

# BMJ Open 'It's the empathy' – defining a role for peer support among people living with chronic kidney disease: a qualitative study

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## ABSTRACT

**Objectives** Persons with advanced chronic kidney disease (CKD) have unique support needs associated with managing a chronic yet often silent condition, complex treatment-related decisions and care transitions. The aim of this study was to explore perspectives on how peer support could address CKD support needs and augment care.

**Design** This study employed a qualitative descriptive methodology. Data were collected through focus groups (cofacilitated by patient partners) and semistructured interviews.

**Setting** Four multidisciplinary CKD clinics across Southern Alberta, Canada.

**Participants** We purposively sampled among adult patients with advanced, non-dialysis CKD and their caregivers, as well as trained peer mentors from The Kidney Foundation of Canada's Kidney Connect programme.

**Analysis** Transcripts were coded in duplicate, and themes were generated inductively through a thematic analysis approach.

**Results** We conducted seven focus groups with a total of 39 patient and caregiver participants. Seven patients and caregivers who were unable to attend a focus group and 13 peer mentors participated in a telephone interview. Although patients and caregivers had limited awareness of peer support, participants acknowledged its central role in affirming their experiences and enabling confidence to live well with kidney disease. We identified four themes related to the anticipated role of peer support in addressing support needs for people with non-dialysis CKD: (1) creating connection; (2) preparing for uncertainty; (3) adapting to new realities; and (4) responsive peer support delivery. Aligning peer support access with patient readiness and existing CKD management supports can promote optimism, community and pragmatic adaptations to challenges.

**Conclusions** Patients, caregivers and peer mentors highlighted a unique value in the shared experiences of CKD peers to anticipate and manage disease-related challenges and confidently face a future living with kidney disease.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Throughout this study, we engaged with patient and community partners to address priorities of enhanced self-management and care experience for people living with chronic kidney disease.
- ⇒ Patient partners contributed their lived experience and methodological expertise through all phases of this research, including study design, collection of rich data through focus group discussions and thematic generation.
- ⇒ Inclusion of participants with varying stages of advanced, non-dialysis chronic kidney disease, their caregivers, as well as trained peer mentors with kidney disease experience provided a breadth of perspectives and depth to our findings.
- ⇒ Most participants had not accessed or were unaware of kidney-focused peer support opportunities, which may have influenced the scope of expressed preferences for peer support delivery.
- ⇒ As most participants were older and primarily English speaking, transferability of findings to younger or more ethnically or culturally diverse individuals with kidney disease may be limited.

## INTRODUCTION

People living with chronic kidney disease (CKD) encounter many challenges related to the complex nature of their condition, associated comorbidities and management demands.<sup>1</sup> Although approximately 10% of the global population is living with CKD,<sup>2</sup> unique metabolic and symptomatic complications arise primarily among those with advanced CKD at increased risk of progression to kidney failure.<sup>3</sup> These individuals are tasked with navigating care transitions, making critical decisions about kidney replacement therapies (such as dialysis or transplantation) and managing complex comorbidities alongside their day-to-day responsibilities.<sup>4,5</sup> As a consequence, people living with advanced CKD

struggle with self-managing their condition and report higher rates of emotional burden and poorer quality of life than those earlier in their disease course.<sup>6,7</sup>

Whereas multidisciplinary CKD care models focus on slowing CKD progression, managing complications and planning for kidney replacement therapies,<sup>8</sup> peer support offers a complementary approach to supporting patients' emotional well-being and informational needs. Peer support refers to a unique type of social support whereby people with lived experience of a condition share knowledge and experiences to support another facing similar health-related issues.<sup>9</sup> Studies examining formal peer support programmes across a variety of chronic illness settings have reported inconsistent but generally positive outcomes related to physical and psychological health, as well as a role in enhanced decisional confidence, illness adjustment and disease-related knowledge.<sup>10-13</sup>

Limited evidence suggests variable uptake of kidney disease-focused peer support despite reported benefits in treatment decision-making, self-management and knowledge.<sup>14</sup> Whereas previous studies have examined perceptions of peer support among individuals with kidney failure (ie, receiving dialysis or transplantation) or users of formal support programmes,<sup>15,16</sup> little is known about anticipated needs and expectations for peer support among persons with advanced, non-dialysis CKD. Given the dynamic nature of CKD, foundational work on the role of peer support in addressing patients' unanswered questions, decision-making and well-being is needed. As such, the purpose of this study was to explore among patients, caregivers and trained kidney peer mentors aspects of support need related to living with advanced CKD and how peer support could address these needs to enhance comprehensive CKD care.

## METHODS

### Study design and setting

We employed a qualitative descriptive methodology to provide insight into individuals' understanding of peer support and views on its role in CKD care.<sup>17,18</sup> Patient and caregiver participants were identified from four multidisciplinary CKD clinics across Southern Alberta, Canada, that focus on managing CKD complications, preventing disease progression and optimising care transitions for individuals at high risk of kidney failure.<sup>19</sup> Peer mentor participants were volunteers from an existing telephone-based peer support programme (ie, Kidney Connect) that is the main source of formal kidney disease peer support available across Canada through regional branches of The Kidney Foundation of Canada, a not-for-profit organisation. This programme operates independently from CKD clinics and is variably introduced to patients during CKD clinic encounters. Programme promotional material is available online, through media campaigns and in clinic waiting areas. Interested individuals can self-refer or be referred by healthcare providers with their consent.

The research team included healthcare providers, patient partners, a community organisational representative and health services researchers with an interest in peer support delivery for people with CKD and research methodological expertise. We ensured rigour to enhance the credibility of our findings, including taking a reflexive approach to problem formulation, data collection and analysis; discussing and documenting analytical decisions; and supporting our findings with rich descriptions and verbatim quotes.<sup>20</sup> We have reported this study in accordance with the Consolidated Criteria for Reporting Qualitative Research.<sup>21</sup>

### Participants

Participants included patients with non-dialysis CKD, their informal caregivers and trained peer mentors. All participants were English speaking and 18 years of age or older. Patients included individuals with advanced, non-dialysis CKD followed in multidisciplinary CKD clinics (ie, with an estimated 2-year kidney failure risk greater than 10% and/or estimated glomerular filtration rate (eGFR) less than 30 mL/min/1.73 m<sup>2</sup>).<sup>19,22</sup> Patient participants were asked to invite potentially interested informal caregivers, where applicable. Patients and caregivers were not required to have had peer support experience for eligibility. Peer mentor participants included Kidney Connect volunteers with lived experience of a variety of types of kidney disease and who had undergone standard training procedures established by their regional programmes.

Using purposive sampling, healthcare providers introduced the study to eligible patients/caregivers during routine CKD clinic visits, and a research team member contacted interested participants to schedule a focus group or telephone interview. Peer mentors were identified by Kidney Foundation staff and invited to participate in a telephone interview. All participants provided written informed consent.

### Data collection

We used semistructured focus groups and individual interviews to explore participants' experiences living with kidney disease, gaps in supports and peer support awareness and needs. We developed the question guide with reference to the peer support literature and with input from patient partners, and made minor revisions following initial focus groups and interviews (online supplemental tables 1 and 2). Open-ended questioning about support needs was informed by an established conceptual framework for peer support (ie, informational, emotional and appraisal support domains),<sup>9</sup> and prompts were guided by the evolving discussions. Patients/caregivers were asked about their support needs and perspectives on peer support whereas peer mentors were asked to reflect on their experiences of both providing peer support and living with advanced, non-dialysis CKD. On conclusion of interviews and focus groups, participants were invited to clarify comments or raise additional points not discussed during the session.

Facilitators experienced in qualitative methods led the focus groups and interviews (SL, DEF, NV, KM), with another facilitator present to take notes during focus groups for contextual data on group dynamics and reactions. As most focus groups were cofacilitated by a patient partner, the team redirected the discussion if its focus diverged from the issue under study. Focus groups lasted 1.5 hours and interviews lasted 45 min, on average. Interviewers and facilitators had no pre-existing relationships with study participants. All sessions were digitally audio recorded and transcribed verbatim.

### Data analysis

Transcripts were entered into NVivo V.12 (QSR International) to facilitate data management, coding and retrieval.<sup>23</sup> Using an inductive thematic analysis approach,<sup>24 25</sup> transcripts were coded in duplicate by research team members (SL, MJE, DEF, NV). A preliminary coding framework was generated, applied to subsequent transcripts and revised through regular team discussions. Coded transcripts were compared across team members, and discrepancies in coding were resolved through discussion and consensus. We generated preliminary themes, which were refined based on feedback from team members and checked against coded extracts and the data set to identify patterns and relationships. Using a reflexive approach, the research team reviewed the final themes for coherence and ensured interpretation was shaped by participant data and not their own perspectives on peer support. Data collection and analysis took place simultaneously, and recruitment ceased once data saturation had been attained (ie, the point at which little or no new information was generated).<sup>26</sup>

### Patient and public involvement

Two patient partners (NV, DC) were involved in the development and undertaking of this study. Both have lived experience with CKD and as trained peer mentors through The Kidney Foundation of Canada's Kidney Connect programme. NV, who has completed a research internship through the Patient and Community Engagement Research programme at the University of Calgary,<sup>27–29</sup> contributed to study design (ie, developing and pilot testing question guides) and coding of transcripts during thematic analysis. One patient partner (NV or DC) attended four of the seven focus groups to assist with group facilitation and enrich the discussion (any questions from participants directed at the patient partners were deferred until the focus groups concluded). Both contributed insights during manuscript preparation and review. Patient partners will engage in subsequent phases of this research programme that aims to adapt, implement and test peer support delivery for people living with non-dialysis CKD in collaboration with relevant partner organisations.

## RESULTS

Fifty-two individuals (31 patients, 15 caregivers, 6 peer mentors) participated in our study. Thirteen eligible

individuals were approached but did not participate due to scheduling conflicts, change in medical status or inability to follow-up after initial contact. We conducted seven focus groups (of five to eight individuals each) with patients and caregivers, and 13 telephone interviews with peer mentors and patients or caregivers unable to attend a focus group (table 1). Approximately half of participants were women, and two-thirds were over age 65 years. Patient participants had CKD from a variety of causes and were at high risk of kidney failure requiring dialysis; 11 had category G4 CKD (ie, eGFR 15–29 mL/min/1.73 m<sup>2</sup>) and 13 had category G5 CKD (ie, eGFR <15 mL/min/1.73 m<sup>2</sup>) (table 2). Three-quarters had been diagnosed with CKD within the last 10 years. All caregivers (12 spouses, 2 friends and 1 child) participated alongside a loved one with CKD with whom they resided and/or to whom they provided unpaid support, such as meal preparation or accompaniment to appointments.

Participants reported several challenges across domains of CKD self-management consistent with those described previously, including gaps in knowledge, information access and tangible supports.<sup>1</sup> Among patients and caregivers, only one patient was aware of a kidney peer support programme (ie, Kidney Connect) but had not accessed it. Participants discussed affirmation of individuals' emotional responses and experiences as the main mechanism by which peer support could encourage people to move beyond their diagnosis, or label, of CKD to a state of acceptance, preparedness and confidence to live *well* with kidney disease. This central concept was captured across participant types and is elaborated in four themes. Participants expressed an expectation of enhanced self-efficacy through knowledge and empowerment as a result of effective peer support, as well as a bolstered support community to help patients face future challenges. In the following themes, we have indicated where a perspective was expressed uniquely by one participant type; otherwise, reported findings apply across participants. Table 3 includes supporting quotes organised by theme and related conceptual category. Relationships between thematic findings, peer support attributes and anticipated outcomes of peer support are summarised in figure 1.

### Creating connection

Participants across roles acknowledged the perceived isolation that accompanied living with a largely silent chronic condition. One patient shared the common sentiment that kidney disease 'is the loneliest journey that you will ever go through' (FG5-03), and others described intentionally withholding or minimising their condition within their social circles due to others' anticipated reactions and misunderstanding of CKD. Participants recalled chance encounters with other patients in clinical settings, such as waiting rooms, as superficial and inadequate for alleviating the fear, isolation and confusion accompanying their CKD diagnosis. This contrasted with the perceived outlet of trusted CKD peers to whom patients

**Table 1** Demographic characteristics of patients, caregivers and peer mentor participants

Characteristics	n (%)			
	Patients n=31	Caregivers n=15	Peer mentors n=6	Overall n=52
Age (years)				
Under 40	1 (3)	1 (7)	0 (0)	2 (4)
40–64	9 (29)	3 (20)	5 (83)	17 (33)
Over 65	21 (68)	11 (73)	1 (17)	33 (63)
Sex				
Men	20 (65)	1 (7)	3 (50)	24 (46)
Women	11 (35)	14 (93)	3 (50)	28 (54)
Education				
High school	10 (32)	6 (40)	2 (33)	18 (35)
College, trade school, university	14 (45)	8 (53)	4 (67)	26 (50)
Graduate school	7 (23)	1 (7)	0 (0)	8 (15)
Employment				
Full time, part-time	23 (74)	4 (27)	4 (67)	13 (25)
Retired	5 (16)	8 (53)	0 (0)	31 (60)
Other (disability, student, not employed)	3 (10)	3 (20)	2 (33)	8 (15)
Marital status				
Married	23 (74)	12 (79)	4 (67)	39 (75)
Common law	2 (6)	1 (7)	0 (0)	3 (6)
Divorced, separated, widowed	4 (14)	1 (7)	2 (33)	7 (13)
Single	2 (6)	1 (7)	0 (0)	3 (6)
Living situation				
With spouse or children	27 (87)	15 (100)	4 (67)	46 (88)
Alone	4 (13)	0 (0)	2 (33)	6 (12)

could ‘vent and talk about how we are feeling’ (FG3-04, caregiver) and feel heard.

Participants voiced unique value in speaking freely with individuals ‘in the same boat’ (FG3-05, caregiver) who could appreciate the legitimacy of their concerns, emotions and day-to-day challenges. Whereas participants tended to reject expressions of pity and offers of help, they embraced the prospect of honest, responsive and non-judgemental communication with peers arising from a place of shared empathy: ‘I don’t want sympathy... It’s the empathy, and it’s really hard to get nowadays’ (FG3-06, patient). Occasions to connect with others facing ‘challenges of caregiving’ (Int-03, caregiver) for persons with CKD were noted to be particularly sparse and highlighted as an area of focused need.

Several patients and caregivers voiced a desire for sustained connections with CKD peers beyond one-off encounters or scheduled sessions. One patient noted the ‘easy bond’ and ‘camaraderie’ (Int-05) that naturally unites individuals sharing a lived experience, on which peer support could build to broaden available CKD support communities. One caregiver discussed the impactful relationships that evolved from a previous caregivers’ course, and peer mentor participants voiced

similar instances where former CKD peer support group members had ‘become a family’ (Int-06). Participants identified other informal occasions for fostering lasting relationships with others affected by CKD, such as educational sessions or community events.

### Preparing for uncertainty

Patients and caregivers identified peers with kidney disease as key resources to help them navigate the uncertain trajectory of their CKD course. As one caregiver stated, ‘I feel like there’s this black cloud and I’m waiting, is his [kidney] function going to drop?’ (FG3-04). As participants were largely asymptomatic and lacked awareness of others’ experiences with CKD, they expressed difficulty in envisioning what their own disease course might entail. They acknowledged the peer mentor as a source of credible, experiential information to prepare them for ‘what may happen’ (FG1-02, patient) and reinforce recommendations from their care team.

Patient and caregiver participants compared others’ CKD experiences with their own to anticipate the likelihood of potential outcomes. They indicated how authentic examples could validate their emotional responses and alleviate their uncertainties and fears

**Table 2** Clinical characteristics of patients (n=31)\*

Characteristics	n (%)
Cause of CKD	
Hypertension	4 (13)
Diabetes	8 (26)
Glomerulonephritis	2 (7)
More than one	10 (32)
Other (eg, sepsis, obstruction)	5 (16)
Unknown	2 (6)
Length of time with CKD (years)	
Less than 5	11 (35)
5–9	12 (39)
10–20	4 (13)
More than 20	1 (3)
Unknown	3 (10)
Current kidney function (eGFR, mL/min/1.73 m <sup>2</sup> )	
<15	13 (42)
15–30	11 (35)
31–45	2 (7)
Unknown	5 (16)

\*All 15 caregivers participated alongside a patient with CKD. CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

concerning CKD progression. Although one individual anticipated learning ‘what you can expect’ (FG7-05, caregiver) through connecting with others with advanced chronic disease, patients and caregivers described few or no encounters with individuals affected by CKD. Peer mentors recalled a lack of supports during their own CKD journey and reflected on the comfort that sharing their CKD experiences had brought others. One mentor acknowledged the ‘bumps in the road... and to know somebody else has done it is very encouraging’ (Int-07).

Patients and caregivers discussed how anticipating what might lie ahead could inform decisions about their kidney care, general health and day-to-day living. Although some patients were approaching kidney failure, they expressed limited understanding of treatment options and either had not yet identified their preferred course of therapy or were unsettled in their decision. Participants across roles endorsed speaking with others who had faced similar decisions to learn not just ‘what the options are’ (FG2-03, patient) but about experiences of dialysis or transplantation. They indicated their preference for support from ‘people that have gone down this road’ (FG6-01, patient) to address outstanding questions and reinforce their decisions. One mentor recalled the ‘wealth of information’ provided by a support person who ‘had done everything that I had done but five or 10 years before me’ (Int-08).

### Adapting to new realities

Across roles, participants reflected on CKD as an important, yet not defining, element of their lives. They admitted struggling with ‘accepting all of this’ (FG3-03, patient) and not fully appreciating the impact of advanced CKD or kidney failure on routine activities. The need for ‘answers to the questions [patients] have about what impacts their life’ (FG2-03, patient), such as the compatibility of CKD with travel, employment and hobbies, was deemed highly individual. Participants suggested peer support could offer pragmatic tools to assert control over their lives and acknowledged others living well with CKD as exemplars for integrating CKD into their lives, rather adjusting their activities to accommodate CKD.

Patients and caregivers described long-standing, responsive relationships with their healthcare team, yet many raised instances of frustration surrounding care processes. Lived experience of similar difficulties was articulated as an asset that positioned peers to normalise experiences, provide encouragement and help ‘advocate for yourself’ (Int-08, mentor). Peer mentor participants recounted similar struggles during their own CKD journey and how hindsight into their own experiences and encounters with other patients equipped them for approaching these issues in a mentor capacity. Both peer mentor and patient participants identified the reciprocal nature of the peer support relationship and a desire to assist others similarly affected by CKD. One mentor described the value in supporting ‘somebody that wants answers to all these questions that I didn’t have the information myself when I was going through it’ (Int-11, mentor).

In focus groups, patients and caregivers expressed sentiments of hope on learning about the experiences of others—connecting with individuals living well with kidney disease ‘kind of uplifts you’ (FG2-04, patient)—and the realisation that a full, meaningful life with CKD or kidney failure is attainable. While this optimism was expected to carry over to formal peer support relationships, it was tempered by a desire for peer interactions that would provide a balanced picture of the realities of living with CKD and equip them with strategies to confidently surmount difficulties. As one patient said, ‘I am very realistic. I’ve got kidney disease, so this is what I’ve got to do’ (FG7-03).

### Responsive peer support delivery

Enhanced opportunities for flexible, responsive peer support were emphasised to reflect the varied and dynamic experiences of living with advanced CKD. Specific preferences for format of peer support delivery varied across participants. The key features contributing to optimal peer support provision in this context are outlined below and summarised in figure 1.

**Table 3** Exemplar quotes across themes and conceptual categories

<b>Theme 1: creating connection</b>	
Perceived isolation	Who am I going to talk to? I have two invisible diseases, and everybody thinks I'm just totally fine, but they have no idea. (FG2-03, patient)
	What I found was that [physician] and his staff and the nurses are incredible. They'll give you as much information as you ever want, but I also want to say that I feel that this is the loneliest journey that you will go through. (FG5-03, patient)
	I didn't know anybody. I thought I was the only guy that's had this thing... When they said kidney disease, and when somebody says disease to you, it's something that, I don't want to be around that diseased person, you know? You feel like you're probably going to get shunned or something. (FG5-04, patient)
A listening ear	This is scary. This is all impacting. It's not just you and I that are worrying. It's them and your kids and your cousins and your neighbours and stuff, and I don't know what you could do for emotional support other than what you are doing here. Listening, and being able to vent and being able to share, and seeing what other people are going through. (FG7-01, patient)
	All of the women in that group [caregivers' course], there were about 10 of us, caregivers for their husbands. And it was wonderful to be able to share our experience in the challenges of caregiving. (Int-03, caregiver)
Empathy	If you don't have the disease or you don't have the issues, it's pretty hard to understand how the other person is feeling. You can talk to all kinds of people, but if you are not in the same boat, you don't really know how they are feeling, how they are coping. (FG3-05, caregiver)
	I don't want sympathy from people. I don't want people feeling sorry for me, like, oh my gosh, you poor thing. It's the empathy, and it's really hard to get nowadays. (FG3-06, patient)
	Our friends that have been friends for 20 years, they didn't understand, and instead of asking questions or doing research they kind of stopped calling... I'm sure it's similar with other diseases, but unless you are going through it, you don't know. (Int-10, mentor)
Community and connectedness	There's absolute value in what people are going through. It's an easy bond to form, and you have that sort of camaraderie when you are going through a similar thing. (Int-05, patient)
	In my [support group] I had realized there was four of these older gals that were all widows, and all of a sudden, I realized they were looking after one another. They were calling each other up to make sure that they were getting to their appointments, that they had food, that they had medicine... They had formed their own little support group internally. (Int-06, mentor)
<b>Theme 2: preparing for uncertainty</b>	
Disease unpredictability	I've got books, I've got binders... It's kind of nice to pretend that you are ok and just carry on. But every month or so you get the number [eGFR] and sometimes it's the same, sometimes it's up one, and sometimes it's down one. (FG1-02, patient)
	I always feel like there's this black cloud and I'm waiting. Is his [kidney] function going to drop? I'm just waiting for it. It's like I'm trying to brace myself for the onset of this kidney [function] to really get a lot less. (FG3-04, caregiver)
Reassurance	Being able to talk to her [caregiver peer] was a huge benefit to know, okay, this is what I'm supposed to be feeling and how this feels and what you can expect. (FG7-05, caregiver)
	People just needed to know that there is someone else out there like themselves who made it through... There are going to be bumps in the road. Nobody is saying it's easy, but it's one step at a time, and to know somebody else has done it is very encouraging. (Int-07, mentor)
	Looking back now after being someone who's been through it and talking to people who are starting dialysis, some of the questions that they ask me, I didn't even think of back then. So I'm thinking, if I'd have asked that question to somebody who had been on dialysis or who had done needling, I could probably have gotten some of the fears away. (Int-09, mentor)
Informed decision-making	I go to these courses or seminars, whatever it was that they tell you about different types of dialysis and transplant, and you spend a couple of hours there and you go home with a bunch of papers. But there's that, and then there's actually talking to someone who's been through the experience... You really need to get that information. I think it would serve most people well to be overeducated in what's going to happen. (FG1-02, patient)
	Knowing what the options are more so than just what you've been told for yourself, and then seeing that in action, somebody living in front of you. (FG2-03, patient)

Continued

**Table 3** Continued

Anticipating outcomes	<p>I think that for me having contact with somebody that's in dialysis or had done dialysis, somebody that has gone on the list for kidney transplant... Hearing from people that have gone down this road, I think that would probably be the biggest help for somebody that's starting off as more of a newbie in the game. What's down the road? The GPS. (FG6-01, patient)</p> <p>She [peer] just basically had done everything that I had done but five or 10 years before me. So she was just a wealth of information on handling the situation with her kids or with her siblings or with her doctors. (Int-08, mentor)</p>
<b>Theme 3: adapting to new realities</b>	
Acceptance and accommodation	<p>That's the one we had thought [peritoneal dialysis] and what we had put down for, because I don't want [dialysis] to hold me here. I want to buy a motorhome... I can set the machine up and do my dialysis in the motorhome. (FG1-04, patient)</p> <p>Just being able to talk to other people that and see how they are living with what they've got... I live a fairly normal life. (FG2-01, patient)</p> <p>What people would benefit from is getting the answers to the questions they have about what impacts their life... I think those kinds of things are highly individualized, but to be access whatever you need from one spot would be ideal. (FG2-03, patient)</p> <p>I think one of the things is accepting all of this what's going on. You've got changes all the time, and you've got to change. Accept the change, deal with it...After a while you just get tired of dealing. You need a support group to help you. (FG3-03, patient)</p>
Normalising experiences	<p>It dawned on me after a couple of years that I was healing emotionally from this... and I realized the other people that were facilitating were starting to as well. (Int-06, mentor)</p> <p>Now I can support somebody that wants answers to all these questions that I didn't have the information myself when I was going through it. I know what their struggles are, and fears, and I just think it's nice to be able to help somebody out that way... Even though I can't give them full answers, I can give them what I've been through. (Int-11, mentor)</p> <p>'I'm tired all the time.' Well, if she hears that from 10 more people that they are tired all the time, then we know it's normal. 'I'm itchy.' Hey, yeah, I'm itchy more now too. Just to hear that from someone else in the same situation and preferably same age-ish group. (Int-12, caregiver)</p>
Pragmatic optimism	<p>You said something that I found very profound, and I quote, 'Dialysis is life sustaining, not a life sentence.' I really like that. (FG6-07, caregiver)</p> <p>We are doing what we can to sustain ourselves in every way possible. At the same time, I am very pragmatic myself. I am very realistic. Okay, I've got kidney disease, so this is what I've got to do, I'm going to do it. (FG7-03, patient)</p> <p>If you look at your disease as something that is insurmountable, it's pretty easy to wallow in it. It's very easy to just say, 'Poor me,' but if you surround yourself with other people that have managed that mine field and gotten through it, you will come out, I think, with a more positive attitude in the end. (Int-08, mentor)</p>
<b>Theme 4: responsive peer support delivery</b>	
Tailored to readiness	<p>I wished somebody when I was at [eGFR] 18, 15 said — hey this is the [expletive] that's going to happen to you. It would have been very nice. But I'm interested in knowing some of that stuff. Other people, I truly understand, they don't want to know. (FG6-05, patient)</p> <p>He [nephrologist] asked me once or twice if I wanted to learn about the disease. I said, no, too scary. I've got so many things on my brain with all of my issues that I just thought, I will never remember anything about it anyways. So I said, no. (FG4-05, patient)</p> <p>When it's crisis mode is when I'll probably ask [for peer support]. And to me that's more of a personality thing... but realizing the smarter thing is probably, well, gee, why not do it now? Because I feel good, I think part of me is still almost half not believing it and half thinking I'm going to turn this [CKD] around. (Int-05, patient)</p>
Breadth of mentor experiences	<p>It would be very good to talk to people that are already there, like doing dialysis... It would be nice to talk to people just to see what the timelines might be. (FG1-03, caregiver)</p> <p>I don't have [CKD]. I don't have diabetes. But he [spouse] does. And living with someone that has it can be really hard sometimes. It would be nice to be able to pick up the phone and talk to somebody and say, 'This is how I'm feeling, this is what's going on. Is this supposed to be normal?' (FG3-04, caregiver)</p> <p>For me, it [ideal peer mentor] would have to be somebody who has kidney disease. I think that person, it would be really the only person that knows exactly how you feel... Somebody who does have it [CKD], understands. Maybe somebody who has started dialysis or somebody who's on the transplant list, and no offence to anybody in here, but maybe somebody in my own age group. (FG3-06, patient)</p>

Continued

**Table 3** Continued

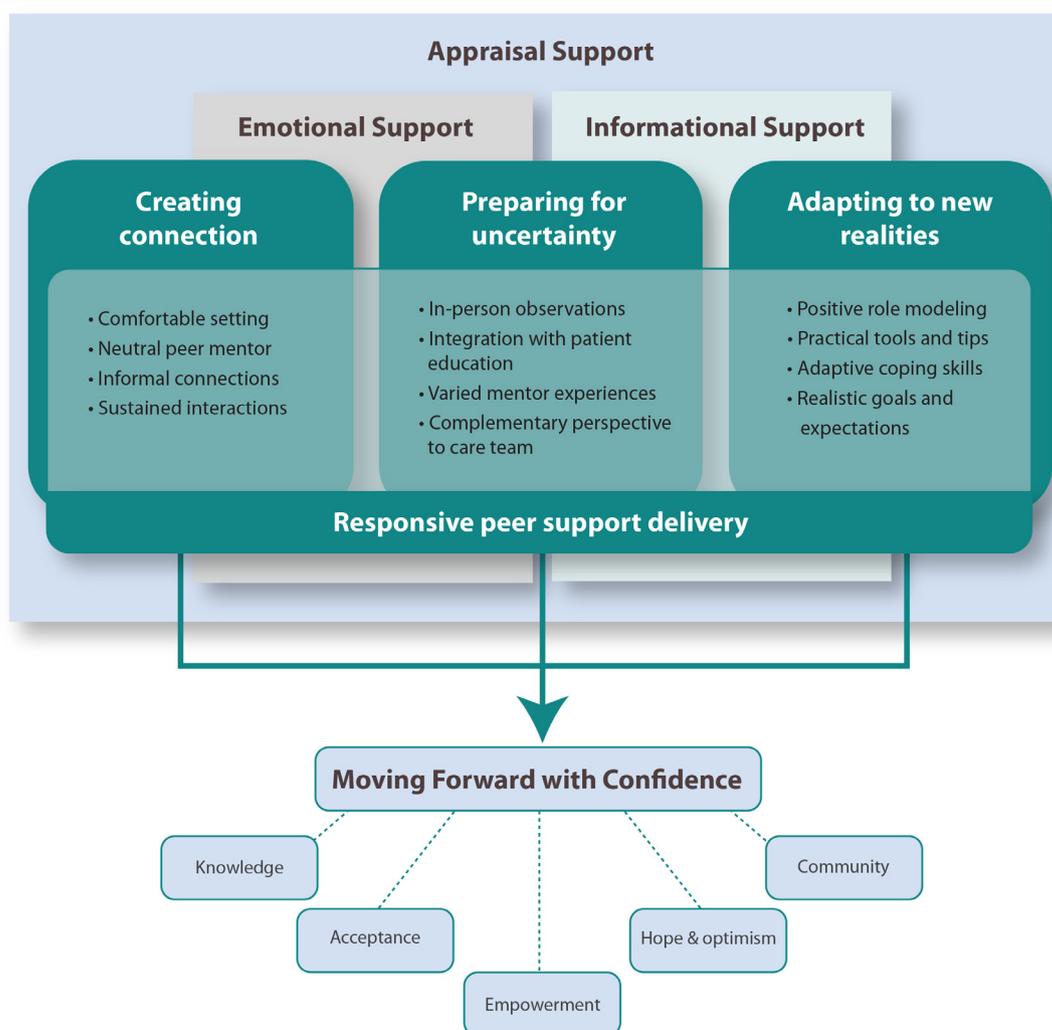
Complementing CKD education	This information doesn't just fall into your lap, because your friends and family, they probably don't know, and your doctor, as good as they are, and the nurse, they have a limited amount of time to educate you. (FG1-02, patient)  It's just nice to have anything extra. The clinic is fabulous, don't get me wrong. They do an absolute fabulous job there. But still, she's a month to two in between [visits], where she's only catching so much of what they are saying. (Int-12, caregiver)
Tangible opportunities	I would like to see the [peritoneal dialysis] tube in somebody, and it wouldn't bother me at all. If I went into a room and I saw tubes... I just want to know what's better for me. (FG2-04, patient)  A support person [assigned] to a group education session. Will approximately last an hour and a half. We'll cover these topics — treatment options for kidney failure, the advantages and disadvantages of each treatment, and what other kidney patients have to say about the treatments they chose... and then it says, you will be invited to see a demonstration of home dialysis if you want to see it. (Int-02, patient)

CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

### Tailored to readiness

Participants varied in their stage of kidney disease, expressed need for support and willingness to access peer support services. Although many described wanting information and support earlier in their disease course, they acknowledged peer support would

prove useful only if and when patients were prepared to engage. One patient mentioned a reluctance to access peer support until 'it's crisis mode' but foresaw becoming 'more open to it' (Int-05) as his health needs evolve. Offering peer support opportunities repeatedly across clinical and educational encounters, flexibility



**Figure 1** Relationship between themes, peer support attributes and mechanisms by which peer support can address expressed needs of people with advanced chronic kidney disease (CKD).

in programme format and commitment, and broad programme eligibility may enhance access once a need is identified by patients and/or their healthcare team.

#### Breadth of mentor experiences

Participants described evolving peer support needs stemming from individual and contextual factors. They underscored the value of accessing varied peer mentors with varied experiences, who know ‘exactly how you feel’ (FG3-06, patient). This included individuals with experience with different kidney replacement modalities (eg, dialysis and transplantation), yet who shared some common characteristics with those seeking support, such as similar age ranges or life circumstances. The distinct and often overlooked difficulties faced by those caring for loved ones with CKD (‘Living with someone that has [CKD] can be really hard’ (FG3-04, caregiver)) highlighted a need for caregiver-focused peer support and availability of caregiver mentors.

#### Complementing, not replacing, CKD education

Participants expressed an appreciation for the depth of information provided by their kidney care team, although they related persistent knowledge gaps, in part, to limited access to healthcare professionals and their lack of lived experience. While participants indicated a preference for receipt of medical information from trained professionals, they articulated how ‘input from all of the different sources’ (FG6-01, patient), including peer mentors, could complement and enhance their knowledge. As one caregiver said, ‘It’s just nice to have anything extra. The clinic is fabulous, don’t get me wrong... but still, she’s a month to two in between [visits]’ (Int-12).

#### Tangible opportunities

Most patient and caregiver participants described limited appreciation of the practicalities of dialysis or transplantation. While educational opportunities through kidney care programmes often involve demonstrations or handling of dialysis equipment, participants discussed wanting interactions with the individuals receiving kidney replacement therapy and not just the machinery. For example, one patient described wanting to ‘see the [peritoneal dialysis] tube in somebody’ to decide ‘what’s better for me’ (FG2-04); another suggested integrating a ‘demonstration of dialysis’ (Int-02) into a peer support session to assist with dialysis modality selection. Such an approach could enable realistic expectations and goal setting, preparedness and strategies to anticipate and manage challenges.

## DISCUSSION

Findings from our study suggest an important role for peer support alongside traditional care models for persons living with advanced, non-dialysis CKD. Although participants had varied experiences, they acknowledged facing similar challenges related to living with a largely

invisible condition, uncertainty and decision-making. In contrast to other social supports, such as family members or healthcare team, peers with lived experience of CKD were considered uniquely positioned to help others navigate and live well with kidney disease. Despite limited familiarity with peer support, many participants expressed wanting to feel understood and connected through shared experiences. Others focused on their desire to anticipate what advanced CKD and kidney failure entail, validate their experiences and reactions and incorporate CKD into their lives (and not the converse). Overall, participants appreciated peer support that is responsive to individuals’ needs and readiness as a way to augment other sources of support and enhance emotional and intellectual well-being.

The importance of appraisal support, which encompasses affirmation of one’s emotional, cognitive and behavioural responses, was highlighted across thematic findings and complemented by informational and emotional support pillars (figure 1).<sup>9</sup> Participants related their emotional struggles to the burden of self-managing or caring for another with CKD, uncertainty of the disease trajectory and lack of appreciation of others facing similar circumstances.<sup>1 30 31</sup> These difficulties were compounded by the need to balance informational needs with the availability of pragmatic resources that individuals could apply to make informed decisions and integrate CKD into their lives.<sup>32</sup> Our findings add to existing literature on the challenges, well-being and quality of life for persons with CKD by providing explicit links between their support needs and established domains addressed by peer support interventions.<sup>9</sup>

Peer support has gained traction in recent years with a shift towards models of patient-centred care that are responsive to individuals’ preferences and values alongside their medical needs.<sup>33 34</sup> However, few studies have explored the needs of patients and their loved ones related to kidney-focused peer support. One study of patient and carer expectations from formal kidney-related peer support described anticipated benefits of informational access, adaptive coping and normalisation.<sup>15</sup> As almost all participants in that study were receiving kidney replacement therapies (ie, dialysis, transplantation), findings do not necessarily account for the unique challenges of living with advanced, non-dialysis CKD that we identified. Other studies conducted among users of kidney disease-related peer support programmes, including individuals with kidney failure and non-dialysis CKD, have reported positive programme experiences and additional advantages of role modelling and empowerment.<sup>14 16 35</sup> In other chronic disease settings, peer support has also contributed to enhanced disease self-management, whereby the knowledge and support from a ‘patient expert’ can promote self-efficacy and positive behaviour change in managing day-to-day living.<sup>11–13 36–39</sup>

As the ones experiencing CKD directly, patients are often viewed as the main beneficiaries of the supports enabled by formal or informal CKD peer relationships.



Our findings suggest a need for focused peer support among caregivers as well. Informal caregivers of people with kidney disease experience high rates of stress, depression and poor quality of life, yet their needs are often overlooked.<sup>40–41</sup> Access to caregiver mentors or dedicated caregiver peer support programmes could enable important connections and equip the caregiver community to also live well with CKD. Our study also highlights a perceived impact of providing peer support on trained mentors—whereas peer mentor participants expressed altruistic motives in supporting others through sharing their own journey, challenges and successes, participants across roles anticipated indirect benefits from their engagement in peer support. Mutually derived meaning, empowerment and altered knowledge and behaviour underscore the inherent reciprocity of mentor–mentee relationships in chronic disease peer support interventions.<sup>13</sup>

Findings from our study have implications for development and/or delivery of peer support for individuals with advanced CKD. While multidisciplinary CKD care programmes are well suited to addressing patients' medical and informational needs, our findings point to persistent support gaps relating to factors including time-constrained clinic visits, evolving patient support needs and lack of CKD lived experience by the care team.<sup>42–43</sup> Strategies to enhance peer support access and address identified barriers to programme uptake (eg, low referrals, mentor–mentee matching, sustainability) require further exploration.<sup>44</sup> As in our study, limited awareness of peer support points to the need for focused promotional efforts among patients and healthcare staff.<sup>44</sup> Our findings suggest the optimal timing for peer support is after intake into a multidisciplinary CKD care environment but before kidney failure is imminent, to enable integration of peer support with other patient-level, provider-level and system-level strategies and enhance patients' readiness for kidney care transitions.<sup>45</sup>

Throughout this study, we engaged with patient and community partners to examine priorities of enhanced self-management and experience for people living with CKD.<sup>46</sup> The main limitation of our study is that findings are context specific and may not reflect the perspectives of the broader CKD population or those in other health settings. Given the nature of the topic, participants may also have been motivated to discuss strongly held views on peer support. However, few were aware of CKD peer support opportunities yet still identified a perceived need, suggesting our results reflect more broadly held perspectives on this issue. We also elicited a variety of perspectives across participant types and rich data through patient partner involvement in focus group discussions. Although we included patients with varying levels of kidney function to reflect the varied and dynamic nature of advanced CKD, the fact that most participants were older and primarily English speaking may limit transferability of findings and highlights a need for dedicated study in younger or more ethnically and culturally diverse individuals.

## CONCLUSION

Peer support is a strategy for addressing the unmet emotional and informational needs of people with advanced CKD. Despite limited awareness of peer support programmes, participants in our study acknowledged the value in connecting with individuals through shared experiences to cope with day-to-day challenges and anticipate decisional needs related to their uncertain CKD course. As the optimal processes for peer support in this setting have not been defined, future work should integrate findings with user preferences for content, format and delivery to tailor peer support opportunities for individuals with advanced CKD.

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