualized to your needs?

Interview guide for providers (nephrologists, nurses, renal social workers)—semi-structured

- Can you tell me a little bit about your career to date?
- Why did you choose a career in dialysis/renal medicine?
- Do you enjoy it?
- What does a good day at work look like?
- What are the challenges to working in this environment?
- How much involvement do you have in organizing care beyond dialysis?
- Do you have any formalized opportunities to discuss patient care, for instance in unit meetings?
- How easy is it for you to keep abreast of what is happening with your patients’?

Interview guide for managers

- Can you tell me a little bit about your career to date?
- Why did you choose a career in dialysis?
- What are the challenges to your role?
- What do you think the challenges are for the nurses on the unit?
- What support systems are in place for the nurses?
- Do you have regular unit meetings with the nurses about patients and their care?
- Do you have any forums in which nurses can be involved in the wider aspects of organizing care?
- How do the nursing staff share patient information with the medical staff?

Appendix C

Overview of Hemodialysis Units Included in Study.

Case-study hemodialysis services

Three hemodialysis units: 1 in-hospital and 2 satellite units affiliated with a large hemodialysis program in western Canada were selected. The study sites include in-hospital and satellite hemodialysis as well as in-center nocturnal and home hemodialysis. These areas were purposively selected to determine whether care provision and experiences varied across different sites. All of the units provided 3 dialysis sessions a day, 6 days a week, Monday to Saturday. The in-center unit also offered nocturnal dialysis. Due to the increasing demand for services in this area, the program has recently opened a number of units on a Sunday.

Nephrologists rotate to cover outpatient hemodialysis care. At the time of this study, 31 nephrologists were included on the rota and covered the 5 weekdays, a week at a time. A nephrologist rounds on all the hemodialysis units once a week. Issues addressed during rounds are typically acute problems and/or dialysis related [observed]. More complex or longstanding problems are usually shared with (and managed by) the patient's primary nephrologist who provides office-based appointments every 3 months or as required. At the end of each week, the rounding nephrologist shares any ongoing issues with the nephrologist following on the rota. The number of weeks a nephrologist spent covering dialysis was dependent upon their specific rota. Some rotas included only 1 week of dialysis a year. Some fee for service nephrologists work primarily in dialysis. Fee for service nephrologists was overly represented on the rota.

There are generally 2 nurses (a Registered Nurse and Licensed Practice Nurse) allocated to a group of 5 patients each dialysis shift. They provide the dialysis treatment and associated care and complete the documentation. Aides will assist, undertaking activities such as gathering equipment, weighing the patient, and cleaning machines. In general, nurses are assigned their patients on a shift-by-shift basis and have no ongoing responsibility for planning or organizing care beyond the immediate dialysis session. Each shift is coordinated by a nurse clinician who has a list of patient issues that require attention and is responsible for liaising with the medical and nursing staff. There is no general verbal handover or sharing of information between the nurses during the shift. Nurses will document concerns in the patient's medical record and relay these to the nurse clinician, who will add these to the daily sheet of patient issues.

Observing rounds during the study period confirmed individual nephrologists have their own ways of working in terms of when they do their rounds and how they do them. Some will speak to each patient in turn and others will review only those identified by the nurse clinician as having a problem. The nurse clinician typically accompanies the nephrologist when rounding. No multidisciplinary rounds were observed, with dieticians, social workers, and pharmacists rounding separately. Similarly, although the nurses were often very knowledgeable about individual patients, there were no formalized opportunities to regularly share/record this collective knowledge. Apart from the nocturnal and home dialysis program, none of the patients had management plans.

Satellite unit 1

Registered patients 91

Observation of practice over 5 visits

As with all the units included in the study, the timing of rounds in this unit varied depending on individual nephrologists and their workload.

Home hemodialysis

Registered patients 81

Observation of practice over 5 visits

Patients who dialyze at home were sent the study information by the unit manager by post. Once discharged, home patients dialyze at the training unit when they require an iron infusion or cannot dialyze at home, for instance if there is a problem with their machine. During their training, patients are assigned to individual nurses, who remain their named nurse on discharge. Participants were opportunistically recruited during their visit to the training unit and interviewed at the program's home training unit.

Nocturnal hemodialysis

Registered patients 31

Observation of practice over 5 visits

In-hospital nocturnal hemodialysis was notably different from the other dialysis services. The relatively small number of patients meant they were well known to staff. Four nephrologists were responsible for rounds which were scheduled every 2 weeks, when each patient was reviewed. A multidisciplinary sit-down round was held every 8 weeks. In contrast to other units, all the patients had management plans.

In-center hemodialysis

Registered patients 110

Observation of practice over 15 visits

This unit has the largest number of patients and at the time of the study, all patients new to hemodialysis start here. In addition, patients who are clinically or cognitively unsuitable to dialyze in a satellite unit or are aggressive and/or abusive are treated here. The turnover of patients here tends to be higher than in other units and many nurses found it a stressful place to work.

Ethics Approval and Consent to Participate

This study has been approved by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary. Informed consent was obtained from all focus group, interview, and survey participants.

Consent for Publication

All authors consent to the publication of this study.

Availability of Data and Materials

The data and materials are not available for this study.

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