Clinical care gaps and solutions in diabetes and advanced chronic kidney disease: a patient-oriented, qualitative research study (TEAM CARE)

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	strategies to better support these high-risk individuals. Involving patient partners in our work improved our connections with patients, along with the quality, acceptability, and relevance of our research.

Clinical care gaps and solutions in diabetes and advanced chronic kidney disease: a patient-oriented, qualitative research study (TEAM CARE)

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Lay Summary

Diabetes care can benefit people with diabetes and advanced kidney disease. Unfortunately however, this care means more medical appointments. In this study we explored the healthcare experiences of people with diabetes and advanced kidney disease and reviewed their solutions for patient-friendly diabetes care.

We included two patients with advanced kidney disease and diabetes to join our study team as full research partners. Our patient partners were involved in all aspects of this study from its beginnings.

Our team interviewed 12 patients with diabetes and advanced kidney disease including those using dialysis. We learned that patients were burdened by numerous medical appointments. They noted communication issues between their care providers and felt that their providers only addressed one aspect of their disease. They faced challenges taking care of their diabetes and found therapies difficult to afford. Patients suggested that coordinated diabetes care, self-management support, and diabetes education might better support their diabetes.

In this project, we learned of the many challenges that patients with diabetes and kidney disease face in our current healthcare system. The development of patient-friendly diabetes care programs to better support these individuals should be considered.

Abstract

Background: Patients with diabetes and advanced chronic kidney disease (CKD) face a high burden of health care. As part of a patient-oriented research (POR) initiative to identify ways to better support their diabetes, in this study we explored their healthcare perceptions and solutions for patient-centered diabetes care.

Methods: We engaged two patients with advanced CKD and diabetes to join our multidisciplinary team as full research partners. Our patient partners were involved in all aspects of our study design, conduct, analysis, and knowledge translation.

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Results: Patients with advanced CKD and diabetes are burdened by medical appointments, strict conflicting diets, costly diabetes therapies, and fragmented and siloed healthcare. They identified that more self-management support, education and coordinated diabetes care might better support their diabetes.

Interpretation: In this POR project, we learned of the many challenges that patients with complex medical comorbidities face while traversing a healthcare system organized around single disease. Researchers and policy makers should study and develop patient-centered diabetes care strategies to better support these high-risk individuals. Involving patient partners in

our work improved our connections with patients, along with the quality, acceptability, and relevance of our research.

Introduction

With better treatments and improved survival, patients with diabetes now often live with other medical conditions.(1) One of the most common comorbidities, affecting 25-50% of patients with diabetes, is chronic kidney disease (CKD).(2)

Patients with diabetes and advanced CKD are at high risk of hypoglycemia,(3) cardiovascular disease,(4) amputations, (5) retinopathy,(6) and other medical conditions.(7) They are often socioeconomically disadvantaged and have lower quality of life.(8) These individuals can benefit from diabetes-related care including glycemic management, cardiovascular protection, and screening for complications.(9–11) Unfortunately, this care means attending numerous medical appointments.(7) Before developing patient-centered strategies to support these individuals, a necessary first step is to understand their struggles, healthcare perceptions, needs and interests.(12)

Patient-oriented research (POR) focuses upon the priorities and outcomes relevant to patients.(13) In this study, we explored the burden of illness and healthcare perceptions of those living with advanced CKD and diabetes. We also identified their solutions for more supportive, patient-centered diabetes care. Herein, we report their healthcare perceptions and solutions.

Methods

Patient Partner Involvement

We invited patients with lived experience of diabetes and advanced CKD to join our research team as partners. Two individuals (one with advanced CKD and one using chronic hemodialysis) joined. During the study, one partner unfortunately passed away.

Our patient partners assisted with the study design, development of the interview guide, and refinement of recruitment materials. They aided in participant interviews, data analysis, review of final outputs, and manuscript preparation. (14)

Design and Setting

This study used a descriptive qualitative approach. (14) We conducted focus groups and 1:1 semi-structured interviews with patients from two large academic centres (London Health Sciences Centre [LHSC], and St. Joseph's Health Care [SJHC]) in London, Ontario, Canada. We report this study using the Guidance for Reporting Involvement of Patients and Public (GRIPP2), (15) and the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklists.(16)

Recruitment

English-speaking adults ≥18 years with type 1 or type 2 diabetes *and* advanced CKD (self-reported CKD approaching dialysis, chronic peritoneal or hemodialysis) were considered for inclusion. We also included kidney transplant recipients if their transplant was less than two years prior. We excluded individuals who were too ill to participate.

We recruited participants from outpatient endocrinology and nephrology clinics, and hemodialysis units between October 2017 and February 2018 using multiple strategies. We asked healthcare providers (e.g. hemodialysis nurses, physicians) and renal support programs

(Patient & Family Advisory Council), to approach eligible individuals. If patients provided consent for our team members to contact them (LG, KKC, SMR), we recruited them by telephone. Participants were also recruited in-person, from outpatient clinics and hemodialysis units. We additionally placed recruitment posters in clinic areas. We purposefully sampled to ensure diversity in age, sex, ethnicity and dialysis status.

Ethics

This study was approved by the Health Sciences Research Ethics Board at Western University, London, Ontario (REB #109561). Participants provided written and informed consent prior to participating.

Data Collection

Between October 2017 and February 2018, we conducted interview sessions moderated by experienced qualitative researchers (SMR, primary care physician; LG, anthropologist) as well as an endocrinologist (KKC) and our patient partner (JO). Our physician investigators (KKC, SMR) had no therapeutic relationship with participants whom they interviewed.

We initially planned to conduct two-hour, in-person (clinic) focus groups. However, due to scheduling difficulties, we also conducted 1:1 semi-structured interviews either in person or by telephone. Sessions were guided by an open and flexible interview guide.

Interviews were audio-recorded and transcribed verbatim by an independent transcription service, then checked for accuracy by each interviewer. Field notes captured interviewer perceptions and nuances of our communications. Transcripts were de-identified to preserve confidentiality.

Data Analysis

We completed our data analysis simultaneously and iteratively with data collection. First, investigators independently reviewed each transcript, noting key themes. The team then met to discuss emerging themes and organize them into broad categories (coding template). With subsequent transcripts, we continued to modify our coding template. We also identified exemplar quotes reflecting the main themes. We ceased this first phase of analysis when all team members agreed that data saturation had been achieved. We used Microsoft Word to maintain our coding template.

Upon completion of this phase, TR and KKC met to further interpret and synthesize the main themes by creating a visual summary. Given the experience of our team, results were analyzed from multiple perspectives: patient, provider, and researcher. We established credibility and trustworthiness of our data using verbatim transcripts, independent and team analysis.

Results

Participants

We approached 37 patients for participation. Seven declined (lived remotely, felt unwell, not interested). Eighteen expressed interest initially, but did not consent (intercurrent illness, scheduling difficulty, lack of contact).

We achieved data saturation after 12 interviews. Participants' mean age was 60 years, 42% were female, 58% were using dialysis, and 25% were kidney transplant recipients (and no longer receiving dialysis) (Table 1).

Findings

There were two broad themes that emerged from the data: 1) the care challenges that patients with diabetes and CKD faced; and 2) the articulation of possible solutions to improve care. Exemplar quotes are identified by type of interview (e.g. FG for focus group, INT for interview), type of diabetes (e.g. T1 for type 1 diabetes), sex (e.g. F for female) and stage of kidney disease (e.g advanced, dialysis).

Care Challenges

Participants described several challenges in their healthcare. We organized these into seven themes, each described below. Our visual summary is illustrated in Figure 1.

Multiple medical appointments and care providers

Having complex comorbidities, participants had many medical appointments. Some found appointments particularly difficult to attend, especially when juggling their dialysis schedules and home life. Their appointments often conflicted with one another.

> 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)

Time demands on health professionals

Participants recognized that their care providers had significant time demands. Appointments were short, and providers didn't have time to address their complex needs.

"I go and see the diabetic doctor. And 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 siloes

With their many appointments, participants described care fragmentation and siloes. Their medical specialists were only focused on one of their diseases and couldn't address others.

"Say you have a number on one [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)

There was complete care fragmentation when patients moved, or when their kidney disease progressed. Patients transitioned from CKD clinics to dialysis teams, and to other medical specialists. With each transition, they had to recount their medical history, and build new relationships with providers. For some, moving from one care team to another, felt like abandonment.

> And this group that we dealt with for years, the social worker, the dietician..all of a sudden, they came in and they shook my hand, and they 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)

Participants also noted siloes between care providers. Management plans were not well summarized, documentation was not shared, and notes were not accessed.

> … I keep bringing up, you guys have gone to the 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 I.D. number and everything comes up. So, why can't you do that? – FG1 (T2MAdvanced)

Participants felt like the "go-between" between providers. They kept detailed records about their own health so that they could share this amongst their care teams. Some felt responsible for care coordination.

> …The specialist is supposed to have the record and he say no I don't have the records… And I think myself the most important thing, 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)

Participants were also frustrated by frequent, duplicated laboratory tests.

"But it would be nice if they would all get together and say, okay, this is what we need." - FG 2 (T2MAdvanced)

Communication with patients

Communication gaps were expressed between patients and care providers. In some instances, participants felt that their disease perspectives and management were not heard.

"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 patient education

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

> 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)

Costs associated with diabetes management

There was a cost burden associated with self-managing diabetes. Supplies were often not covered and participants had out of pocket expenses for appointments.

"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…" – FG 1 (T2MDialysis)

Technologies

Participants recognized the increasing availability of technology to support self-management. Often however, they could not afford these technologies and found them difficult to use, especially if visually impaired.

> That would boggle my mind that they would create a piece of machinery for you to test your blood sugar…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. – FG 4 (T2MDialysis)

Diets

Dietary challenges were expressed by almost all participants. There were frustrated by diabetes and kidney diets that were strict and conflicting. Diets changed as their CKD progressed. There was frustration there were no experts knowledgeable in both kidney and diabetes diets.

> 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 two diets kind of counteract. Like they're telling you one thing for sugar and they're telling you one thing for renal, so yeah there is a big change. – INT3 (T2FDialysis)

Possible Solutions

Recognizing the gaps in their healthcare, we asked participants about strategies that might better support their diabetes.

Coordinated care

With multiple medical appointments, participants hoped that their care could be better coordinated, and even provided at a single appointment.

"Just you go in with one visit and you can cover the gamut. You can talk to the dietician and you can talk to wound care. It's all there." – FG4 (T2MDialysis)

We also asked them about their interest in the provision of diabetes care in the dialysis unit. They expressed openness to education and counseling, foot screening and glycemic management.

"It [dialysis-based program] would be a captive audience." – FG2 (T2MDialysis)

"Sure, keep you busy. You can do two things at once." – FG3 (T2MDialysis)

Self-management support

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

> 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 sugars and all that. My INR can go in there, pulse, blood pressure, weight, doctor's appointments and stuff like that. It's the handiest thing. – FG2 (T2MAdvanced)

Education

Participants valued any opportunity for education. They wanted to learn more about their diabetes and kidney disease, diets, and complications. They suggested that websites, patient libraries, and waiting room resources might be valuable.

"…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)

Interpretation

Patients with diabetes and advanced CKD experience many challenges in their healthcare. They have numerous appointments, face siloed and fragmented care, conflicting and restrictive diets, and communication gaps with their providers. Their own self-management is hindered by the cost of diabetes supplies and technology.

Comparison with previous research

There has been a paucity of research to investigate the challenges of living with both diabetes and advanced CKD from the patient perspective. In Australian and American studies of patients with diabetes and CKD, some expressed frustration with short appointments, duplicated tests and conflicting and segregated medical advice (17,18). They felt that the burden of care coordination rested upon their shoulders.(17)

Where care solutions have been explored, self-management support has been suggested as a means to empower patients who have demanding and complicated disease.(18) Targeted, culturally relevant education, might also help patients learn about their condition and treatments, both early and in advanced CKD.(18–20) Multidisciplinary clinics might promote communication between providers, reduce siloes, and make appointments more convenient. (18) Some patients have suggested that communication be mandatory between providers, and that parking costs be covered for appointments.(18)

Reflection on patient engagement

Patients were involved in this research project from its beginnings. This experience led to challenges, but also had benefits for our investigators and our study.

Regarding challenges, one of our patient partners passed away during the study. Our team not only dealt with his loss, but with the need to find a new partner. Because POR was new for our team and institution, there were also new processes to explore (e.g. ethics). To facilitate our learning, our engagement liaison (LG) held a joint workshop with both patients and investigators.

We also noted a disconnect between the timelines of patients and investigators. From an investigator perspective, protocols need to written, grants obtained, and ethics submitted, before research can be conducted. Patients however, want research to be completed quickly and lead to better patient care as soon as possible. (21)

There were however, several benefits of including patient partners in research.(22) As an interviewer, our partner had natural connections with our participants, resulting in honest, candid conversations. During analysis, he brought his lived experience, and interpreted nuances and themes that we did not capture. Given his strong interest in moving this research into actionable benefits for patients, he kept us adherent to timelines, and suggested knowledge translation activities (e.g. educational video for patients with newly diagnosed diabetes).

Involving patient partners in research also benefitted our investigators. Our team came from a diversity of experience, and were able to share and reflect upon our own biases about each other. Physicians gained a clearer understanding of the great burden that multimorbidity places upon our patients, and our patient partner learned that investigators care about the well-being of patients and have a vested interest in doing more to support them.

Strengths and limitations

There are many strengths to the current study. We followed a strong qualitative approach and interviewed patients with a range of backgrounds to gain insight about their struggles from advanced CKD through dialysis. Where most studies of patients nearing or using dialysis do not address the priorities of patients,(13) patients contributed to all aspects of this work.

A limitation was that this was a small study from two academic centers and so our findings may not resonate with teams in other jurisdictions. Our participants were only English-speaking; non-English speaking individuals might have expressed 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. Finally, we only captured views of patients who agreed to participate in research.

Conclusion and Directions

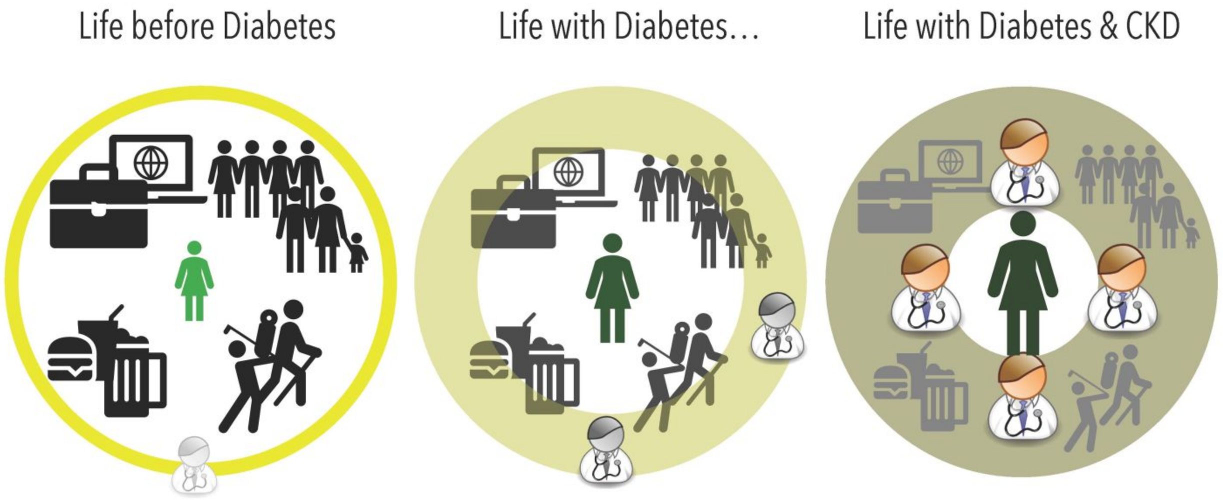
Living with diabetes and advanced kidney disease is difficult, and patients face many challenges in their health care. The findings from this work will directly inform efforts to develop patient-centered diabetes care strategies for those living with advanced CKD.

Table 1. Characteristics of 12 study participants

Age, yrs (mean)	60.2
Female	5 (41.6)
Type 2 diabetes	10 (83.3)
Duration of diabetes, yrs (mean)	19.3
Current dialysis	7 (58.3)
Hemodialysis	5 (71.4)
Peritoneal dialysis	2 (28.6)
Duration of dialysis, yrs (mean)	2.5
Transplant recipient	3 (25)

Unless indicated, data presented in number (percent).

Figure 1. Visual summary of themes



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Guidance for Reporting Involvement of Patients and Public (GRIPP) 2: Short-form checklist

Section and topic	Item	Reported
Aim	Report aim of PPI in the study	Introduction page 5
Methods	Provide a clear description of the methods used for PPI in the study	Methods page 5-6
Study results	Outcomes – report the results of PPI in the study including both positive and negative outcomes	Methods page 6 Interpretation page 16-17
Discussion and conclusions	Outcomes – comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Interpretation page 16-17
Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this experience	Interpretation page 16-17

Abbreviations: PPI, patient and public involvement

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6-7
Sample size	12	How many participants were in the study?	9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	8, Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7-8
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-15
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-15
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-15
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-15

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.