#### UNPLUGGING WHILE PLUGGED IN: A PEER TO PEER EXPLORATION OF THE IMPACTS OF DIALYSIS ON THE MENTAL WELLNESS OF PATIENTS WITH CHRONIC KIDNEY DISEASE

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FUNDER: This work was supported by the Alberta Health Services Kidney Health Strategic Clinical Health Network

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#### **Executive Summary**

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March 31, 2020

#### Introduction

This qualitative study explored the impact of chronic kidney disease (CKD) and dialysis on the mental wellness of patients. The study informed the Kidney Health Strategic Clinical Network™ (KHSCN) of the patient experience of trying to maintain mental health while on dialysis. The study included 11 patients on all dialysis modalities, as well as those with a history of dialysis who have received a renal transplant. Through exploring the impact of CKD on mental wellness, coping strategies and recommendations to support patients in managing their mental wellness were also uncovered.

#### Methods

The Patient and Community Engagement Research (PaCER) methodology is an innovative research style in which participants and researchers are peers. PaCER uses iterative cycles of data collection and analysis ensuring a continuous integration of data and the development of a working theory. In this study, iterative cycles of individual and shared thematic analysis were utilized for focus group data, while narrative analysis was employed for the individual narrative interviews. Common themes uncovered during shared analyses were brought forward to patient partners for validation and deeper exploration. The purpose of using this methodology was to better understand the experiences, priorities, and recommendations of patients living with end-stage renal failure (ESRF) and being treated with dialysis in the province of Alberta.

#### Results

This study highlighted several perceived gaps in care identified by participants, the most glaring gap being the lack of psychosocial support available to patients and those supporting them. The ability of patients to self-advocate and develop personalized coping strategies improved their perceived care, while issues with miscommunication, navigation of the health system, a lack of education, and a perceived lack of empathy and validation on behalf of health care providers negatively impacted their care.

Two main categories and their respective sub-categories were uncovered in this study:

#### 1. Experiential findings

- a. Real impacts of CKD and dialysis on a patient's mental health
- b. Communication and system navigation impacts on mental health
- c. CKD and dialysis impact the patient's support network
- d. Perceived lack of empathy and invalidation from health care providers

- 2. Coping strategies
  - e. Advocate for self or find patient advocates/experts for you
  - f. Importance of personalized coping strategies while on dialysis

#### Discussion

Patients experience a disproportionate burden to become drivers of their health care needs. Without the ability to advocate for oneself, navigate a complex health system, and develop personalized coping strategies, mental wellbeing inevitably suffers for both the patient and their support network. Participants communicated their frustration over their perceived lack of focus on mental wellbeing, despite a rich base of evidence pointing to the markedly increased risk of mental health concerns in this population. On the surface, there would appear to be a simple solution to this issue: ask patients how they are feeling and treat their response with the same vigor as one would treat laboratory values. The reality according to our patient partners, however, is that even if health care providers ask this question and/or administer a mental health assessment, there is a perceived lack of psychosocial support available to patients on dialysis.

#### Recommendations

The recommendations suggested by patient partners during the REFLECT stage represent actions that patients and the health care system could collectively implement to support improved self-management for patients living with CKD and being treated via dialysis. The recommendations also point towards a strong desire from the patient perspective to be viewed as an entire person, rather than an isolated disease. Recommendations are stratified into patient actions and health system actions.

#### a. Patient Actions

- Support patients to become advocates to drive their own care. This could be accomplished through patient-to-patient peer mentoring, especially if a patient is too ill to self-advocate, provide training in health system navigation, and seeking opportunities for partnerships with health care providers in research/projects/initiatives.
- Set actionable goals for oneself mentor patients in SMART goal setting if this skill requires development.

#### b. Health System Actions

- Implement a peer mentoring unit for patients and resource adequately.
- Leverage the abilities of the psychosocial team greater scope of practice for Social Workers who have received training in counselling and system navigation (going beyond basic financial/tax information)
- Improve connections with psychosocial team and include mental health professionals in patient rounds as part of the multidisciplinary team.

- Create a health system navigation resource (or suite of resources) that can be provided to patients at the start of their journey.
- Introduce the idea of transplantation much earlier in the patient's journey.
- Physician participation in the kidney community (e.g., the annual Kidney Foundation Gala, Kidney Health Patient Forum) to be seen by patients and families as partners in care.
- Change approach from "what are your numbers?" to leading with "how are you doing?" Implement a follow up process for mental wellness if the patient requires additional support.
- Implement a mental health assessment at treatment initiation and at regular intervals throughout the patient's journey.

#### Introduction

Unplugging while plugged in an exploration of the impacts of dialysis on the mental wellness of patients with chronic kidney disease is a peer to peer exploration of how dialysis impacts mental wellness for patients with chronic kidney disease (CKD). According to a study by Schouten (2016), the prevalence of anxiety- and depression-related symptoms in dialysis patients ranges from 38-53% and 37-42%, respectively. Given the significant proportion of dialysis patients who exhibit mental health concerns throughout their journey, the connection between mental health, wellness, and dialysis is concerning and requires inventions by the health system. As noted in the literature, positive wellbeing is associated with openness, independence, medical adherence, and quality of life (James, 2018) while mental health concerns for dialysis patients is associated with increased risk of hospitalization, morbidity, mortality (Schouten, 2019). Despite these connections, the literature on CKD, dialysis, and mental wellness is not as extensive as other chronic conditions such as heart disease and cancer (Zhong, 2018). This is especially true when it comes to qualitative studies that not only represent the patient voice, but also follow the PaCER methodology (Figure 1). Working in collaborating with Alberta's Kidney Health Strategic Clinical Network, who provided funding for patients to be trained using the PaCER method and who funded this study, this research began with two central objectives. First, to explore the impacts of dialysis on the mental wellness of patients with CKD and second, the understand and explore the coping strategies used by patients as they navigate stressors associated with dialysis treatment.

#### **Background and Rationale**

Alberta's Kidney Health Strategic Clinical Network (KHSCN) estimates that 1 in 10 Canadians has kidney disease (Alberta Health Services, 2016). In Alberta, the KHSCN estimates 450,000 Albertans are affected by kidney disease, resulting in a cost of almost \$5 billion per year to the health system (AHS, 2016). Every year, approximately 500 Albertans are diagnosed with end-stage renal failure (ESRF) and are placed on dialysis (KHSCN, 2015).

Dialysis is a life-sustaining maintenance treatment required by chronic kidney disease (CKD) patients diagnosed with ESRD. Regardless of modality type (hemodialysis or peritoneal dialysis), dialysis treatment is unable to replicate the full functionality of a healthy kidney and as a result patients often experience co-morbidities and negative health outcomes (Farrokhi, 2014), including a substantial decrease in quality of life and functional impairment (Hadayati, 2009). Dialysis is a demanding therapy requiring patients to adhere to strict dietary and fluid restrictions, while maintaining a rigid schedule of testing and treatment resulting in "an intense burden" for patients with ESRD (Palmer, 2015). Given these circumstances, dialysis patients experience numerous psychological challenges due to the demands placed by treatment, with depression being the most common among individuals with end-stage renal failure (Treadwell, 2017).

The new demands and stressors include but are not limited to new adjustments to complicated diets, fluid restrictions, treatment (dialysis), and concerns over their caregivers. When taken together, this may lead to pain, fatigue, and impaired overall well-being (Kittiskulnam, 2016). The physical and emotional toll of dialysis may result in patients and their caregivers experiencing such high levels of fatigue and malaise that it's not uncommon to "lose" entire days following treatment. Given these circumstances, dialysis patients experience numerous psychological challenges due to the demands placed by treatment, with depression being the most common among individuals with end-stage renal failure (Treadwell, 2017).

Drawing on previous qualitative data, Tong (2014) notes that approximately 20% of deaths in dialysis patients is the result of withdrawing from dialysis treatment. While this study focused on palliative care strategies for CKD patients, the authors highlighted the need for patient strategies that promoted emotional resilience, sense of well-being, and self-value. Regarding the impact on a kidney patient's mental health, Schouten (2019) notes "It is important to gain insight into the magnitude of these mental health problems and the associated adverse outcomes to improve treatment and quality of life."

Treadwell (2017) indicates 20% to 30% of dialysis patients experience depression. Kittiskulnam (2016) reports that the rate of depression among patients with CKD is underestimated and is 3 times higher than the risk faced by the general population. Schouten (2015) found that the prevalence of anxiety symptoms in dialysis patients ranges from 38% to 53%, while depression symptoms range from 37% to 42% when using self-reported questionnaires.

Hedayati (2012) indicates that patients who experience depression and anxiety are more likely to die or require hospitalization compared to those without having depression. Multiple studies (Kittiskulnam, 2016; Hedayati, 2012; Treadwell, 2017; Cukor, 2009) argue that depression may lead to greater levels of non-adherence for dialysis patients compared to patients without depression and thus, increased risk of morbidity and mortality.

Ossareh (2014) outlined the connection between mental wellness and emphasized the need address the mental health of patients arguing that "addressing and treating depression in patients on dialysis can positively impact adherence to treatment, mental health, and physical well-being". Recognizing this severe burden, Kittiskulnam (2016) adds, "A multidisciplinary team approach including a psychiatrist, psychologists, or social workers should be taken in the treatment of depression."

Despite the documented physical, financial, and emotional toll of ESRF and dialysis, there is a paucity of research highlighting the experiences of patients living with ESRF and treated with dialysis. This is the only known study which aimed to explore the impacts of ESRF and dialysis on the mental wellbeing of patients utilizing a patient-led, patient-to-patient research methodology (Shklarov et al., 2017; Marlett et al., 2015).

#### Methods

#### Patient and Community Engagement Research (PaCER) Model

Patient and Community Engagement Research Program (PaCER) is part of the O'Brien Institute for Public Health in the Cumming School of Medicine at the University of Calgary. Academically, it is also part of the Community Rehabilitation and Disability Studies in the department of Community Health Sciences. The PaCER mandate is to provide research development, supports and services to health researchers and teams, research foundations and Alberta Health Services and health care providers interested in adopting patient and community engagement methods as part of their research and planning processes. PaCER achieves this by teaching patients and caregivers to become skilled in engaging other patients, caregivers and communities in research and, upon graduation, making PaCER graduates available to health care and research clients. The PaCER method has a distinct structure defined as SET, COLLECT, REFLECT (Figure 1) to ensure that participants are meaningfully engaged throughout.



Figure 1. Overview of the three phases of the PaCER research methodology. SET: This opening exploratory procedure invites representative patients and other expert in the area of the study to become advisors and help co-design and set the stage for the study by refining the particular protocols (recruitment, locations, alliances), questions and data collection.

COLLECT: Particular techniques of data collection and analysis depend on the specifics of research questions and purposes of each given study.

REFLECT: At this stage, participants from the initial set focus group (item 1) review findings and analysis with the PaCER team and suggest knowledge utilization and recommendations for further research. This stage completes the circle of PaCER procedures and prepares the data to be shared with the relevant health system.

SET and REFLECT focus groups are the hallmarks of the PaCER method, serving to ensure a meaningful patient involvement and contextual validity.

The PaCER methodology is an innovative research style in which participants and researchers are peers. PaCER combines participatory action research and classical grounded theory with iterative cycles of data collection and analysis ensuring a continuous integration of data and the development of a working theory (Marlett & Emes, 2010).

In this study, iterative cycles of individual and shared thematic analysis were utilized for focus group data, while narrative analysis was employed for the individual narrative interviews. Common themes uncovered during shared analyses were brought forward to patient partners for validation and deeper exploration. The purpose of using this methodology was to understand the experiences and priorities of patients living with ESRF and being treated with dialysis in the province of Alberta

#### **Recruitment and Inclusion Criteria**

This study used a combination of purposive and convenience sampling of patients who had been diagnosed with chronic kidney disease and had personal experience with dialysis (all dialysis modalities were included). For the purposes of this study, kidney transplant recipients were also included provided they had experience with dialysis prior to and/or since their transplant occurred. Participants who were over the age of 18, able to speak English fluently, were treated within the Canadian health care system, were a current resident of Alberta, and consented to participating in a focus group and/or interview were included.

Participants were recruited through personal contact, social media platforms Facebook and Twitter (Appendix 1)the Kidney Foundation of Alberta North and South branches (Appendix 1), Alberta Innovates Strategy for Patient-Oriented Research (SPOR) Support Unit (Appendix 1), and print media (postcard and poster – Appendices 2 and 3, respectively) was sent to dialysis units

and the home dialysis program. Interested individuals were invited to speak with a research team member to ensure understanding of the study and assess eligibility.

#### Participants

Participants were individuals who self-identified as having chronic kidney disease and personal experience being treated by any dialysis modality within Canada and who currently resided in Alberta. Participants were recruited through PaCER interns and through word-of-mouth. The most effective strategy to recruit participants for this study came from existing relationships with members of the Alberta Kidney Foundation. Eleven individuals participated in the study, however, nine were included in the data set: 2 participants attended the SET focus group (not part of data set), 4 attended the COLLECT focus group, 5 attended the REFLECT focus group, and 6 were interviewed. Some of the individuals participated in both interviews and focus groups. Eight participants were from Edmonton, 1 was from Calgary, 1 was from Medicine Hat, and 1 was from Ontario. The age range of participants was 29 - 57, with most being in their 40s. 4 participants were female (44%) and 5 were male (56%) (Table 1). Dialysis modalities varied among participants, with 2 (22%) currently using in-centre hemodialysis, 0 (0%) currently using home hemodialysis, and 2 (22%) currently on peritoneal dialysis. Three participants spent less than 1 year on dialysis, two spent 1-3 years on dialysis, and four participants spent 4+ years on dialysis. Five (56%) participants had received a kidney transplant (Table 2). Additionally, two potential participants were unable to attend a focus group or interview because of feeling too unwell.

Participant No.	Age	Sex	Ethnicity	Location
1	40	М	Indo-Canadian	Edmonton, Alberta
2	40	F	Caucasian	Edmonton, Alberta
3	48	М	Caucasian	Edmonton, Alberta
4	29	М	Caucasian	Edmonton, Alberta
5	57	F	Caucasian	Edmonton, Alberta
6	45	М	Caucasian	Edmonton, Alberta
7	47	М	Caucasian	Calgary, Alberta
8	37	F	Caucasian	Edmonton, Alberta
9	44	F	Indo-Canadian	Edmonton, Alberta

Table 1. Demographic information of participants

Participant No.	Dialysis Modality	Kidney Transplant (Y/N)	Time on Dialysis (years)
1	PD and HD	Y	3
2	Home PD	N (waiting)	<1
3	Home PD	N (waiting)	<1
4	In-centre PD	Y	<1
5	In-centre HD	Y	5
6	In-centre HD	Y	3

Table 2. History of chronic kidney disease and treatment modalities among participants

#### **Data Collection and Analysis**

7

8

9

HD

PD and HD

PD and HD

The PaCER methodology (Figure 1) is iterative and responsive to directional shifts related to information received during focus groups and interviews (Marlett et al., 2014). Participants were partners in this study and were involved in all stages of the study (Gill et al., 2016; Gillis et al., 2017; Miller et al., 2016). Firstly, we sought to explore the impacts of dialysis on the mental wellness of patients with CKD and second, explore recommendations made by patients to improve mitigation of stressors associated with dialysis treatment.

Y

Ν

Ν

4

5

20+

The SET stage is the initial exploratory phase of the PaCER methodology and seeks to explore the topics of interest with patients who have expertise in this area (Canadian Institutes of Health Research, 2014). The topics of greatest interest to SET participants are used to frame the guiding questions for the COLLECT phase and narrative interviews. This phase is audio-recorded, and flip chart notes are taken; however, information does not become part of the study data set as it is viewed as guidance for data collection and not data to inform the study.

The COLLECT phase of the study built upon the topics of interest discovered during SET. The purpose of the COLLECT focus group and narrative interviews was to identify, refine, and summarize patient experiences related to the study's main concern: the impact of CKD and dialysis on the mental wellbeing of patients. The COLLECT focus group and narrative interviews all began by asking the same open-ended question: "how has CKD and being on dialysis impacted your mental wellness?"

Discussion among participants was encouraged using probing questions to elicit deeper meaning around patient stories. Five PaCER interns supported data collection during COLLECT,

with 1 individual facilitating the conversation, 2 individuals flip charting, and 2 individuals recording process notes. The focus group was audio-recorded, and data was analyzed as a 2-step iterative process:

step 1) individual open coding, and step 2) shared analysis amongst the research team. Information from the interviews was analyzed using narrative analysis and compared between interviewees. Data from the COLLECT focus group was used to guide the probing questions for the narrative interviews and subsequent REFLECT focus group.

Building upon the advice of patient partners from the SET phase and emerging categories uncovered during the COLLECT focus group and narrative interviews, the purpose of the REFLECT focus group was to seek validation and relevancy from patient partners. Emerging categories from the COLLECT focus group and narrative interviews were presented to participants of the REFLECT focus group for discussion and prioritization. Following validation and relevancy of the findings by patient partners, the data from REFLECT was analyzed in the same iterative fashion as the COLLECT focus group.



Figure 2. Graphical representation of the iterative nature of the PaCER methodology. Participants in the SET phase = 2; COLLECT phase = 4, narrative interviews = 6 (5 from COLLECT); REFLECT = 5 (1 from SET, 2 from COLLECT, 2 from narrative interviews)

#### **SET Phase Description**

Six patient advisors agreed to participate in the SET focus group, however, four were unable to attend. A total of two female patient advisors participated remotely (online) in the SET focus group. Despite the small number of participants, the group lasted for five hours. Flip chart notes were taken by hand in Edmonton and online from Calgary. Participants were asked to assess the validity of the notes and invited to provide any additions or clarifications to the notes. Probing questions (e.g., "can you elaborate?", "can you think of a time when...?", etc.) were employed to uncover greater detail about the patient experiences. Since both participants were attending remotely, the online version of the flip chart notes was used to facilitate this process. Flip chart notes formed the basis for the guiding questions used in the COLLECT focus group and narrative interviews. The SET focus group was audio-recorded to supplement the flip chart notes taken.

Topics of most importance to the patient advisors included:

- Loss (of control, relationships, and independence) and the recognition of death as a possibility
- Trauma (related to the disease and the treatment)
- Isolation and the importance of feeling like part of a community
- Anxiety and uncertainty (waiting for the other shoe to drop)
- (Mis)communication with health care professionals (lack of understanding and information)

#### **COLLECT** Phase Description

The COLLECT focus group was delivered through a blended approach involving patient partners in Edmonton and Calgary who were linked through an encrypted online meeting platform. A total of four participants attended the focus group (3 male and 1 female). One participant attended from Calgary while the remaining three attended from Edmonton. The focus group lasted for four hours and flip chart notes were taken digitally from Calgary and by hand in Edmonton. The flip chart notes were supplemented with audio recordings taken from both Calgary and Edmonton. Participants were asked the foundational question *"how has chronic kidney disease and dialysis impacted your mental wellness?"* Participants were supported to explore additional details of their stories through probing questions. Narrative interviews (n=6; 4 participants from COLLECT) were following the COLLECT focus group. Following the 2-step iterative data analysis process described above, two emerging categories with accompanying sub-categories were identified by patient partners which address aspects of the study's main concern.

#### **Reflect Phase Description**

Five participants (3 male and 2 female) attended the REFLECT focus group. Of these participants, 1 was involved in the SET phase, 2 were interviewees, and 2 were involved in the COLLECT focus group. The focus group was scheduled for two hours but a significant amount of discussion among participants resulted in the session lasting approximately three hours. The

majority of the REFLECT focus group was devoted to review and discussion of the six emerging category posters and subsequent ranking of relevance of each category to the group. Each poster was reviewed first by the patient partners individually, followed by group discussions for each category. Once the categories were validated and prioritized by patient partners, the remainder of the session was devoted to discussion of recommendations which may address the emerging categories. No significant changes were made to the posters as discussion yielded minor clarifications of the emerging categories uncovered in the previous round of iterative analysis.

#### **Research Credibility and Trustworthiness**

A high degree of credibility and trustworthiness in this study was of great importance to the research team. Several strategies were employed to increase the credibility and trustworthiness of this study, including: 1) PaCER interns continuously acknowledged and reflected upon biases from previous experiences as patients prior to facilitating focus groups, interviewing patients, and analyzing data (Bogdan & Taylor, 1975; Kirk & Muller, 1975; Patton, 1990), 2) as researcher-patients, the study team had insider knowledge of the experiences of participants (Shenton, 2004), 3) discussions with peers, mentors, and supervisors were held and advice sought regarding ethics, methodology, data analysis, and themes (Lincoln & Guba, 1986; Shenton, 2004), 4) the REFLECT focus group served as a checkpoint to ensure accuracy of findings (Patton, 1990), 5) a combination of data collection methods (focus groups and interviews) and analysis methods (open coding and narrative analysis) were utilized in a 2-step iterative fashion (individual and shared analysis) (Lincoln & Guba, 1986; Patton, 1990), 6) a literature review was conducted to assess this study's findings against existing evidence (Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004), and 7) all participants were patients with first-hand experience with CKD and dialysis and there was no health care provider input. In this way, the study could focus more into the experiences related to the main concern while avoiding the greater presence of reflexivity common when health care providers participate (Berger, 2015).

#### Findings

Whether the result of a long and slow decline in kidney function, or the aftermath of a cataclysmic illness or injury, end-stage renal disease (ESRD) requiring dialysis is a complex, isolating experience. Participants spoke frankly about their experiences with this life-altering disease and treatment modality. This narrative evolved into six categories which attempt to describe the complicated web of experiences of life while on dialysis. Two main categories and their respective sub-categories were uncovered in this study:

- 1. Experiential findings
  - a. Real impacts of CKD and dialysis on a patient's mental health
  - b. Communication and system navigation impacts on mental health
  - c. CKD and dialysis impact the patient's support network
  - d. Perceived lack of empathy and invalidation from health care providers

- 2. Coping strategies
  - e. Advocate for self or find patient advocates/experts for you
  - f. Importance of personalized coping strategies while on dialysis

#### A) Real Impacts of CKD and Dialysis on Patient's Mental Health

Experiencing renal failure and starting treatment through dialysis was described as a "horror". All sense of the normalcy of life is lost in an instant and patients struggle with a profound sense of grief, isolation, and a loss of identity. Previously determined plans are delayed and/or cancelled outright, employment suffers, and patients and those around them are left to pick up the pieces. This may result in depression, grief, post-traumatic stress disorder (PTSD) and loss of identity. Participants strongly identified their perception that the current system is not addressing mental health and rarely even provides the basic information on how to access the mental health supports in the system.

- "I mean you can find [00:55:12 KHT Reflect FG] yourself a new normal, but to me it was a hard. That was the hardest part."
- "This is probably honestly given I got a lot of physical challenges; you know in different parts of my life. But the mental health challenge that came with me was probably is speaking in the present is the most significant trauma that has occurred in my life, and I've been through a lot". [01:02:57 KHT Reflect FG]
- "Being taken out at the knees" [00:11:25 KHT Collect FG]

#### B) Communication and System Navigation Impacts On Mental Wellness

Coping with ESRD and dialysis is made considerably more difficult given the immense stress of the situation. Patient partners described a significant learning curve, for which support from health care providers was woefully inadequate. Hearing differing advice from every source sought regarding diet, medications, treatment modalities, and prognoses only served to increase stress for newly diagnosed patients. A lack of access to relevant information and a defined process was viewed by patient partners as a strong contributor to mistrust with the health system. Patient partners described that it was overwhelming for them to understand the do's and don'ts of being a CKD patient on dialysis and agreed that this was a main reason why they needed to become self-advocates.

- "The flow of information, especially with the transplant process as well... you're always getting kind of misinformation or [00:44:40] information for one person's always different from another person and not really consistent." [00:44:25 KHT Collect FG]
- "I made my choice based on going to do my blood work and a young six-year-old girl mentioned how she went through this and she chose peritoneal and home. That's how I

made my decision. I don't think this is major life event should be under appreciated and underrepresented by a professional health care system where you are kind of making your decision on a whim or based on he said she said kind of stuff, so it is disappointing the lack of education involved with choosing which form of dialysis should go. [01:32:06 KHT Reflect FG]

- "Just my own research online, which is not always the best" [1:02:13 KHT Collect FG].
- "I have had almost no transplant conversations with my dialysis people. That's not their focus. [01:45:06 KHT Reflect FG] It's not really what they do. Your transplant discussions are going to go along somewhere else."

#### C) CKD and Dialysis Impacts the Patient's Support Network

Despite the isolating nature of dialysis, the journey undertaken by patients with ESRD has significant impacts on those people around them, but this impact remains largely unrecognized by the healthcare providers. Participants expressed that there are currently no psychosocial supports offered to families and support systems. In addition, support systems are not trained or provided adequate support on how to live and care for a dialysis patient.

Patient partners highlighted feelings of guilt and shame over their declining health status and how difficult it can be for loved ones to witness. To alleviate some of the stress experienced by family and friends, some participants opted to minimize their condition and/or retreat internally rather than be honest with their support networks. "Faking it" around those closest to the patient partners was a coping mechanism for some participants, despite relying heavily on the support of those who patients felt they needed to protect. They discrepancy of how they were feeling physically and mentally and how they were presenting themselves added to anguish of not being authentic to those closest to them. This impacted the relationships.

- "I tried to minimize my family's knowledge kind of it kind of I mean if we had young kids growing up, I made sure that you get to dialysis on my own and then a lot of times my husband would pick me up afterwards" [01:11:56 KHT Reflect FG].
- "So, I always worry about him. Now, you know, I feel like he must be strong all the time and he doesn't talk about how things affect him, and he always says I'm fine mom, I'm fine mom. What I think is the same thing as me saying I'm fine, right? So, it's the hardest and one of the biggest things was just dealing with that? And faking it, right? Well because you at the same time you fall apart around the people that you're closest to, but you also fake it the most around them too." [00:25:28 KHT Collect FG]
- "Pushed my wife over the edge and then the opposite direction. So, she went from being a potential living donor for me in April, to walking out and leaving. At the end of August so..." [01:16:25 KHT Collect FG]

• "I'd like to see a little more in the way of family supports up front like so much effort is put into you as the patient and not so much into the interaction with my wife and kids."[01:14:39 KHT Collect FG]

#### D) Perceived Lack of Empathy and Invalidation form Health Professionals

Patient partners experienced frustration that their health care providers focused solely on the treatment and the physical markers, numbers, and metrics of kidney disease as a tool to evaluate health. This perceived failure to address the person over the disease leads to increased feelings of stress, anxiety, and amplifies the loss of identity felt by patients. The expectation expressed by some health care providers that a patient undergoing treatment should be feeling a certain way (e.g., "better"), or should not be experiencing a symptom (e.g., cramping) invalidates the patient's experience and expertise in their bodies. Patients voice so hidden illness also receive appropriate and timely care.

- "Don't appreciate being broken down by blunt tool assessment" [00:52:33 KHT Collect FG]
- "You're on dialysis, you shouldn't be getting cramps anymore. It's like, well I am but does that matter?" [1:24:25 KHT Collect FG]
- "I mean should there not be a standard question that everyone is asking like, how are you doing? Not, what are your numbers? Do you know? What was your orange juice intake versus have you thought of killing yourself...No one bothers to ask those questions?" [02:24:02 KHT Reflect FG]

#### E) Advocate for self or find patient advocates/experts for you

ESRD and patients' experiences with dialysis are highly variable and individualized, however, a common thread tying these stories together is the need to advocate for oneself. In this study, the ability to become a self-advocate was viewed as the core skill necessary to maintaining mental wellness and receiving appropriate care while on dialysis. Self-advocacy was also viewed as being a vital trait for anyone seeking to alter their treatment or begin the process of trying to become a transplant recipient. Given the gaps in the health system, self-advocacy puts patients in the driver's seat and empowers them to navigate and understand the system to receive the care needed.

- "I learned everything I could about kidney disease, and I fought, I went right to my health and I tried to do everything with boost it on my own [00:35:39 KHT Collect FG] continue to do so and you know now it's amazing difference."
- "you got to be able to stand up for yourself or have someone to advocate for [01:44:03 KHT Reflect FG] you."

#### F) The Importance of Personalized Coping Strategies While on Dialysis

Participants shared a variety of coping strategies they have used to maintain their mental wellbeing and support an improved quality of life. Acknowledging that there is no single solution for every patient, the importance of finding coping strategies that work for the individual patient could not be overstated. An important component of moving beyond avoidance and toward developing healthy coping strategies was the ability to set goals for oneself. At its essence, coping while on dialysis is akin to finding ways to unplug while being plugged in [to the dialyzer].

- "I think just even journaling [01:17:25 KHT Collect FG] finding support groups that you can go to, you know, just even meditation or deep breathing, you know going for a small walk getting out in nature. Those are all the things that really helped me or even just sitting on the front step, right, you know. finding those things that bring you a little bit of comfort."
- "Yeah, I mean, I think it's I think it really is a matter of not letting this therapy and treatment run your life". [01:29:50 KHT Reflect FG]
- "Setting goals for yourself is a powerful simple tool to keep pushing yourself forward" [2:07:44 KHT Reflect FG].

#### **Strengths and Limitations**

One considerable strength of this study is that the patient partners were highly engaged and active members of the kidney health community. Their experience, expertise, and passion provided this study with many realistic and actionable recommendations to support an improved patient journey. Patient partners expressed solutions (e.g., patient to patient peer support) not acknowledged in the literature. Another strength of this study is that focus groups and interviews were conducted with participants of various ages, genders, ethnicities, and kidney health journeys. Patient-to-patient research allows for participants to be more relaxed and often share richer and deeper information because of the perception there is little power imbalance (Berger, 2015). Also, when patients participate in analysis, they have a different perspective than professionals or caregivers and therefore an authentic patient voice is possible. Additionally, as part of the patient partners' ongoing involvement in renal advocacy efforts, multiple audiences can be potentially reached to support knowledge translation activities. Lastly, participation in this study offered a sense of community and validation, something which can be extremely lacking with such an isolating disease.

There are also several limitations inherent in this study. Firstly, the exceptional advocacy and strength exhibited by the patient partners can also be viewed as a limitation. Participants identified that they cannot speak for others who are unwilling or unable to lead their own care, so those voices are missing from this study. Another limitation of this study is that most of the

patient partners have received renal transplants and are basing their experiences from memory. This may not accurately reflect the current experiences of patients on dialysis as completely as if the study had included only current patients on dialysis. This study only included participants who were fluent in English, which may have inadvertently excluded non-English speaking patients with experiencing additional barriers to appropriate care. Since this study only involved nine patient partners, all of whom are actively engaged in the kidney health community, the ability to show generalizability to the overall patient population is unlikely. In addition, participants in this study were all from the same health care system and therefore, their experiences may not reflect those in other jurisdictions. Lastly, several participants were required to withdraw from participating in this study related to the complex nature of this patient population (e.g., feeling too unwell to participate) and treatment schedules.

#### Discussion

Receiving a diagnosis of kidney disease or outright kidney failure is life-altering. While each patient's health journey is unique, participants expressed a sense shock in receiving their diagnoses of kidney failure and the need to transition to dialysis. The literature outlines a link between dialysis and an increased risk of negative outcomes, including mental health concerns such as depression and anxiety (Treadwell, 2017; Palmer, 2015; Farrokhi, 2014; Hadayati, 2009). While none of this study's participants indicated that they experienced diagnosed depression before starting dialysis, all articulated the challenges of dialysis on their physical, emotional, and mental wellbeing.

Participants repeatedly referenced the theme of having their "wings clipped", which described how dialysis contributed to their perceived loss of freedom, identity, and quality of life. Kittiskulnam (2016), noted that lifestyle adjustments, the strict renal dietary and fluid guidelines, the fear of dialysis itself, and the feeling of burdening caregivers add significant stress to patients. Patient partners discussed many of these issues. Findings from this study were categorized into two overarching categories. The first category identified by participants recognized the major challenges patients encountered throughout their dialysis journey which negatively impacted their mental wellness. The second theme focused on the strategies employed by participants, which they felt positively supported them throughout their journey.

#### Factors negatively impacting the mental wellness of patients undergoing dialysis

#### Communication and system navigation impacts on mental wellness

Participants spoke in-depth about their experiences communicating with health care providers during this highly stressful time. "The flow of information, especially with the transplant process as well... you're always getting kind of misinformation or information for one person is always different from another person and not really consistent" (FG 10.27.19). In contrast, a

study by Donald et al., (2019) that incorporated both patient and caregiver perspectives regarding how to manage CKD, identified activation through information as key to management of health. To the authors, this was defined as the requirement of patients to have access to meaningful, relevant, and timely information regarding their health status. Moreover, studies by Tong et al., (2014) and Vandenberg et al., (2018) found that respectful, attentive, and individualized forms of communication may empower patients to convey their values and preferences about their personal care. One particularly disturbing experience was described by a patient partner as suffering with declining health resulting from reduced kidney function but was still unable to access treatment. The participant recounted "they said I had to hit a minimal percentage of kidney function before I could start dialysis...it didn't make sense why you had to get sicker before you could get treatment...I thought it was a joke, why are doctors punishing me?" (KHT Interview ME 10.27.19). These were the experiences of patients attempting to access general information to support the self-management of their disease. When asked specifically about mental health assessment and support, the gaps in care grew increasingly stark.

#### CKD and dialysis impact a patient's support network

Participants spoke passionately about their frustrations over the lack of mental health assessment and support available to both patients and their support network. Despite the isolating nature of dialysis, participants were quick to acknowledge the collateral psychosocial damage experienced by their support networks. "So, there's your mental health, but then there's the circle around us that it is also bringing down" (00:11:41 KHT Collect). The immense stress of the treatment regimen while attempting to cope and advocate for oneself is made even more difficult when patients feel they must provide support to those who are trying to support them. Patients spoke of feeling guilty for the focus placed on them while those supporting them are left to watch helplessly. This was particularly apparent for participants recalling the process of finding a living donor for transplantation. Friends and family prepare themselves physically and emotionally for the possibility of giving patients a new life through a kidney donation, only to find out very bluntly that they are not a match. End of story. "I was unaware of how disappointing it would be for these folks to also carry that burden; they were ready to do something and were then told they couldn't" (00:21:16 KHT Collect FG). At the same time, support systems were key in providing the help needed while on dialysis. One patient explained how the support of his wife is the only reason he was able to survive dialysis and escape the depression he experienced. "My wife was my rock, my backbone, my stone...if it wasn't for her, I probably would have walked away. She encouraged me" (KHT Interview ME ). Patients expressed the need for health systems to not only have resources for patients, but their families who also bear the burden of kidney disease. Given the importance social networks have on patients, these resources would be welcomed.

#### Perceived lack of empathy and invalidation by health care providers

This category was more difficult to tease out and as it was very nuanced. Including elements of miscommunication, insufficient patient education, and unmet expectations was the idea of invalidation towards patients. Participants were quick to point out that overall, medical care in

Alberta is of very high quality and that they did not perceive health care providers to be actively seeking to invalidate their experiences. More specifically, this category reflected the almost unwavering focus of health care providers on medical management of the physical and physiological complications accompanying CKD and dialysis. Laboratory values are treated as gospel, while patients may be quietly experiencing depressive episodes, anxiety, and an overall declining mental health. An alarming disconnect between health care providers and patients was summarized by one participant anecdote: "*What was your orange juice intake versus have you thought of killing yourself...No one bothers to ask those questions*" (02:12:02 KHT Reflect FG). This story very clearly highlighted the medical fixation on one aspect of care for patients on dialysis (potassium from drinking orange juice in this example) while ignoring a person who could be at-risk of harm because of a line of questioning that may feel uncomfortable to some.

#### Factors supporting positive mental wellness outcomes

#### Self-advocacy

Patients' experiences with dialysis are highly variable and individualized, however, a common thread tying these stories together is the need to advocate for oneself. Being the driver of one's health care decisions or having a trusted advocate to act on one's behalf was considered a vital trait for maintaining mental wellness by participants of this study. Self-advocacy in the context of this study was defined by participants as becoming an expert on their medical condition, medications, history, and treatment. Without self-advocacy, participants feared they would become lost in the complexities of the health care system. More than this feeling of being "lost", the prevalence of depression in patients with CKD is estimated to be 20% - 30% (Palmer et al., 2013; Hedayati & Finkelstein, 2009; Treadwell, 2017; Kittiskulnam et al., 2016). Despite negative outcomes related to depression and anxiety including increased hospitalizations, decreased adherence to treatment, and increased mortality (Treadwell, 2017), only a fraction of patients with CKD receive adequate treatment for depression (Hedayati et al., 2012). Participants spoke of the perception of needing to act as "the bridge between" (01:45:36 KHT Reflect FG) dialysis and transplant teams and that "sometimes some things just aren't right and you got to be able to stand up for yourself or have someone to advocate for you" (01:44:03 KHT Reflect FG).

#### Personalized coping strategies

Ronksley et al., identified the need for patients with CKD to manage their self-care. An important component of self-management is finding ways to cope with issues as they arise. "*I think it really is a matter of not letting this therapy and treatment run your life*" (01:29:50 KHT Reflect FG). This statement reflects the movement from a core skill (self-advocacy) to concrete action (developing personalized coping strategies). While no single coping strategy will work for every patient with CKD, the importance of actively seeking ways to maintain one's sanity cannot be overstated. Two overarching styles of coping were identified by participants: 1) avoidance and 2) problem-solving. Avoidance is associated with a reduced quality of life (Barberis et al., 2017) and was recognized by one participant as potentially unhealthy (FG 01.20.20). Keeping

busy, establishing a routine, and setting goals were all identified by participants as coping strategies which have helped them to regain aspects of control, purpose, and identity, which were lost as their journeys began. "*finding that rhythm after a few weeks and I learned to love it – that has totally changed my outlook*" (01:26:48 KHT Reflect FG).

Recognition that CKD and dialysis does have real impact on patients' mental health This study found that majority of the participants experienced depressive episode (+/- clinical depression), grief, and a sense of loss which impacted their mental wellbeing. It was expected by some of the participants that with receiving transplant, most of their limitations would be gone. However, this expectation was met with disappointment as in some cases, participants found that dialysis followed by transplant did not alleviate all symptoms, and in one instance, was associated with significant trauma resulting in Post-Traumatic Stress Disorder (PTSD). Participants indicated that it was important for them to understand the definition of "feeling better", as this would help them to better regulate their expectations surrounding dialysis and transplant. Pieper et al., found an association between wound healing [of the dialysis access site] and depression. Mirroring this finding, several of the participants in this study who experienced complications related to access site failures faced anxiety and depression. By identifying patients on dialysis at risk of similar complications, health care providers can proactively assist in the management of mental health concerns that may arise from the treatment. An example of this proactive approach in practice is in the management of postpartum depression syndrome. Doctors, nurses, residents, and other health care staff are trained to assess depression during post-natal checkups. This approach was found to be quite effective in identifying depression early by direct assessment.

Patients who are engaged in their health care experience better outcomes (Frampton et al., 2017). This simple statement is undercut by the difficulties experienced by patients as they attempt to be more engaged in their care. Patient partners described a disproportionate burden to become drivers of their own health care needs. Without the ability to advocate for oneself, navigate a complex health system, and develop personalized coping strategies, mental wellbeing inevitably suffers for both the patient and their support network. This ability to self-advocate described by participants was a skill developed out of perceived gaps existing in the health system. Participants communicated their frustration over their perceived lack of focus on mental wellbeing, despite a rich base of evidence pointing to the markedly increased risk of mental health concerns in this population. On the surface, there would appear to be a simple solution to this issue: ask patients how they are feeling and treat their response with the same vigor as one would treat laboratory values. The reality, however, is that even if health care providers ask this question and/or administer a mental health assessment, our patient partners found minimal psychosocial support available to patients on dialysis.

#### Recommendations

The recommendations suggested by patient partners represent actions that patients and the health care system could collectively implement to support improved self-management for patients living with CKD and being treated via dialysis. The recommendations also point towards a strong desire from the patient perspective to be an entire person, rather than an isolated disease. Recommendations are stratified into patient actions and health system actions.

#### a. Patient Actions

- Support patients to become advocates to drive their own care. This could be accomplished through patient-to-patient peer mentoring, especially if a patient is too ill to self-advocate, provide training in health system navigation, and seeking opportunities for partnerships with health care providers in research/projects/initiatives.
- Set actionable goals for oneself mentor patients in SMART goal setting if this skill requires development.

#### b. Health System Actions

- Implement a peer mentoring unit for patients and resource adequately.
- Leverage the abilities of the psychosocial team greater scope of practice for Social Workers who have received training in counselling and system navigation (going beyond basic financial/tax information)
- Improve connections with psychosocial team and include mental health professionals in patient rounds as part of the multidisciplinary team.
- Create a health system navigation resource (or suite of resources) that can be provided to patients at the start of their journey.
- Introduce the idea of transplantation much earlier in the patient's journey.
- Physician participation in the kidney community (e.g., the annual Kidney Foundation Gala, Kidney Health Patient Forum) to be seen by patients and families as partners in care.
- Change approach from "what are your numbers?" to leading with "how are you doing?" Implement a follow up process for mental wellness if the patient requires additional support.
- Implement a mental health assessment at treatment initiation and at regular intervals throughout the patient's journey.

#### Conclusion

Dialysis is a double-edged sword. On one side, it is a life-sustaining treatment for people experiencing ESRD, and on the other, it is an isolating and burden-filled experience that is associated with many negative health outcomes. Both the literature and our patient participants outlined the challenges and system gaps they experience during dialysis. Communications issues, impacts on social networks, a perceived lack of empathy, the need to become a self-advocate, the need to adapt to a new routine, in combination with an overall lifestyle medication, impacts patient's mental health. Patient partners provided great recommendations and insights from their lived experiences to improve the experiences of patients with CKD on dialysis. These recommendations were tangible and may provide an improved patient experience if implemented. While self-advocacy can help patients to feel in control and be an active participant in maintaining their mental wellness, the current system needs to evolve to include both preventative mental wellness strategies and timely access to mental health diagnosis and treatment for patients on dialysis. The gap of most concern identified by this study is the lack of psychosocial support available to patients on dialysis in Alberta. As patients continue live longer, combined with the influx of newly diagnosed patients requiring dialysis, a pathway to improve access to psychosocial support and patientcentered care for patients on dialysis is warranted.

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#### Acknowledgements

PaCER researchers would like to acknowledge the support and guidance of Dr. Nancy Marlett, Gina Samuel, Marlyn Gill, Nancy Verdin, Suzanna Koczkur, Patrizia Ranieri, Karina Pintson and the entire PaCER team.

We acknowledge Dr. Abir Aboutahdah (late) for her work in this study.

We acknowledge the guidance and support provided by the Alberta Health Services Kidney Health Strategic Clinical Network (KHSCN)

We thank patient partners Kenneth Litchfield, Sean Delaney, Vinay Mosher, Elliot Rose, Darren Reyes, and Sonia Dhaliwal for their participation and invaluable contributions to this research.

We thank all the patient participants for their participation and invaluable contributions to this research.

Facebook Information					
Link	https://www.facebook.com/PacerKidneyHealth/				
Page name	Pacer Kidney Health Research				
Username	@PacerKidneyHealth				
About us	Title: A Peer to Peer Exploration of How Dialysis Impacts Mental Wellness for Patients with Chronic Kidney Disease				
	The Patient and Community Engagement Research (PaCER) program trains patients to become qualitative health researchers. PaCER is committed to finding better, stronger, and more creative ways of engaging patients in health care.				
	The PaCER program is a part of the O'Brien Institute for Public Health at the University of Calgary. PaCER is committed to changing the role of patients in healthcare by co-designing and developing research by patients, with patients, and for patients. For more information go to <u>www.pacerinnovates.ca</u>				
	The 2019 PaCER Kidney Health Cohort consists of 5 members and 2 members all based in Alberta. Through patient to patient & peer to peer methods, the cohort is exploring how dialysis impacts mental wellness for patients with chronic kidney disease.				
Twitter Information					
https://twitter.com/Pac	erKidney				
Pacer Kidney Health Res	search				
<pre>@PacerKidney</pre>					
Kidney Health student re	esearch using PaCER's patient to patient & peer to peer methodology.				

#### Appendix 1: Social Media and Poster Information for Media Release

Exploring how dialysis impacts mental wellness for patients with CKD.

#### **Pictures for use in MEDIA Campaigns**

Health Research By patients, with patients, and for patients

Unplugging While Plugged In EXPLORING MENTAL HEALTH

DURING DIALYSIS

#### Share **YOUR** experiences on dialysis Is this opportunity right for you?

- Do you have experience with dialysis?
- Do you want to advise student researchers?
- · Are you willing to share your experience in a peer to peer focus group (in person or
- online) or through a telephone interview regarding your experience on dialysis?





This study has been approved by the University of Calgary Conjoint Health Research Ethics Board REB: 19-0966

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## Health Research By patients, with patients, and for patients



# Unplugging While Plugged In

EXPLORING MENTAL HEALTH DURING DIALYSIS

# Share **YOUR** experiences on dialysis

#### Is this opportunity right for you?

- Do you have experience with dialysis?
- Do you want to advise student researchers?
- Are you willing to share your experience in a peer to peer focus group (in person or online) or through a telephone interview regarding your experience on dialysis?
- Are you 18 + years?





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#### **Appendix 2: Recruitment Poster**



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#### Appendix 3: Recruitment 4X6 Postcards to leave at units & with patients (Double sided)



