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The Case for Trauma-Informed Chronic Disease Care: Exploring Trauma Among Adults With Obesity On Dialysis

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ABSTRACT

This study describes how U.S. dialysis patients with obesity experience trauma and manage it and co-occurring chronic diseases. We interviewed 40 adult hemodialysis patients and 20 physicians and dietitians. Transcripts were inductively coded using trauma theory. Patients described trauma that impacted their ability to manage co-morbidities. Providers characterized patient trauma and their own vicarious trauma while working in dialysis care. Nearly all patients reported trauma, most with characteristics of chronic, emotional, and/or medical trauma, and many described trauma from systems and vicarious trauma across relationships. Complex intersecting trauma exacerbates chronic disease burdens and may impact treatment effectiveness, successful management of co-morbidities, and patients' relationships. Results demonstrate the need for trauma interventions within chronic disease treatment and community settings.

KEYWORDS: trauma-informed; chronic disease; kidney disease; mental-health; dialysis

THE CASE FOR TRAUMA-INFORMED CHRONIC DISEASE CARE: EXPLORING TRAUMA AMONG ADULTS WITH OBESITY ON DIALYSIS

Globally, chronic kidney disease (CKD) affects approximately 10% of the adult population (International Society of Nephrology, 2023). In the United States, approximately one in seven adults suffers from chronic kidney disease, with over 500,000 people currently receiving dialysis for end stage kidney disease (ESKD) and 100,000 new dialysis patients every year (Centers for Disease Control and Prevention, 2024; United States Renal Data System, 2020). Common comorbidities include diabetes, cardiovascular disease, hypertension, and obesity. Although transplantation is the optimal ESKD treatment, patients with severe obesity are often transplant-ineligible. Thus, an estimated 40% of ESKD patients receiving center-based hemodialysis treatment have obesity (Lavenburg et al., 2022).

Dialysis-dependent patients often face personal, family, and community-level challenges that exacerbate the impact of ESKD. There is evidence that depression is both common and clinically under-addressed in dialysis populations across cultures and settings (Fernandez et al., 2022; Hardy et al., 1991; Tagay et al., 2007; Wong et al., 2022). There are significant racial and ethnic inequities in ESKD incidence, with African American/Black American adults four times more likely and Hispanic/Latino and American Indian/Alaska Native adults two times more likely to develop kidney failure than non-Hispanic White adults (United States Renal Data System, 2016). Drivers of these inequities include lifetime exposures to adverse social determinants of health. Evidence suggests dialysis patients experience high levels of food insecurity and malnutrition, with patients from historically marginalized backgrounds at a higher risk due to structural racism (Mokiao & Hingorani, 2021). In a global context, ESKD is rapidly rising in low- and middle-income countries

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with implications for prevention including the promotion of mental health and effective disease management (Tonelli et al., 2020). Despite this, few studies among ESKD patients have differentiated trauma or contextualized it across the life course. Furthermore, a model for trauma-informed weight-loss-related care for ESKD patients whose obesity limits their access to transplantation does not exist.

This study describes the nature of trauma and poor mental health outcomes among ESKD patients with obesity and healthcare providers who serve this patient population in the U.S. Results are followed with a discussion of implications in the larger context of chronic disease in general and evidence-based recommendations for systems-level trauma-informed prevention in dialysis settings specifically. Our two research questions were: 1.) How do patients with ESKD and obesity describe their experience of trauma? and 2.) How do they describe managing it alongside co-occurring poor physical and mental health? To our knowledge, this is the first study to describe trauma types among a U.S. sample of adult ESKD patients with obesity. This inquiry is vital to understanding mental health barriers to successful treatment of ESKD and its common co-occurring chronic diseases.

TRAUMA THEORY IN MEDICAL CONTEXTS

Trauma is a biopsychological phenomenon defined broadly as chronic or acute exposure to threat or harm that has lasting effects on behavior, mental health, and the ability to respond positively (Christopher, 2004). The mental health field has recently developed "trauma-informed" approaches to address multiple forms of trauma across the life course and in diverse settings (Substance Abuse and Mental Health Services Administration, 2014). Trauma-informed approaches consider not only the impacts of more recognizable acute traumatic events, understood as post-traumatic stress disorder (PTSD), but also chronic stressors, including persistent and collective traumas, such as exposure to poorly resourced, unsafe, or blighted neighborhoods, racism, and structural disadvantage (Jenkins et al., 2022). Specific to populations who experience frequent or intense medical diagnoses and procedures, trauma related to medical care experiences can occur and result in poor mental health, maladaptive coping, and/or treatment avoidance (Hercz, 2017). Because exposure to trauma can be ongoing within these settings and is not limited to a single traumatic event in the past, medical trauma can be inextricable from systems-level trauma, or vicarious trauma, felt through observing fellow patients who are also experiencing trauma in these settings (Eagle & Kaminer, 2013). Patients can develop poor, unhealthy coping mechanisms for managing persistent exposure to trauma. In this study, patients and providers described several of these trauma types.

MATERIAL AND METHODS

Participant Sample

This analysis used qualitative data collected in 2020–2021 within a National Institutes of Health-funded study that focused on the lived experience of co-existing obesity and dialysis dependence (Harhay et al, 2023). We conducted semi-structured in-depth interviews with a geographically diverse convenience sample of 40 dialysis-dependent patients with obesity (body mass index (BMI) of ≥ 30 kg/m2) across 22 states, and 20 ESKD healthcare professionals (including physicians and dietitians) across 24 states. Patient participants were recruited through direct outreach via flyers and word-of-mouth at three geographically diverse dialysis centers, and nationally through the National Kidney Foundation's patient email communication network. Clinician respondents were also recruited via professional networks and word-of-mouth. Participants who contacted the study team to express interest were screened for eligibility and provided verbal informed consent. Eligible participants were scheduled for a single 90-minute audio-recorded telephone interview and received $50 for participation. The study was approved by the Drexel University Institutional Review Board.

Data Collection

The qualitative data collection in the overall parent study was designed using a descriptive phenomenological approach to understand the lived experiences of hemodialysis patients with obesity, and the clinicians who work with this population (Harhay et al, 2023). Patient and provider interviews followed semi-structured guides developed by the researchers. The senior researcher (AK) trained five of the coauthors who were graduate research fellows in qualitative interviewing procedures; the principal investigator (MH) trained the team in ESKD and dialysis contexts specific to this patient population. Training included supervised mock interviews, reviewing audio recordings, ongoing debriefing, and transcript reviewal. All interviews were conducted by one of the five trained coauthors or the senior researcher. Patient interview domains included lifetime experiences of ESKD, health, fitness, diet, weight, body size, and healthy vs. unhealthy weight loss. Provider interview domains explored professional roles working with dialysis patients, and observations regarding healthy vs. unhealthy weight loss in patients. Both interview types collected brief socio-demographic information, as asked by interviewers. Complete versions of the interview guides can be found in the supplemental materials (Appendix A).

Data Analysis

Audio recordings were transcribed verbatim, with two poor quality recordings summarized from interviewer notes. Memos, capturing interviewers' additional observations, were reviewed throughout coding and analysis. De-identified transcripts were coded using NVivo software (QSR International, 2015). Initial deductive codes were developed using existing literature and research questions and were structured around thematic areas of psychosocial background across the lifespan, including health and body size and dietary behaviors, and relationships to medical care. A social ecological model was used to explore how individual people, families, communities, and medical systems influence the context in which patients develop and manage ESKD and obesity (Golden & Earp, 2012).

Interviewers did not specifically ask about trauma. However, participants directly and indirectly shared experiences of trauma, occasionally using the word "trauma," but more often using related descriptive language. Initial analysis included a code for trauma, based on its prominent role in literature addressing chronic health conditions and health disparities. For this analysis, we used a second round of coding to inductively explore trauma types, sources, and responses, and to generate trauma-specific codes.

RESULTS

Over the years, I haven't talked about this with mental health professionals so much, but I think I have a form of PTSD from being sick, from dialysis. Maybe not dialysis itself, but the secondary illnesses that come with it…having to have all these—all of a sudden, "Your labs are continuously high. You need to do this," or having an infection. There was a period of time where…I was constantly getting infections. I'm terrified of something happening and my life being interrupted. That's the one thing that I can consistently say throughout everything with kidney disease is: my life, the way I want it to be, constantly gets interrupted. So, I definitely have PTSD of "Okay, what's going to happen that I don't know about?"

(**Patient 14**, woman, age 47, 24 years on dialysis)

Descriptive Results

Of 121 ESKD patients who were screened for eligibility, 40 patient participants completed interviews. The median patient age was 55 years (interquartile range (IQR) 46, 63), median BMI was 39.5 kg/m2 (IQR 35, 42), and median years on dialysis were 5 (IQR 3, 8). Fifty-eight percent of patients were women. Patient participants self-identified race as follows: 2.5% as Asian American, 35% as African American/Black, 12.5% as Hispanic/Latino, 2.5% as American Indian/Alaska Native, 5% as more than one race, 50% as White, and 5% declined to identify their race. Twenty-four respondents (60%) reported having diabetes and 16 (40%) lived in a household receiving government assistance for food.

Provider (n = 20) median age was 45 years (IQR 39, 52) with a median of 14 years (IQR 8, 22) in their profession. Seventy percent of providers were women. Fifteen percent of providers self-identified as Asian American, 5% as African American/Black, 20% as Hispanic/Latino, 5% as more than one race, 65% as White, and 10% declined to identify their race. Professions included 20% nephrologists, 50% renal dietitians, 5% transplant dietitians, 15% transplant nephrologists, and 10% transplant surgeons. Some participants identified as multiple races/ethnicities; therefore totals do not add up to 100%.

Patient Mental Health Results

Five specific types of trauma were inductively identified: 1) chronic trauma, non-acute exposure to traumatic experiences or acute experiences that resulted in long-term trauma; 2) emotional trauma, resulting in poor mental and/or emotional health such as depression; 3) medical trauma, psychological and physiological effects of injury, pain, fear-inducing diagnoses, and care experiences; 4) systems-level trauma, where societal structures and systems exacerbate or result in trauma; and 5) vicarious trauma, which participants experienced through witnessing the trauma of other patients, providers, and/or family members (Farragher & Bloom, 2010). Two themes captured patient and/or provider responses to trauma that they brought up during interviews. These themes were described as either 1.) strategies such as coping mechanisms or recommendations for reducing trauma or 2.) patients' inadequate coping including undermining health behaviors such as maladaptive coping through binge eating or treatment avoidance.

Nearly all patients described trauma. Of those, the majority described trauma as chronic, including terms such as "my whole life," "been through war," or "every day" when describing pain and stress. Most patients also described emotional trauma with impacts on mental health, with references like "depressed" or metaphors like "heavy heart." Sometimes, emotional trauma descriptions linked ESKD and obesity to previous trauma such as the following: "I…had to protect myself by being fat…I was fearful of being attractive to men, and that goes back to child abuse" (Patient 31). Medical trauma, mentioned by nearly all patients, identified medical environments and procedures, especially dialysis, as traumatizing. For example, Patient 13 said, "…physically, emotionally, mentally [dialysis] is the worst thing I've experienced in my years on this earth."

Both systems-level and vicarious traumas were described by most, but not all patients. Examples of reported systems-level traumas included the following patient's experiences of poor facilities and poor staff communication about this

TABLE 1. Descriptive Characteristics of Participants, Patients (n = 40) and Providers (n = 20)

Patient participant characteristics (n = 40)	Median (interquartile range) or % (n)
Age in years	55 (46, 63)
Body mass index (bmi), kg/m2	39.5 (35, 42)
Years on dialysis	5 (3, 8)
Female	58% (23)
Race/ethnicity:	
Asian American	2.5% (1)
African American/Black	35% (14)
Hispanic/Latino	12.5% (5)
More than one race	5% (2)
American Indian/Alaska Native	2.5% (1)
Prefer not to report	5% (2)
White	50% (20)
Diagnosed with diabetes	60% (24)
Currently waitlisted for kidney transplant	22.5% (9)
Household receives government food assistance	40% (16)
Receives donations (food pantry, church, etc.)	10% (4)
Often or occasionally worried that food would run out before you could buy more (past 12 months)	20% (8)
Often or occasionally unable to afford to eat balanced meals (past 12 months)	15% (6)
Household finances in a typical month:	
There is enough money to pay the bills, and some left over to save or spend	70% (28)
There is only enough money to pay the bills	25% (10)
There is often not enough money to pay the bills	5% (2)
Health insurance prior to starting dialysis:	
Medicaid	7.5% (3)
Medicare or VA benefits	27.5% (11)
No health insurance	17.5% (7)
Private insurance	47.5% (19)
PROVIDER PARTICIPANT CHARACTERISTICS (n = 20)	
Age (years)	45 (39, 52)
Years working in profession	14 (8, 22)
Female gender	70% (14)
Race/ethnicity	
Asian American	15% (3)
African American/Black	5% (1)
Hispanic/Latino	20% (4)
More than one race	5% (1)
Prefer not to report	10% (2)
White	65% (13)
Profession	
Nephrologist	20% (4)
Renal dietitian	50% (10)
Transplant dietitian	5% (1)
Transplant nephrologist	15% (3)
Transplant surgeon	10% (2)

problem: "They kept blaming me. Well, come to find out, the tank was reinfecting me over and over" (Patient 14). Then, another patient shared his experience of racialized responses from health care providers where his symptoms were minimized and resulted in delaying his ESKD diagnosis "The nephrologist was like, 'oh, well, it's nothing. You're a Black man'" (Patient 22). Vicarious trauma was poignantly illustrated by a story from Patient 6 as follows: "One lady at our dialysis center, she freaked out and started screaming in the middle of her session. They didn't want the rest of the patients to hear. But we heard they sent her home, and then actually she did die about a month later." Some patients explicitly referenced trauma using terms such as "PTSD," "emotional baggage," "abuse," "anxiety," "stress," and "depression." Other trauma-coded content interpreted participants' reactions to experiences via proxy terms ("pain," "loss," "hurt," "sadness"), indicating enduring traumatic effects. **Table 2** displays thematically organized examples of how patients described their trauma.

Patients described experiencing and coping with multiple forms of trauma throughout their lives and while managing co-occurring chronic diseases. They shared about singular traumatic events that were experienced in medical, systems level, and emotional contexts, such as witnessing death. They also commonly shared about their chronic experiences of different types of trauma over time, such as invasive and painful medical treatments, or the loss of resources that supported a healthy lifestyle. These examples of trauma, as further discussed below, might intersect where a traumatic occurrence might affect others, such as providers, or might constitute multiple types of trauma, such as both physical and emotional pain from a medical incident.

TABLE 2. Examples of Trauma Themes Described by Patient Participants who have ESKD and Obesity

Type of Trauma	Examples from Patient Participants
Chronic	"So, my body at that point, it just felt like it had been through a war." **—Patient 14** (woman, age 47, 24 years on dialysis) I've had heart problems my whole life." **—Patient 6** (Man, age 33, 1 year on dialysis) "I'm not happy with what I have to do every day just to be here, and that affects my diet, and that affects my health because it turns all around and I get sicker." **—Patient 19** (man, age 51, 1 year on dialysis)
Emotional/Mental Health	"It's just hard not to have a heavy heart when you do this constantly." —**Patient 19** (Man, age 51, 1 year on dialysis) "There was always somebody there that I either had to protect myself [from] by being fat, and [then] I would want to get thin, and I would, and then I'd be afraid, and then I'd get it [the weight] back on again because I was afraid. I was fearful of being attractive to men. And that goes back to child abuse." —**Patient 31** (woman, age 72, 2 years on dialysis,) "Like this time of the year, I was depressed because my son was killed on December 27th, and that Christmas, they've got all these Christmas programs, and that's depressing on top of your bad health—I think it's really depressing." **—Patient 9** (woman, age 64, 11 years on dialysis)
Medical	"But physically, emotionally, mentally, [dialysis] is the worst thing I've experienced in my years on this earth." **—Patient 13** (woman, age 37, 6 years on dialysis) "I got the necrotizing fasciitis infection that caused me to have kidney failure along with the amputation." **—Patient 5** (man, age 58, 12 years on dialysis) "They didn't think I was going to make it." **—Patient 6** (man, age 33, 1 year on dialysis)

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Systems	"And they kept blaming me. Well, come to find out my machine had been moved. The biotech didn't disinfect the carbon tank. And so, it was reinfecting me over and over." **—Patient 14** (woman, age 47, 24 years on dialysis) "… the nephrologist was just like, 'Oh well, it's nothing. You're a Black man. You're stressed out. Don't worry about it.'" **—Patient 22** (man, age 46, 3 years on dialysis) "I lived in there—we called it a White neighborhood because that's where all of the money… and anyway, I had a little apartment over there before I had the baby. I used to ride my bike to work. I was walking. I was doing all this stuff. Then when I had—I couldn't afford to live there.…I had a baby, so my life had…so I went back to a sedentary environment because the area where I moved in was not conducive to stuff like that as where I am right now." **—Patient 2** (man, age 53, 5 years on dialysis) "She said, 'Well, you can't be my patient if you're going to take that.' I said, 'Why not?' And she, 'Because the hydrocodone. That'll just negate everything. They'll take my license away.' I'm like, 'I don't know why, because it's not THC; it's CBD.' But I really did notice a difference, and if I could, I would just like to switch from one to the other possibly." **—Patient 31** (woman, age 72, 2 years on dialysis)
Vicarious	"Watching my girlfriend die just really messed me up." **—Patient 6** (man, age 33, 1 year on dialysis) "One lady at our dialysis center, she freaked out and started screaming in the middle of her session. And she said she was done. She said she wasn't getting a kidney, and she wanted to die. They didn't want the rest of the patients to hear. But we heard [and] they sent her home, and then actually she did die about a month later." **—Patient 8** (man, age 63, 5 years on dialysis) "I was in the hospital, and I was very sick in March. And when I got home, I found out a couple days after that that the nurse, who had been watching my son, got COVID. So then, I was terrified that my son and I would get COVID. And it was a horrible time." **—Patient 40** (woman, age 69, 8 years on dialysis)
Responses to trauma	
Strategies	"I noticed over the last couple of years it's harder and harder for me to relax, which is one reason why I work on meditation." —**Patient 14** (woman, age 47, 24 years on dialysis) "Well, I go to dialysis. I'm always in counseling. And now, we're trying new—they put those electrodes on my head and read that [the impulses], and then ask you questions. It's like biofeedback therapy; I'm doing that now." —**Patient 9** (woman, age 64, 11 years on dialysis,) "I'm just trying to just deal with it and do something else, [to] take my mind just off of eating and do something else to occupy my head." —**Patient 34** (woman, age 55, 1 year on dialysis)
Inadequate coping	"I think I've sort of given up on it. Since I was denied for another transplant, I just kind of gained the opinion that I just don't care anymore. I try not to gain so much that I can't move around on my own. I mean, I can make it to the bathroom and stuff on my own still. But I don't really care if I'm at my recommended weight anymore." **—Patient 16** (woman, age 49, 42 years on dialysis) "I'm always smiling. I'm always joking. But I feel useless. I feel like a burden. I feel like 'Am I going to get better?'" —**Patient 19** (man, age 51, 1 year on dialysis) "Now, I just kind of stop—not stop caring, but just—I just, you know, I take my pills and all that, but I'm going to eat what I want to eat." —**Patient 6** (man, age 33, 1 year on dialysis)

Provider Mental Health Results

The five trauma types were consistent in both patient and provider interviews. In provider interviews, the most described and coded trauma was emotional and/or medical trauma for patients, with impacts on both patients' and providers' mental health. Almost all provider-described trauma was systems-level trauma, and vicarious trauma was occasionally described as providers experienced trauma alongside patients. Provider interviews were designed to explore their observations of and experiences working with ESKD patients with obesity and their weight loss behaviors. In the context of these conversations, like patients, providers consistently discussed trauma and even strategies they thought would help to mitigate it. Most providers shared strategies they believed would support healthy, rather than maladaptive, coping mechanisms related to living with ESKD and obesity.

Providers described multiple impacts of trauma on themselves, on patients, and on treatment and care. Providers described trauma in patients by using terms such as "anxiety disorder," "emotional eating," or "psychological issues." Impacts on treatment were described by providers as patient experiences that undermined effective care, such as lacking "readiness" or "desire" to participate, "noncompliance," and high-risk behaviors, such as alcohol abuse. Finally, impacts on providers were described, including experiences of vicarious trauma, as well as reactions to ineffective treatment outcomes. **Provider 103** mentioned feeling "unsuccessful as a provider," and **Provider 106** described her fear and frustration with a patient as "I…feel responsible that (sic) how can I get through to him to make him understand…[he is] playing Russian roulette with [his] life." Providers also shared strategies that could support patients' weight loss and mental health. These strategies illustrated how providers understood the impact of trauma on patients with obesity. For example, **Provider 110** described a systems-level approach to teach patients a mnemonic to recognize emotional eating: "HALT…. They're supposed to ask themselves: Are they Hungry, Angry, Lonely, or Tired? before they eat." Providers acknowledged population-level changes needed to improve health outcomes for their patients. These included increasing access to affordable, healthy foods and decreasing the saturation of poor-quality fast foods in communities. Others acknowledged the importance of social support, noting successful diet adherence "…really comes back to your support at home" (**Provider 115**). See **Table 3** for examples of how providers spoke about trauma impacts and solutions.

TABLE 3. Provider Perspectives on Trauma Impacts and Solutions

Trauma Impacts	
On patient	"…lack[ing] ability to self-care." **—Provider 111** (Nephrologist, man, 8 years in profession) "…the biggest barrier is the…internal psyche and psychological issues." **—Provider 115** (Transplant surgeon, man, 27 years in profession) "…patients with anxiety disorder that were terrified to go to the grocery store and were kind of shut in, and we found later, had relied on neighbors and what happens in those situations is you take the food you can get… we probably saw more weight gain…during the pandemic." **—Provider 111** (Nephrologist, man, 8 years in profession) "…emotional eating…"**—Provider 103** (Renal dietitian, woman, 14 years in profession); and **Provider 107** (Renal dietitian, woman, 21 years in profession)
On Treatment	"…showed up at the hospital after drinking eight beers. And I am thinking, oh my gosh! Your liver is going to go next—come on! 'What can we do to help you?' **—Provider 106** (Renal dietitian, woman, 14 years in profession) "…lack of readiness." **—Provider 106** (Renal dietitian, woman, 14 years in profession) "About half the time they're—some of them are just trying to recover from the treatment. So, yeah. Motivation, desire." **—Provider 104** (Renal dietitian, woman, 6.5 years in profession) "I've noticed about some of the patients who report poor appetite and go to the hospital a lot …are noncompliant with the recommendations that we provide. They don't come to dialysis treatment three times a week as recommended. Some cut their treatment short." **—Provider 113** (Renal dietitian, man, 3.5 years in profession)

On Provider	"I'm like, 'You're playing Russian roulette with your life.' And it's hard because I think he still [does]. Even though they are adults, they're their own people and make their own choices, I think you still kind of feel responsible that (sic) 'How can I get through to him to make him understand?'" **— Provider 106** (Renal dietitian, woman, 14 years in profession) "…weight management is my least favorite topic to discuss with patients…it makes me feel unsuccessful as a provider." **—Provider 103** (Renal dietitian, woman, 14 years in profession)
Provider Participant Strategies/Solutions	
Healthcare systems	"…motivational interviewing approach, getting them to talk and [get] them to come up with their own solution." **—Provider 104** (Renal dietitian, woman, 6.5 years in profession) "We probably should have encouraged her and provided a little more guidance." **—Provider 111** (Nephrologist, man, 8 years in profession) "HALT. It stands for they're supposed to ask themselves: 'Are they hungry, angry, lonely, or tired?' before they eat. Because, many times, they're not physically hungry, but they just want something to eat, [to feel] right, emotionally." **—Provider 110** (Renal dietitian, woman, 27 years in profession)
Population level	"…finances to buy healthier foods" **—Provider 101** (Renal dietitian, woman, 17 years in profession) "…fresh foods, versus the fast-food two-dollar meals" **—Provider 108** (Renal dietitian, woman, 15 years in profession) "…our rural population is [in] a bit of a healthy food desert." **—Provider 111** (Nephrologist, man, 8 years in profession) "…lack of access to good, nutritional food." **—Provider 111** (Nephrologist, man, 8 years in profession) "…people that are engaged in work typically can maintain or lose their weight." **—Provider 115** (Transplant surgeon, man, 27 years in profession) "…it really comes back to your support at home…that's obviously going to impact effectiveness of diet adherence." **—Provider 107** (Renal dietitian, woman, 21 years in profession)

Providers spoke about their own traumatic experiences of witnessing patient suffering or decline. This vicarious trauma also validated trauma reported in patient interviews. Ongoing patient suffering was seen as affecting providers' well-being and ability to work effectively with patients. Providers often acknowledged that poor coping isn't solely self-induced by patients, and this furthered providers' sense of powerlessness to help patients in the face of larger family—or systems-level—challenges. Providers' maladaptive coping with chronic workplace trauma may have also influenced their ability to engage emotionally and create positive patient/provider relationships.

Intersecting Trauma and Poor Mental Health

As **Figure 1** illustrates, patients commonly reported their trauma to have multiple dimensions, and thus represented the intersection of multiple trauma types. Most centrally for their histories as ESKD patients, trauma was often both chronically occurring and medical in origin, including long hospitalizations, multiple infections, disability, amputation, surgeries, and near-death experiences. Intersecting medical and vicarious trauma occurred when patients experienced both their illness, as well as its impact on loved ones. However, not all traumas were directly attributed to illness experiences. Patient experiences of both chronic and emotional trauma could be considered evidence of continued traumatic stress, a commonly reported experience that was coded as multiple trauma types or intersections. Continued traumatic stress encompasses current and future threats (hence not limited to the past as in PTSD), beyond interpersonal contexts, such as abusive relationships (Eagle & Kaminer, 2013). For example, patients described socioeconomic constraints to managing their health throughout their lives, the emotional burden of chronic suffering, chronic mental health challenges, the long-term effects of losing loved ones, persistent fear of medical care, and even considering food and diet as sources of stress and anxiety throughout their lives.

FIGURE 1. Intersecting Types of Trauma

Note: Exemplar quotes from patient and provider interviews illustrating where one experience describes the intersection of emotional and medical trauma.

Description: Two comment boxes originate from a grey Venn diagram where emotional trauma and medical trauma sections overlap. One comment box floats above the Venn diagram and the other floats below the Venn diagram. In each comment box is an exemplar quote from a study participant that illustrates the area of overlap between medical and emotional trauma.

…now I'm fearful of being told—or not told but being dismissed… I've had a couple- I said-about the infections in 2017. I am terrified of something happening and my life being interrupted.

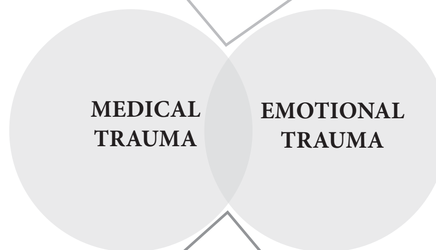
*— **Patient 14** (Woman, age 47, 24 years on dialysis)*

If medically, I was very unhappy because things were not going the way they should have been going, I gained weight because I was over-eating then at the same time.

*— **Patient 18** (Woman, age 74, 2 years on dialysis)*

And then it kind of was a shock just being in the freaking hospital. I had never been-- and I had never been sick before.

*— **Patient 28** (Man, age 59, 6 years on dialysis)*



…it's hard to drum up the emotional strength to get out when you're feeling so tired and kind of drained from the effects of dialysis.

*— **Provider 112**, (Transplant Surgeon)*

They have a lot on their plate in terms of medical issues, and their family, and psychosocial issues…mentally and logistically, they don't have the bandwidth to specifically address their weight problem.

*— **Provider 118**, (Transplant Nephrologist)*

Unfortunately, usually when weight loss occurs is from patients who have been recently hospitalized, or have poor appetite, or something that happened unfortunately, mental issues.

*— **Provider 113**, (Renal Dietician)*

DISCUSSION

Summary of main findings

For dialysis-dependent people, trauma exposure and related poor mental health (Devins, 2014) can lead to maladaptive coping behaviors and barriers to well-being (Lando et al., 2006). The dialysis experience itself can result in trauma. Patients require several weekly treatments where they are seated for approximately four hours near other patients and where health emergencies take place regularly. Prolonged trauma exposure can limit one's ability to develop and maintain health routines that depend on certain predictabilities, safety from threat and harm, and absence of anxiety (Lahav, 2020). For example, chronic exposure to medical treatments and procedures can constrain one's mobility, money, and time to exercise regularly or prepare healthy meals.

Within dialysis settings, providers also vicariously experience their patients' traumas, affecting their ability to deliver high-quality care and potentially leading to a sense of helplessness in their role, as well as their own mental health threats, including burnout (Erdley-Kass & Betru, 2015). Dialysis centers are complex environments that repeatedly expose patients and providers to multiple traumas but where psychotherapy is not a primary focus (Hooper, 1994). Exposure to trauma in hemodialysis settings demands feasible preventive and protective solutions to manage existing trauma and prevent new trauma. Addressing trauma in chronic disease treatment settings, such as hemodialysis centers where patient-provider relationships are important for effective ESKD treatment, also has the potential to improve healthful maintenance on dialysis and successful kidney transplantation.

Overall, our analysis indicates that chronic, emotional, and medical trauma are highly prevalent in this diverse U.S. sample of dialysis-dependent adults with co-existing obesity. Data from healthcare providers who work with this patient population confirmed that trauma in this population and setting also affects providers, that systems and structures can both induce and exacerbate trauma, and that trauma negatively affects effective ESKD treatment, including obesity management. This finding supports other research linking trauma to obesity (Sinha, 2018; Wiss et al., 2020).

Contribution to existing literature

Trauma-informed approaches are increasingly recognized as best practice across healthcare, educational, and organizational settings (Bloom, 2013; Erdley-Kass & Betru, 2015; Goddard et al., 2022). They include care practices, intentional organizational preparedness, and population-level prevention, where one-on-one psychotherapy is not feasible or appropriate. Such approaches can be used to address the relationships between trauma, stress, and poor health outcomes and to ensure optimal therapeutic care practices (Albee, 1982; Goddard et al., 2022). The U.S. Substance Abuse and Mental Health Services Administration's (SAMHSA) framework of trauma-informed care (TIC) consists of "realizing the impacts of trauma, recognizing the signs" and "responding" to "resist re-traumatization" (2014).

This study adds to the evidence of the need for trauma-informed practices in the context of dialysis settings in the U.S. (Erdley-Kass & Betru, 2015; Hercz, 2017). The themes that emerged underscore the value of developing interventions that are founded in TIC. Intersecting trauma can have severe implications for patients and providers in dialysis settings, and thus has potential for high-impact interventions to improve the quality of life of patients, providers, and their loved ones. Differentiating trauma types in this study's context is important to understanding patient barriers to successful weight management.

Trauma is itself an emotional and mental response to threat exposure (Christopher, 2004). Trauma can also be thought of as either conscious or subconscious fear and/or anxiety. Medical trauma can result in pain and fear of ongoing treatment or care environments. Emotional trauma can influence a patient's coping mechanisms which, if unhealthy, can exacerbate chronic medical conditions. Emotional trauma can also have repercussions for treatment if patients develop social anxiety, depression, or lack of empowerment, all of which may undermine their participation in disease management and healthy weight loss. In this study, providers offered their own perspectives on what might be effective in improving patient experiences. These strategies were not typically based on scientific evidence or best practices for hemodialysis patients but are important reflections of their clinical experiences.

Addressing the links between trauma (including dialysis-related suffering), mental health outcomes, and patient quality of life can prevent ongoing experiences of trauma during ESKD treatment for patients as well as their families and providers (Anderson et al., 2022; Bossola et al., 2009; Hamama-Raz et al., 2017; Kato & Reinsal, 2019; Lacson & Barth, 2019). Dialysis center-based, trauma-informed care can empower both patients and professionals, as well as strengthen their treatment partnership, all towards improving patient quality of life and transplant eligibility. These findings substantiate other research demonstrating the need to address mental health in chronic disease treatment and prevention more broadly (Rahimi et al., 2019). Adapting TIC to the unique needs of dialysis patients with obesity provides the potential to improve weight loss success and reduce the effects of trauma on their physical and psychological well-being. Addressing trauma-related mental health barriers in this population is promising for their successful management of other commonly co-occurring diseases, including diabetes, hypertension, cardiovascular disease, and obesity.

Strengths and Limitations

While qualitative inquiry provides rich detail into the perspectives and experiences of the participants, *the findings of this study may not be transferable to all patients* with ESKD and obesity or providers who care for these patients. However, the geographic diversity of participants strengthens our analysis. Further, our data was limited to telephone interviews conducted during the COVID-19 pandemic. In-person interviews, especially in patients' homes, may have yielded observational data helpful to understanding barriers to healthy weight loss in context. This analysis used data from a larger study on patient and provider perspectives on healthy and unhealthy weight loss. Future research should be designed to study and understand trauma specifically across diverse ESKD populations and settings. Furthermore, our obesity criterion was based on BMI, which may have limited nuanced understanding of body composition, nutrition, lifestyle, and comorbidities. However, BMI-defined obesity standardized patient participants' minimum body size across a national sample and is often used for evaluating transplant eligibility (Segev et al., 2008). Given these limitations, it would be helpful to explore trauma and coping strategies among ESKD patients who successfully achieve transplant-eligible body sizes.

Recommendations

Based on our findings of patient and provider experiences, the literature on chronic disease and mental health, and best practices in mental health fields, we support TIC in dialysis settings. A review of potential approaches is beyond the scope of this paper. Two group-level TIC approaches are discussed below. The feasibility of any interventions in dialysis settings would however depend on site-specific assessments including patient needs, staff needs and the capacities unique to each dialysis center. Considering the staff and patient burden of any intervention in dialysis settings, group interventions might be more cost-effective and convenient than interventions that rely on individual patient-provider interactions. Group approaches might leverage close relationships among patients and providers and the physical spaces and times where patients and providers interact during dialysis treatment, thus maximizing existing resources and patient reach (Holliman et al., 2023).

Two group-level approaches are worth considering in these settings and populations: 1.) a trauma-informed approach such as The Sanctuary ® Model (Bloom, 2013); Sanctuary Institute, 2023.) and 2.) the therapeutic process of using eye movement desensitization and reprocessing (EMDR) (Jarero et al., 2016).

The Sanctuary Model offers a collaborative trauma-informed framework for communities (in this case patients and providers) to make concrete plans for and engage in trauma-responsive practices that emphasize the psychological and social safety of all participants (Bloom, 2013).To equitably address trauma with ESKD patients specifically, this approach encourages accountability within the dialysis community to support equal access to transplant as the standard of care for all ESKD patients who want it, including those who manage co-occurring ESKD and poor mental health. The Sanctuary® Model is manageable across a range of training timelines and capacities and has been successfully used in many clinical and workplace settings (Bloom, 2013).

Another group-level trauma therapy approach that has already been successfully adapted to clinical settings is the Eye Movement Desensitization and Reprocessing-Integrative Group Treatment Protocol (EMDR-IGTP) (Jarero et al., 2016). This approach uses guided eye movement, tapping, or other forms of sensory stimulation to engage the parasympathetic nervous system in re-processing current, previous, or future trauma (Rahimi et al., 2019). EMDR and reprocessing with individual patients who are on dialysis has also resulted in statistically significant improvements in anxiety and depression (Rahimi et al., 2019).

This study also indicates the need for trauma-informed approaches and public health interventions to prevent trauma for people with high risk of chronic disease and obesity, beyond and before the onset of ESKD and dialysis treatment. At the population level, trauma-informed approaches in schools can encourage effective processing skills and behaviors as part of children's development to mitigate maladaptive responses to trauma and chronic disease burdens over the life course. At a systems level, trauma-informed approaches also have potential in all medical settings where patients and providers are regularly exposed to high-stress circumstances and traumatic events. Addressing and preventing trauma has exponential promise to reduce its psychological, physical, and social impacts on entire communities and environments in which kidney disease and obesity develop and are managed.

CONCLUSION

Few studies in the U.S. have addressed mental health and psycho-therapeutic approaches to those with co-existing ESKD and obesity. Our findings help to fill this gap and provide recommendations that are rooted in patient experiences and can inform clinical and community-based practices and care guidelines that address trauma in this population. Screening for mental health conditions is critical to understanding these patients' barriers to attaining healthy and transplant-eligible weight, and for tailoring interventions to most effectively improve patient health (Rahimi et al., 2019). This study further confirms the importance of integrating trauma-informed approaches, such as The Sanctuary Model, into ESKD patient care to address existing trauma and pre-

vent new trauma effects. Lastly, our findings and recommendations demonstrate the value of laying the foundation for equitable care in chronic disease management where structural and systemic factors (i.e., access to affordable healthy foods and mental health care) contribute to trauma and its poor mental and physical health outcomes. Chronic disease prevention requires that we to promote the right to full health for all.

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Supplementary Exhibits A and B

Patient and Provider Interview Guides

The Case for Trauma-Informed Chronic Disease Care: Exploring Trauma Among Adults With Obesity On Dialysis

Supplementary Exhibit A: Patient interview guide.

DREXEL UNIVERSITY INTERVIEW GUIDE A
for Patient Respondents
Parent Study Title: Identifying Healthy and High-Risk Weight Loss Phenotypes to Optimize Obesity Management in End Stage Kidney Disease Study 1
Principal Investigator: Meera Nair Harhay, MD, MSCE
IRB No.: 2004007728
PI Version Date: Version 1, 8/8/2020

Patient Interview - Introductory Grand Tour Questions
To start, I'd like to ask you to tell me a little bit about your health. How did you first learn that you had kidney problems? (if not already mentioned)
And how did you first learn that your kidneys had stopped working, and that you had kidney failure?

And how about when you began dialysis?

(If not already mentioned)
Have you ever been told by a doctor that you have diabetes?
Have you ever been told you have hypertension, or high blood pressure?

Have you ever had a kidney transplant? Can you tell me a little bit about what happened? Are you on the waiting list now for (another) transplant?

What parts of being on dialysis are most unpleasant or most challenging for you? What are some aspects of dialysis that you find positive?

Can you describe a typical day for you on the days you come for dialysis?

And how about the days you are not receiving dialysis? What do you usually do on those days?

(If not already mentioned) Do you have a job or do any work for pay?
What do you do?

And what kinds of work did you do for most of your life?

HEALTH AND FITNESS

Please tell me some of the ways you feel your health has changed, since you began dialysis.

What are some things you noticed about your overall strength and stamina, since you began dialysis?

How about your memory, and how clearly you can think about things? How about your sleep and your ability to relax? How about your appetite, and your ability to enjoy the foods you like? What are some other changes you have experienced?

What are some of the ways you take care of your health these days? **(Probes: activity, medication, sleep, relaxation, social)**

When you were growing up, and up until you learned that you had kidney disease, how did you stay active?
What were some sports you played? What types of exercises did you do?
How active were you at work or around the house?

(Probe: walk to school or work, have active hobbies, have a job with lots of movement, etc.)
How about now?
How do you stay active when you are not on dialysis?

DIET AND WEIGHT

Now I would like to ask you about the foods you eat, and your diet.

Who does most of the meal planning at home?
How does your household typically plan for meals?

Who does most of the food shopping at home? Where do they usually shop for food?
Please describe a typical grocery shopping trip for your household.

Who does most of the cooking at home?
What are some foods cooked often in your household?
How are these foods usually prepared?

How careful do you feel you need to be about what you eat?
How much do you watch the foods you eat?

What are some reasons you might avoid certain foods?

What are some reasons you might try to eat more of certain foods? **(Probes: Foods avoided, foods encouraged, quantity, preparation at home or outside the home, etc.)**

I'd like to talk a little bit about how emotions might affect how we eat. For example, some people eat to forget about their worries, or they feel that eating helps them feel better when they feel tired or depressed or anxious.

Do you find yourself eating differently when you feel down?

Can you tell me about those situations?

WEIGHT AND BODY SIZE

Now I want to ask you some questions about your weight, and what size your body has been at different times in your life.

How would you describe your body when you were growing up and in school? How did your body change after you became an adult?

Before you got kidney disease and began dialysis, how did you maintain your weight?
What were some challenges you had with maintaining your weight? Please tell me about the times you went on a diet to lose weight.

Compared to how you are now, how would you describe your weight before you had kidney disease and began dialysis?
What are some reasons your weight changed after you went on dialysis?

Right now, how do you feel about how much you weigh?
How satisfied are you with how much you weigh?
If you could weigh any amount you wanted, what would your ideal weight be right now? More than you are now, less than you weigh now, or about the same weight as now?

Now that you are on dialysis, what makes it easier to manage your weight**? (Probes: technology, people, habits)**
What makes it difficult to manage your weight?

What would make it easier to lose weight?
How do you feel about medications and/surgeries for weight loss? **(Probes: what if any have you heard of? do you have any experience, have you ever been offered these, do you know anyone who has, do you think they are very common….)**

Since beginning dialysis, what comments have you heard from any of the doctors, or nurses, or people you see for your care, about your weight?

Please describe a time when someone told you that you needed to lose weight. **(Probes: who told, reason for needing to lose, strategies recommended, how difficult was it, any success?)**
Tell me about a time when you might have lost without trying, during your kidney disease and dialysis.

What did you hear from your doctors or nurses, or people you see for your care, about this weight loss? **(Probe: How could they tell it was unhealthy?)**

PERSONAL EXPERIENCE WITH HEALTHY AND UNHEALTHY WEIGHT LOSS

Please tell me about a time when a medical professional, such as a doctor, nurse or dietician, might have told you that you were having a healthy weight loss. What did they tell you, and how did they know it was healthy?

And how about weight loss that was not healthy, and they were worried about? Has that happened to you? What did they say?

In general, how do dialysis doctors determine/figure out the best weight for someone on dialysis?

What do they look for to tell if someone is having healthy weight loss or unhealthy weight loss? **(Probe: Any lab tests? Any questions to ask the patient?)**

How important is it for people who are on dialysis to be at a healthy weight?

What are some reasons to be careful about your weight if you are a person who is on dialysis?
Now let's think about you, specifically. How important is it for you to be at your recommended weight?

What are some things that would be different for you, either in your dialysis treatment or in your life in general, if you were at your recommended weight?

How important is it for your future health to be at your recommended weight?
How important is your weight for your future health as a person with kidney disease? How about for a transplant?

How does weight enter into waiting for a transplant, or how well it goes during the transplant and afterwards?

In general, what advice or recommendations do you get from doctors or nurses about how much you should weigh?
What are some of their recommendations to reach this recommended weight? How do you feel about their advice?

What are some of the things that you may think are good for you, that they recommend against?

What are some things they encourage you to try to do, which you think are not that good for you?
What are some other experiences, feelings, or thoughts you would like to share with me about weight and weight loss for people on dialysis?

KEY INDICATORS RELATED TO THE CONCEPTS OF HEALTHY AND UNHEALTHY WEIGHT LOSS

Step 1: Free Listing on Key Domains
(diet, appetite, clinical biomarkers, function, mobility, quality of life)
I am going to ask you tell me all of the words or ideas that come to your mind when I ask you about certain things that might be associated with people on dialysis who lose weight.

First, can I ask you about how the doctors and nurses know that someone has lost or gained weight.

What are some of the things they look at?
(Any tests or special ways to know?)

Treatments, and dialysis procedures of someone who loses weight?

Again, let's think of someone who loses weight.
What foods do you think of?

Any special foods to avoid, or foods to have more of?

What are their eating patterns? How often, or how much?

What is their attitude towards food? Their appetite, and how much they enjoy their foods?
How about any medications or supplements?

How about how they look? How do they act?

Any special signs or symptoms for dialysis patients related to weight loss?

How about their activities, what they can do, and what they feel like doing?

How about their mood, and their ability to enjoy what they are doing?

How about their thinking, and how well they can concentrate on things?

Does anything else come to mind, when you think of losing weight while on dialysis?

STEP 2: PILE SORTING ACTIVITY

HOW TO DISTINGUISH BETWEEN HEALTHY AND UNHEALTHY WEIGHT LOSS

Now I am going to ask you about losing weight in general, and patients who experience weight loss over time while on dialysis. This can be either healthy or unhealthy weight loss.

Sometimes doctors and nurses talk about the difference between healthy weight loss and unhealthy weight loss for people who are on dialysis.

What comes to mind when you hear healthy weight loss? Please describe a person on dialysis who would be having a healthy weight loss. How would doctors and nurses know it was healthy?

Now let's think of a person on dialysis who would be having an unhealthy weight loss. What would that be like?

I am going to go back through the list of things you just mentioned and ask you to help me sort them into two piles – I would like you to tell me if you think that each item is usually a measure of healthy weight loss, or if you think of it as something that mean an unhealthy weight loss. If you can, tell me just a bit about why you think each thing is healthy or unhealthy.

Sometimes something can be either healthy or unhealthy, and you can let me know that as well.

(GO BACK THROUGH EACH ITEM IN THE FREE LIST SECTION)

Is there anything else you want to tell me about losing weight on dialysis, and when it is healthy or unhealthy for patients? Do doctors and patients always agree on weight issues? What are some of the things you have heard about this from other patients or from dialysis staff?

And has the COVID-19 pandemic changed this for you? What are some of the ways that your experience as a dialysis patient, and your ideas about healthy weight, have changed during COVID-19?

Demographic Questions

We are almost finished. Now I am going to ask you just a few questions about yourself.

(If information is on the screener, confirm rather than ask as new)

First, I want to confirm how old you are. Are you ***[age from screener]****? And you identify as* ***[gender from screener]?***

And you told us that you consider you race or ethnic background to be [race/ethnicity from screener] – can pick as many as applies

- ☐ White / Caucasian
- ☐ Black / African American
- ☐ American Indian / Alaska Native
- ☐ Asian
- ☐ Hispanic or Latino
- ☐ Other:

Not counting yourself, how many other people live in your home with you, and regularly eat meals with you?
Are any of those children under age 18? How many?

Do you, or anyone in your home receive any government assistance to help with food? That would include WIC, SNAP or food stamps.

When did you start receiving these benefits? Have you had changes to your benefits recently?
Do you or anyone in your home sometimes get donations of food, such as from a food pantry at a church or other place?

In the past 12 months, how often would you say that you and your household worried whether your food would run out before we could buy more? Would you say it was often, just once in a while, or not at all?

And in the past 12 months, how often would you say that you and your household could not afford to eat balanced meals, and have the variety of foods you would like to have? Would you say that happened often, just once in a while, or not at all?

And in a typical month, which of these statements describes you and your household?

1) There is enough money to pay the bills that are due, and some left over to save or spend.
2) There is only just enough money to pay the bills that are due.
3) There is often not enough money to pay the bills that are due.

And finally, what kinds of health insurance did you have before you got sick with end stage renal disease and began dialysis? **(Probe if not clear – is that a kind of Medicaid or government medical insurance, a private insurance through work, or some other type of health insurance?)**

Supplementary Exhibit B:

Health care provider interview guide.

DREXEL UNIVERSITY INTERVIEW GUIDE B
for Health Care Providers
Parent Study Title: Identifying Healthy and High-Risk Weight Loss Phenotypes to Optimize Obesity Management in End Stage Kidney Disease Study 1
Principal Investigator: Meera Nair Harhay, MD, MSCE
IRB No.: 2004007728
PI Version Date: Version 1, 8/8/2020

INTRODUCTORY GRAND TOUR QUESTIONS

As we explained, we are having discussions with health care professionals involved in caring for patients with end-stage kidney disease, to try to understand how clinicians help their patients who are overweight manage their weight.

In particular, we are interested in weight loss for obese and overweight patients who are undergoing hemodialysis.

First, please tell me about your professional role in regard to dialysis patients.
What is your position at this unit?
Are there any other dialysis units you work at?
(Probe if not mentioned above: How many days each week or each month do you care for center-based dialysis patients?)

What does a typical work day look like for you, when you are working with dialysis patients? What are the different types of patients you see at your dialysis center?

For example, what are your patients' characteristics, considering racial and ethnic diversity, socioeconomic status and educational attainment?

And how about patients who have obesity? What are some characteristics of your typical patients with obesity? How are they different from patients without obesity?How common is obesity in your patient population?
What percentage of your patients would you estimate have obesity? Why is obesity common/uncommon in your patient population?

Among obese patients, what proportion of them (do you think) would like to lose weight?
Among obese patients, what proportion of them (do you think) are actively trying to lose weight?

What are some of the barriers (probe: emotional, physical, logistics, socioeconomic, dialysis treatment environment, medications)?

Can you share any weight loss success stories?
Can you share any weigh loss stories of struggle?

Do any patients stand out to you and if so why?

What do you think made the difference?

How do you navigate the emotional, mental, and physical health sensitivities of weight loss with patients?

WEIGHT CHANGE AMONG OVERALL ESKD PATIENTS

What are some trends you observed with weight loss for the patients at your dialysis center?

Please describe a typical dialysis patient who will lose substantial amounts of weight over time (for example, 10% or more of their body weight). Just to be clear, this is not weight gain or loss between dialysis sessions, but overall weight.
How common/prevalent is weight loss among your patients?
What are some other health conditions that might influence this weight loss?
What are some **behavioral patterns** you have noticed among patients who lose weight?
Please describe a typical dialysis patient who will gain weight?

How common/prevalent is weight gain among your patients?
What are some other health conditions that might influence this weight gain?
What are some **behavioral patterns** you have noticed among patients who gain weight?

Please describe a typical dialysis patient who will maintain their weight?
How common/prevalent is it for your patients to maintain the same weight?
What are some other health conditions that might influence this weight maintenance?
What are some b**ehavioral patterns** you have noticed among patients who stay the same weight?

WEIGHT CHANGE AMONG ESKD PATIENTS WITH OVERWEIGHT/OBESITY

Now, let's talk specifically about your dialysis patients who have obesity. How might these patients' weight change over the course of their kidney disease?

Please walk me through the typical experience of a dialysis patient with obesity, who loses weight.
How common/prevalent is it for dialysis patients with obesity to lose weight over time?
What are some b**ehavioral patterns** you have noticed among these patients?
(probes: medication compliance, dietary practices, activity levels) employment, peers who are also losing weight, openness to education)

Focusing again on just obese patients, what are some specific recommendations they might receive from the clinician team in your dialysis center about their weight?

How do you approach dialysis patients with obesity about their weight?
How common/prevalent is it for patients with obesity to get recommendations to lose weight?
What do these recommendations look like?
What are some effective strategies you have seen to support patients with obesity on dialysis in their weight management? What about ineffective strategies?

What are some reactions you get from patients with obesity when they are recommended to lose weight?
What are some reasons patients might want to lose weight?
What are some reasons patients might be unwilling to lose weight?

What are some of the strategies you encourage patients to use when they agree to lose weight?

Please tell me about a time when you have encouraged a patient with obesity to attempt weight loss, but they were not able to do so.

Please describe a time when a patient with obesity lost weight unintentionally, without trying.
What would be a typical scenario for that sort of weight loss?
How might that unintended weight loss affect the patient's treatment? How might that unintended weight loss affect the patient's quality of life?

HEALTHY VS. UNHEALTHY WEIGHT LOSS AMONG DIALYSIS PATIENTS WITH OBESITY

Now I would like to ask you to help me understand how you and your colleagues distinguish between healthy weight loss and unhealthy weight loss in a dialysis patient with overweight or obesity.

First, please describe a typical dialysis patient with obesity, who is experiencing healthy weight loss.
What indicators would you use to determine that their weight loss is healthy? (Probes: lab tests, weight loss trajectory or how fast or slow it occurred, asking patient about behaviors and diet/foods, role of fasting, general feeling and mood, sleep, energy level, physical appearance, muscle tone and strength, other indicators).

Now, please describe a typical dialysis patient with obesity, who is experiencing unhealthy weight loss.
What indicators would you use to determine that their weight loss is healthy? (Probes: lab tests, weight loss trajectory or how fast or slow it occurred, asking patient about behaviors and diet/foods, role of fasting, general feeling and mood, sleep, energy level, physical appearance, muscle tone and strength, other indicators).

Please compare unhealthy and healthy weight loss patterns among your dialysis patients with obesity.
What are the most important indicators that could distinguish between healthy and unhealthy weight loss?

What are some challenges you and your clinical colleagues have when distinguishing between healthy and unhealthy weight loss in patients with obesity? What strategies do you use here, to manage weight loss healthfully? And to avoid unhealthy weight loss?

How important an issue is unhealthy weight loss for the patients you treat?
And for the field in general?

UNHEALTHY WEIGHT LOSS IDENTIFICATION TOOL FOR THE DIALYSIS SETTING

One goal of this research is to develop a reliable tool, consisting of a set of clinical metrics – maybe just a few items long – to help clinicians distinguish between healthy and unhealthy weight loss in dialysis patients.
Do you feel this would be useful for you and your colleagues? Why or why not? Would you use a tool like this? How would it fit into your regular clinical practice with your patients?

Are there any advantages you can think of in using a validated tool to help you identify unhealthy weight loss among your patients? What would some of those be?
How about barriers? Can you think of any barriers to using this tool?

Do you think a tool for patients to help them manage their weight might be helpful? What form would a helpful took take? Can you think of any patient barriers to using such a tool?

What else would you like to share with me, about this issue?

How do feel like the Covid-19 pandemic has affected patients with obesity on dialysis?

Has it added challenges for patients who want to lose weight?

Finally, I have just a few more questions about your background.

Can you tell me your age?

Could you tell me what race or ethnic group you identify as?

And how many years have you been working in your profession, after you completed training?

And approximately how many years have you been providing care for center-based dialysis patients?

CLOSING REMARKS

Thank you very much for sharing all this information with me. We appreciate you making time to join our study.

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