

Clinical care gaps and solutions in diabetes and advanced chronic kidney disease: a patient-oriented qualitative research study

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Abstract

Background: Patients with diabetes and advanced chronic kidney disease face a high health care burden. As part of a patient-oriented research initiative to identify ways to better support patients' diabetes care, we explored their health care experience and solutions for patient-centred diabetes care.

Methods: We engaged 2 patients with advanced kidney disease and diabetes to join our multidisciplinary team as full research partners. They were involved in our design and conduct of the study, the analysis of the results and knowledge translation. We conducted qualitative interviews (1:1 semistructured interviews and focus groups) with patients with a history of both diabetes (type 1 or 2) and advanced kidney disease including those using dialysis. We identified overarching themes using individual and team analysis and conducted interviews until data saturation was reached.

Results: Twelve participants were interviewed between October 2017 and February 2018. Six people were interviewed in 2 separate focus groups (consisting of 4 and 2 participants) and 6 participated in 1:1 interviews with our team. Participants described being burdened by medical appointments, strict conflicting diets, costly diabetes therapies and fragmented, siloed health care. They indicated that self-management support, education and coordinated diabetes care might better support their diabetes care.

Interpretation: Patients with complex medical comorbidities face many challenges traversing a health care system organized around single diseases. Researchers and policy-makers should study and develop patient-centred diabetes care strategies to better support these high-risk patients.

Plain language summary: Diabetes care can benefit people with both diabetes and advanced kidney disease, but getting this care can be an ordeal. In this study, we explored the health care experiences of these patients and reviewed how to better support their diabetes care. We partnered with 2 patients with advanced kidney disease and diabetes by inviting them to join our study team as full research partners. They were involved in all aspects of this study from its beginnings. We then interviewed 12 patients with diabetes and advanced kidney disease including those using dialysis. Patients reported being burdened by too many medical appointments, noted communication issues between their care providers and felt each of their providers addressed only 1 aspect of their disease. They faced challenges caring for their diabetes and found therapies difficult to afford. Patients suggested that coordinated diabetes care, self-management support and diabetes education might help them manage their diabetes. In this project, we learned of many challenges that patients with diabetes and kidney disease face in our health care system. Researchers and policy-makers should consider patient suggestions when developing new diabetes care strategies.

With better treatments and improved survival, patients with diabetes often live longer than in the past, but with other medical conditions.¹ A common comorbidity, affecting 25%–50% of patients with diabetes, is chronic kidney disease.²

Patients with diabetes and kidney disease are at high risk of diabetes-related complications,^{3–5} are often socioeconomically

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disadvantaged and have lower quality of life.⁶ They can benefit from glycemic management, cardiovascular protection and screening for diabetes complications,⁷⁻⁹ but this means attending numerous medical appointments.¹⁰ Before developing patient-centred strategies to support these people, a necessary first step is to understand their health care struggles and needs.¹¹

Patient-oriented research focuses on priorities and outcomes relevant to patients.¹² In this study, we sought to answer 2 questions: (1) What is the burden of illness and the health care experience of those living with advanced kidney disease and diabetes? and (2) What are some patient solutions for supportive diabetes care? Herein, we report their health care experiences and proposed solutions.

Methods

Design and setting

We used a descriptive qualitative approach.¹³ We conducted focus groups and 1:1 semistructured interviews with patients from 2 academic centres (London Health Sciences Centre and St. Joseph's Health Care London) in London, Ontario, Canada. We report this study using the Guidance for Reporting Involvement of Patients and Public,¹⁴ the Patient Engagement in Research Description Framework¹³ and the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklists.¹⁵

Recruitment

English-speaking adults 18 years and older with type 1 or type 2 diabetes *and* advanced chronic kidney disease (self-reported disease approaching the need for dialysis, chronic peritoneal or hemodialysis, kidney transplant recipient within the previous 2 yr) were eligible for inclusion. We posted recruitment materials in clinical areas and dialysis units. We also distributed the materials to diabetes and renal care providers and asked them to approach patients who might be eligible. If a patient provided consent to contact, team members (L.G., K.C., S.R.) recruited participants by telephone. Our team members also recruited participants from outpatient clinics and hemodialysis units. We purposefully sampled to encourage diversity in age, sex, ethnicity and dialysis status.

Data collection

Between October 2017 and March 2018, we conducted interview sessions moderated by qualitative researchers, physicians and our patient partner (S.R., K.C., L.G., J.O.). Our physician investigators (K.C., S.R.) had no therapeutic relationship with the participants they interviewed.

We initially planned to conduct 2-hour, in-person focus groups. Because of scheduling difficulties, we also conducted 1:1 semistructured interviews in person or by telephone. All sessions were guided by a semistructured interview guide, developed from a literature review (Appendix 1, available at www.cmajopen.ca/content/7/2/E258/suppl/DC1).

Interviews were audio-recorded, and the recordings were transcribed verbatim by an independent transcription service.

Each interviewer then reviewed the entire transcript of each interview in which they had participated to ensure accuracy. Field notes captured interviewer perceptions and nuances of communications. Transcripts were deidentified.

Patient engagement

To ensure this study was centred around patients, we recruited 2 people (1 with advanced kidney disease [J.O.] and 1 using hemodialysis [P.D.]) to join our team as collaborators at the execution phase. They were recruited through recruitment posters and health care professionals. Interested patient partners were put in contact with our advisor-liaison (L.G.). She had them submit a curriculum vitae and then met with them in person to discuss the details of the project to make sure that it was a good fit. Our partners had no therapeutic relationship with the physician investigators. Through in-person meetings, phone calls and emails, they helped develop our protocol (J.O., P.D.) and aided with recruitment materials, participant interviews, analysis, manuscript preparation and knowledge translation (J.O.).¹⁶

Analysis

We completed thematic data analysis simultaneously and iteratively with data collection.¹⁷ We independently reviewed transcripts noting key themes, and as a group we built a coding template (S.R., K.C., J.O., B.R., T.R., L.G.). With subsequent transcripts, we modified our template and identified exemplar quotes. We ceased data collection when all agreed that data saturation had been achieved (i.e., no new themes were emerging). We used Microsoft Word to maintain our template. Two team members (T.R. and K.C.) then collapsed the codes into higher order themes and identified relationships between them. We (S.R., K.C., J.O., B.R., T.R., L.G.) then finalized the themes and relationships.

A patient (J.O.), providers (K.C., S.R.) and researchers (B.R., T.R., L.G.) conducted the analysis. For confirmability, we used independent and team analysis, verbatim transcripts and an audit of all analyses. For dependability, we followed the COREQ checklist to ensure our methods were systematic, articulated and replicable.

Ethics approval

This study was approved by the Health Sciences Research Ethics Board at Western University, London, Ont. (REB no. 109561). Participants provided written and informed consent.

Results

Participants

We approached 37 eligible participants. Seven declined (lived remotely, subjectively unwell, uninterested). Eighteen expressed interest but did not consent (intercurrent illness, scheduling difficulty).

We conducted 2 focus groups of 4 and 2 participants that were 2 hours in duration (facilitated by S.R. on Nov. 22, 2017, at the London Health Sciences Centre and on Dec. 5, 2017,

at St. Joseph’s Health Care London). We conducted 6 semi-structured interviews that were 1 hour in duration, either in person or by phone: in-person interviews were conducted at the London Health Sciences Centre by L.G. on Jan. 12, 2018, and by K.C. on Feb. 2, 2018, and telephone interviews were conducted by K.C. on Feb. 22 (2 interviews), Feb. 23 and Mar. 2, 2018, after which we reached data saturation. The mean age of the participants was 60 (range 36–78) years, 41.6% were women, 83.3% were white and 58.3% were using dialysis (Table 1).

Findings

We report participants’ comments on 2 topics: care challenges they faced and their solutions to improve care. Exemplar quotes are identified in Tables 2 and 3 by interview type (FG, focus group; INT, interview), type of diabetes (e.g., T1, type 1 diabetes), sex (e.g., F, female) and stage of kidney disease (advanced, dialysis).

Care challenges

Participants described several health care challenges. We organized them into 8 themes: multiple medical appointments and care providers; not enough time with health professionals; care fragmentation and silos; communication gaps; not enough education; cost of diabetes management; access to technology; and diets (Table 2).

Participants reported that they often found it difficult to attend multiple medical appointments. This became especially challenging when they were juggling dialysis and their home life. Appointments often conflicted.

They also felt that their medical appointments were often too short and that providers did not have time to address their complex needs.

With many appointments, participants experienced care fragmentation and silos. Specialists focused on 1 of their

diseases and did not have time to address others. There was complete care fragmentation when participants moved or when their kidney disease progressed, requiring new care teams. With each transition, they had to recount their medical history and build new provider relationships. For some, this felt like abandonment. Participants noted silos between providers. Management plans were not well summarized, documentation was not shared and notes were not accessed. They also felt like the “go-between” between providers. They kept records about their health, so they could share this information, and they felt responsible for care coordination. In addition, participants were frustrated by frequent, duplicated laboratory tests that arose from care silos.

Participants noted communication gaps with providers. In some instances, they felt their disease perspectives were not heard.

Some felt ill informed about diabetes complications and the complexities of their disease.

There was a cost burden associated with self-managing diabetes. Supplies were often not covered, and there were out-of-pocket expenses.

Participants recognized the availability of technology to support diabetes. They often could not afford technologies and found them difficult to use.

Dietary challenges were commonly mentioned. Participants found diabetes and kidney diets conflicting. Diets changed as their kidney disease progressed. There were no experts knowledgeable in both kidney and diabetes diets.

Possible solutions

Recognizing the gaps in their health care, participants spoke about strategies that might better support their diabetes. We grouped their suggestions into 3 themes: coordinated care; self-management support; and education (Table 3).

Participants expressed a desire for coordinated care, even care provided at a single appointment. We asked participants about the possibility of providing diabetes care in the dialysis unit. They expressed openness to education and counselling, foot screening and glyceemic management.

Participants valued self-management support. Some used applications to track blood glucose and dialysis parameters and wondered if this would be helpful to others. Others suggested that diabetes flow sheets might keep self-management on track.

Finally, participants valued opportunities for education. They wanted to learn about their diseases, diets and complications. They suggested websites, libraries and waiting room resources.

Interpretation

Participants in our study described several health care challenges. They faced conflicting and restrictive diets and communication gaps with providers. Their self-management was hindered by the cost of diabetes supplies and technology. With their multiple medical conditions they had frequent, short and fragmented medical appointments, which

Table 1: Participant characteristics (n = 12)

Characteristic	No. (%)*
Age, mean (range), yr	60.2 (36–78)
Female	5 (41.6)
Ethnicity	
White	10 (83.3)
Aboriginal	1 (8.3)
Mediterranean	1 (8.3)
Type 2 diabetes	10 (83.3)
Duration of diabetes, mean (range), yr	19.3 (5–30)
Current dialysis	7 (58.3)
Hemodialysis	5 (71.4)
Peritoneal dialysis	2 (28.6)
Duration of dialysis, mean (range), yr	2.5 (0.1–5.5)
Transplant recipient	3 (25)

*Unless otherwise indicated.

Table 2: Health care challenges described by study participants

Theme	Quotations
Multiple medical appointments and care providers	<ul style="list-style-type: none"> • They'll [providers] set up appointments and then they'll end up having appointments at the same time. ... Or sometimes they'll set up an appointment for me on this day and then the next one is on the next day, instead of trying to set them up so one's in the morning and one's in the afternoon. — FG2 (T2MAdvanced)
Not enough time with health professionals	<ul style="list-style-type: none"> • I go and see the diabetic doctor. First of all, they've only got 10 or 15 minutes, because they just don't get any time. There are too many patients. — FG1 (T2MAdvanced)
Care fragmentation and silos	<ul style="list-style-type: none"> • Say you have a number on 1 [blood test] and it's out of range, they're like, well, you'll have to talk to this specialist about that. We don't deal with that. — FG1 (T2MAdvanced) • And this group that we dealt with for years, the social worker, the dietitian ... all of a sudden, they came in, shook my hand, said it's been nice knowing you, basically. And the minute we crossed the hall, all the people were gone out of the system, never to be dealt with again. And no one had ever said to us, at any time, when this happens, you're going to lose all these support people you've had for all this time. — FG1 (T2MDialysis) • I keep bringing up, you guys have gone to computers, why can't you look this stuff up, all the blood tests, all the results? It's there in front of you, you type in my ID number and everything comes up. So, why can't you do that? — FG1 (T2MAdvanced) • The specialist is supposed to have the record and he says no I don't have the records. ... And I think the most important thing is the records belong to me. I should have it myself before everybody else because I go to different places and I don't know what's going on. — FG3 (T2MDialysis) • But it would be nice if they would all get together and say, okay, this is what we need. — FG2 (T2MAdvanced)
Communication gaps	<ul style="list-style-type: none"> • I told her when I do this you have to do this, and she just didn't even listen to me. She opened the thing and my clamp opened and blood went everywhere. — INT1 (T2FDialysis)
Not enough education	<ul style="list-style-type: none"> • When I was diagnosed, it's almost like the doctors are afraid to tell you what's going to happen to you. ... They don't want you to freak out about it, so they either sugar coat it, or like, well, you're not that bad now. — FG1 (T2FAdvanced)
Cost of diabetes management	<ul style="list-style-type: none"> • In terms of the cost, a lot of things aren't covered. Needles for insulin are not, which I have a bone to pick with that. — FG1 (T2MDialysis)
Access to technology	<ul style="list-style-type: none"> • That would boggle my mind that they would create a piece of machinery for you to test your blood glucose. ... A lot of diabetics have low vision and you have the instructions on the machine itself, error message and stuff there and you can't see them. I just ignore them. — FG4 (T2MDialysis)
Diets	<ul style="list-style-type: none"> • With [diabetes] we were taught to eat whole wheat breads and with the renal disease you're taught not to eat any of that, you're taught to eat white so the 2 diets kind of counteract. Like they're telling you 1 thing for sugar and they're telling you 1 thing for renal, so yeah there is a big change. — INT3 (T2FDialysis)

Table 3: Possible solutions suggested by study participants

Theme	Quotations
Coordinated care	<ul style="list-style-type: none"> • Just you go in with 1 visit and you can cover the gamut. You can talk to the dietitian and you can talk to wound care. It's all there. — FG4 (T2MDialysis) • It [dialysis-based program] would be a captive audience. — FG2 (T2MDialysis) • Sure, keep you busy. You can do 2 things at once. — FG3 (T2MDialysis)
Self-management support	<ul style="list-style-type: none"> • The best thing I've got is an app on my phone. ... It keeps track of all my medications. It keeps track of your vitals, so you can put in your blood glucoses and all that. My INR [international normalized ratio] can go in there, pulse, blood pressure, weight, doctor's appointments and stuff like that. It's the handiest thing. — FG2 (T2MAdvanced)
Education	<ul style="list-style-type: none"> • You should be able to go on a website and see that information, that should be available to you as a patient. ... So that in the age that we now live in, that information is available. — FG1 (T2MAdvanced)

is consistent with what has been reported at a population level in Canada.¹⁰ Given their health care experience, participants suggested that coordinated care, self-management support and education might be helpful strategies to support their diabetes in a patient-centred manner.

There has been little research investigating the challenges of living with both diabetes and advanced kidney disease from

the patient perspective. In Australian and American studies, patients expressed frustration with short appointments, duplicated tests and conflicting and segregated health care.^{18,19} They felt responsible for coordinating their care.¹⁸

Where care solutions have been studied, consistent with our research, self-management support was suggested to empower patients with complex disease.¹⁹ Targeted, culturally

relevant education was also suggested to inform patients about their disease and treatments.¹⁹⁻²¹ Multidisciplinary clinics could promote communication between providers, reduce silos and make appointments more convenient.¹⁹ Patients also suggested that communication be mandatory between providers and that parking costs be covered for appointments.¹⁹

We followed a strong qualitative approach and interviewed patients who had advanced kidney disease through dialysis. Where most studies of patients with advanced kidney disease do not address patient priorities,¹² we involved patients from the outset of our study to ensure that our work was centred around them.

Limitations

One of our patient partners (P.D.) passed away early in the study, when we were writing our protocol, and we lost the helpful partnership of a person using dialysis. Our study was small and recruited participants from 2 academic centres, so our findings may not resonate with teams in other jurisdictions. We cannot ensure that our findings represent a diversity of opinion because of the small number of participants. If we had included people who did not speak English they might have mentioned other barriers to care. As organizing focus groups was challenging, we changed to 1:1 interviews midway through the study. However, in reviewing transcripts we did not notice any substantive differences in how participants responded.

Lessons learned from patient involvement

Including patients as partners brought challenges but also immensely benefited our study and team members.

Because of the novelty of this research, there were new processes to explore (e.g., the ethics associated with including patients as partners in research). To facilitate learning, L.G. held a patient-oriented research workshop with investigators including patient partners. Occasionally, we had different timeline expectations. Investigators needed to follow several steps to conduct this study (e.g., funding, ethics approval), but patient partners wanted the research to be completed quickly and lead to better care immediately.²²

In terms of benefits, as an interviewer, J.O. naturally connected with participants, resulting in candid conversations. He brought his lived experience to the analysis of the transcripts and interpreted nuances and themes that the other research team members did not capture. He encouraged adherence to timelines and suggested knowledge translation activities (e.g., an educational video for those newly diagnosed with diabetes). Our team members were also able to share and reflect upon the biases they had about each other. Physicians gained a clearer understanding of the burden of multimorbidity on patients, and our patient partner learned that investigators have a sincere interest in doing more to support patient care.

Conclusion

Living with diabetes and advanced kidney disease is difficult and patients face several challenges including gaps in their health care. Coordinated care, patient education and

self-management support are patient-centred strategies to explore, develop and study.

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