CONTEXTUAL PREDICTORS OF HOSPITALIZATION AND QUALITY OF LIFE AMONG PEOPLE ON HEMODIALYSIS

by
Kathryn Taylor

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Abstract

Background: People on hemodialysis are hospitalized frequently but some are hospitalized more than others. Food insecurity, housing instability, and substance use disorder are risk factors for chronic kidney disease progression that may explain disparities in hospitalization risk among people on hemodialysis. They may also impact health-related quality of life, a patient-reported outcome associated with acute care utilization.

Objectives: This dissertation study examined relationships between individual and area-level indicators of socioeconomic position; food insecurity, housing instability, and substance use disorder (framed as contextual risk factors); and hospitalization and quality of life among people on hemodialysis.

Methods: We enrolled a convenience sample of 322 people receiving hemodialysis at facilities in the Baltimore and Washington, D.C. metropolitan areas from February through December 2021. Using baseline survey data, we conducted multivariate and mixed effects logistic regression to test associations between (1) individual and area-level indicators of socioeconomic position and (2) food insecurity and housing instability (aim one). Using electronic medical record data from 6 months of study follow up, we applied Cox regression and multivariate linear regression models to test associations between (1) baseline contextual risk factors (i.e., food insecurity, housing instability, or substance use disorder) and (2) hospitalization and quality of life among people on hemodialysis.

Results: Over 30% of participants experienced food insecurity in the previous 12 months. 18% reported housing instability. People experiencing food insecurity were more likely to report moderate or high-risk use of tobacco and cannabis or other drugs. Younger age was a risk factor for food insecurity and housing instability. Additionally, residential segregation moderated associations between age, gender, and food security (aim one). Food insecurity, housing

instability, and moderate or high-risk substance use were not associated with all-cause hospitalization. However, food insecurity was associated with missed hemodialysis treatments, hospitalizations due to fluid overload or hyperkalemia, and poor kidney disease-related quality of life (aim two).

Conclusions: Contextual risk factors, particularly food insecurity, impact health outcomes across the trajectory of chronic kidney disease and are common among people on hemodialysis. Stakeholders can address food insecurity among people on hemodialysis now while health equity research in chronic kidney disease continues.

Thesis Readers and Final Oral Exam Committee

Sarah Szanton
Thesis Advisor
Dean and Professor
Johns Hopkins University School of Nursing

Deidra Crews
Thesis Co-Advisor
Professor
Department of Medicine, Division of Nephrology
Johns Hopkins University School of Medicine

Patricia Davidson
Professor Emeritus
Johns Hopkins University School of Nursing

Nancy Perrin
Professor
Johns Hopkins University School of Nursing

Michael Fingerhood
Professor
Department of Medicine, Division of Addiction Medicine
Johns Hopkins University School of Medicine

Alternate Committee Members

Steve Sozio
Associate Professor
Department of Medicine, Division of Nephrology
Johns Hopkins University School of Medicine

Chakra Budhathoki
Associate Professor
Johns Hopkins University School of Nursing

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didn’t have a home; to the man who died in a hospital across town with a potassium of 8: This dissertation represents one small step toward creating a system that serves you.

Table of Contents

List of Tables

List of Figures

CHAPTER 1: Introduction

Background and Rationale

Epidemiology of End-Stage Kidney Disease in the United States

Racial disparities characterize end-stage kidney disease (ESKD) epidemiology in the United States. Over 800,000 people in the United States have ESKD. The number of people with ESKD has increased by approximately 20,000 each year for over 2 decades, due to improved survival and increased rates of diabetes and hypertension, major proximate risk factors for kidney disease.[1] For Black people, the current adjusted prevalence rate is nearly 6500 per million persons while it is 1500 per million persons for Whites. The incidence rate of ESKD among Black people in the United States is 3-fold higher. After controlling for community-level poverty and other indicators of social deprivation, Black people with ESKD are less likely than White people to receive home dialysis, be preemptively waitlisted for a kidney transplant, or receive a living-donor kidney transplant.[1] These differences amount to a social justice issue, particularly given the decrease in quality of life and life expectancy associated with ESKD. This dissertation study contributes to a body of antiracist research aimed at identifying and dismantling the root causes of racial disparities in health outcomes across the trajectory of chronic kidney disease.

In discussions of racial disparities in ESKD incidence, researchers must distinguish between race, which is socially constructed and a proxy for complex systems of oppression and privilege; and genetic ancestry, which deals with inherited traits.[2] Over the last decade, geneticists and other researchers have identified and explored the role of the apolipoprotein L1 (APOL1) gene and its variants in ESKD incidence among people with West African ancestry. Like the relationship between sickle cell disease and malaria, APOL1 variants are protective against a parasite that causes sleeping sickness, but people who "carry" variants on both chromosome pairs are at increased risk of chronic kidney disease progression and ESKD.[3] Approximately 13%

of Black people in the United States have two copies of the APOL1 variant.[4] However, not everyone with high-risk APOL1 status develops ESKD. An inflammatory stressor, sometimes referred to as a "second hit," may be required to trigger kidney disease progression.[5] In a large prospective cohort study with 25 years of follow up, Black participants had higher ESKD incidence rates and faster kidney function decline compared to White participants regardless of APOL1 status.[6] Ancestry and environment, including social context and structural racism, are relevant in ESKD epidemiology.[7]

The associations between race, social context, and progressive chronic kidney disease and ESKD are complex. In a cross-sectional study of over 2000 Black and White adults in the Baltimore area, researchers found that having an annual household income below 125% of the federal poverty level increased odds of chronic kidney disease (eGFR > 60 mL/min/1.73 m^2) in Black participants (OR, 1.91; 95% CI, 1.54 – 2.38) but not White participants (OR, 0.95; 95% CI, 0.58 – 1.55) after controlling for age, insurance status and relevant comorbidities.[8] In a separate cross-sectional study using data from a large cohort (n = 23,538), subgroup differences in kidney function reversed as eGFR declined, such that White participants were more likely to have eGFRs between 40 and 60 mL/min/1.73 m^2 while Black participants were more likely to have eGFRs between 10 and 19 mL/min/1.73 m^2. This trend was attenuated after controlling for covariates including age, gender, comorbidities, annual household income and community poverty, but Black participants were still at increased risk for advanced kidney disease (eGFRs between 10 and 19 mL/min/1.73 m^2; adjusted OR Black:White participants, 2.21; 95% CI, 1.25 – 3.93).[9]

Kidney researchers have developed conceptual models to clarify the pathways from race and poverty to ESKD through intermediary factors including material conditions related to residential segregation and health behaviors related to chronic stress.[10,11] In a large

retrospective cohort study (n = 2320) with 12 years of follow-up, participants with chronic kidney disease reporting food insecurity had lower incomes, were disproportionately non-White, and had higher rates of diabetes and hypertension compared to food-secure participants. They were 2.6 times more likely to develop ESKD after adjusting for age, gender, and race.[12] A retrospective cohort study of adults (n = 15,345) with advanced CKD (stages 3 – 5) found that homelessness increased risk of ESKD or death by 28% after controlling for comorbidities, lab values, and sociodemographic variables (adjusted HR, 1.28; 95% CI, 1.04 – 1.58).[13] Substance use, particularly of heroin and cocaine, is also associated with ESKD incidence.[14] While the effects of cocaine itself may directly damage the kidney through hypertension and renal artery sclerosis, heroin use may damage the kidney indirectly via increased risk of HIV and hepatitis C.[15] These factors may contribute to health outcomes after ESKD diagnosis and initiation of renal replacement therapy, though their impact has not been well-studied.

Outcomes among People with ESKD on Hemodialysis

Healthcare for people with ESKD is costly to patients and payers and outcomes are relatively poor. Though people with ESKD make up 1% of the Medicare population, they account for 7% of Medicare spending. One-third of Medicare spending is for inpatient care.[1] Survival and hospitalization rates vary by renal replacement modality but are worst for people on hemodialysis (Table 1).[1] Additionally, people on hemodialysis have physical functioning and general health scores on the 36-item Short-Form Health Survey (a patient-reported measure of health-related quality of life) that are nearly 1.5 standard deviations below those of the general United States population.[16] Recent ESKD federal policy incentivizes dialysis facilities to transition people on hemodialysis to home modalities and improve kidney transplantation rates.[17] However, hemodialysis remains the most common modality by far for incident and prevalent

people with ESKD (85.1% and 61.1%, respectively).[1] As the prevalence of ESKD continues to increase, there is a need for tertiary prevention interventions that reduce costly inpatient utilization and improve health-related quality of life for people on hemodialysis.

The leading causes of hospitalization among people on hemodialysis are cardiovascular disease and infection. Even at earlier stages of chronic kidney disease, the impact of kidney function decline on multiple organ systems[18] increases risk of sudden cardiac death, cardiac arrythmias, cardiomyopathy, and coronary artery disease.[19] Chronic kidney disease impairs immune response through multiple pathways.[20] Additionally, infection-related hospitalization rates are seasonal. Hospitalizations related to dialysis access infection (highest in summer) alternate cyclically with hospitalizations due to flu and pneumonia (highest in winter).[21] A discussion of COVID-19 hospitalizations in the context of the present study follows in the *Conceptual Framework* section below.

Within this high-risk population, some people are hospitalized more frequently than others. In a prospective cohort study of people on hemodialysis in Baltimore (n = 146), 85% of participants experienced a hospitalization within the study's 12-month follow up period. The median number of hospitalizations was 1 and the maximum was 9.[22] Multiple risk factors contribute to differences in hospitalization. Younger people on hemodialysis have the highest hospitalization rates at 1.97 per person-year.[1] CMS adjusts the standardized hospitalization ratio for age, body mass index, cause of ESKD, comorbidities, gender, and nursing home status in its value-based payment program.[23] Racial disparities in hospitalization rates also exist. In a large retrospective cohort study of people on hemodialysis using data from the USRDS, White people had higher all-cause hospitalization rates than Black (RR 0.95, 95% CI [0.94 – 0.96]) or Hispanic (RR 0.89; 95% CI [0.88 – 0.90]) people after controlling for multiple demographic, behavioral and clinical indicators. However, in younger age groups (age 18 – 30), White people had *lower* all-

cause hospitalization rates compared to Black people (RR 1.27, 95% CI [1.19 – 1.35]). In older age groups (age > 80), their all-cause hospitalization rates were *lower* than those of Black (RR 1.08, 95% CI [1.05 – 1.11]) *and* Hispanic people (RR 1.08, 95% CI [1.03 – 1.13]). Additionally, Black people had more hospitalization days due to dialysis-related infection compared to White people across all age groups.[24]

Large observational studies have demonstrated that Black people on hemodialysis have better health-related quality of life than White people.[25,26] However, research exploring racial differences in health-related quality of life among people on hemodialysis have not conceptualized race as a social construct.[27] For example, one study found that Black people on hemodialysis had better health-related quality of life at higher levels of comorbidity but controlled for education level, marital status, and private vs public health insurance.[25] These variables represent the social context that generates racial differences. A separate study found associations between unemployment, lower education level and poorer health related quality of life but did not report participant race.[28] In light of these limitations, research on racial disparities in health-related quality of life among people on hemodialysis remains inconclusive.

Contextual Risk Factors among People on Hemodialysis

Given their relevance in ESKD incidence, contextual factors may explain some variation in hospitalization rates and quality of life after hemodialysis initiation. Limited quantitative research suggests that food insecurity and substance use are common among people on hemodialysis in some communities. Housing instability has not yet been studied. One study of 98 people on hemodialysis across 3 dialysis facilities in Louisiana reported that 16% of participants were food insecure and 13.3% were severely malnourished.[29] Separate large cohort studies using administrative data from the *End Stage Renal Disease Medical Evidence Report Medicare Entitlement and/or Patient Registration* form ("CMS 2728") estimated the nationwide

prevalence of "drug dependence" in the hemodialysis population at 1 and 1.5%.[30,31] However, cross-sectional studies using valid screening tools in urban hemodialysis facilities have reported rates of current substance use disorder at 19%[32] and alcohol use disorder at nearly 30%.[33]

Dialysis facility clinicians do not routinely screen for food insecurity, housing instability, or substance use, so they do not know which people are at risk. In the previously referenced Louisiana study, Black race was a predictor of food insecurity.[29] People with documented "drug dependence" on the CMS 2728 are also more likely to be Black men; but this finding may represent clinicians' implicit bias if they are more likely to ask Black men about substance use, and belies the complexity of the relationship between socioeconomic position, substance use, and its consequences.[34-37]

Additionally, it is unknown whether these contextual factors impact hospitalization or quality of life among people on hemodialysis. People on hemodialysis with documented "drug dependence" on the CMS 2728 have a 26% higher rate of infection-related hospitalization (adjusted RR, 1.26; 95% CI, 1.14 – 1.40)[38] and a 35% increased risk of one-year mortality (adjusted HR, 1.34; 95% CI, 1.27 – 1.41).[39] but studies have not used validated measures of substance use disorder to test the association of substance use across a spectrum of severity and all-cause hospitalization or quality of life. Food insecurity, housing instability, and substance use disorder may be modifiable, particularly since people on hemodialysis have thrice-weekly contact with the health care system. If an association exists between contextual factors and patient outcomes, it may strengthen the case for addressing them as tertiary prevention.

Purpose and Study Aims

To address these gaps, this dissertation study examined relationships between individual and community-level indicators of socioeconomic position, contextual risk factors, and person- and payer-centered outcomes among people on hemodialysis.

Specific Aims

This dissertation study had two overarching study hypotheses:

(1) Food security, housing instability, and substance use disorder will cluster within sociodemographic subgroups.

(2) This "risk factor clustering" will increase risk of all-cause hospitalization and decrease quality of life among people on hemodialysis.

To test these hypotheses, we conducted a study with the following specific aims:

Aim 1: Among people on hemodialysis, determine associations between indicators of socioeconomic position and food insecurity, housing instability, and substance use disorder.

Aim 2: Examine the independent associations of food insecurity, housing instability, and substance use disorder with all-cause hospitalization and quality of life.

Conceptual Framework

In a seminal paper by Bruce Link and Jo Phelan, the authors argued that epidemiologists should explore social factors as "fundamental causes" of disease. They wrote, "We suggest that medical sociologists and social epidemiologists need to counter the trajectory of modern epidemiology toward identifying risk factors that are increasingly proximate to disease – ones for which 'biological plausibility' can be argued. One way they can do this is by 'contextualizing' individually-based risk factors. By this we mean that investigators must (1) use an interpretive framework to understand why people come to be exposed to risk or protective factors and (2) determine the social conditions under which individual risk factors are related to disease."[40] Around the same time in a commentary for the *Lancet*, Vicente Navarro challenged Americans to consider the role of social class in health, and consider that racial health disparities are caused, not by race, but by rac*ism* – power structures that keep Black people in lower social classes relative to Whites. For example, according to recent data from the Centers for Disease

Control and Prevention's Behavioral Risk Factor Surveillance System Black people "were more likely than whites to have <12 years of education, to be unemployed, live below the poverty level, and less likely to live in a household where the head of household owned the home."[41]

In alignment with Link and Phelan, the study was guided by a conceptual framework that connects social factors, mediating and proximal risk factors, and patient outcomes. Figure 1 is an adaptation of the World Health Organization's Commission on the Social Determinants of Health framework.[42] It explains how individuals' socioeconomic positions differentially expose them to social determinants of health or contextual risk factors, like food insecurity, housing instability, and substance use disorder. In this adaptation of the World Health Organization's framework, contextual risk factors are associated with clinical indicators, physical functioning, and symptom burden, known predictors of hospitalization among people on hemodialysis.[43-46]

Existing research, as well as the conceptual model, supports the plausibility of these associations. For example, people on hemodialysis must restrict fluids and maintain a diet that is high in protein while simultaneously low in salt, potassium, and phosphorus. People experiencing food insecurity may eat more microwavable or frozen foods that are typically high in salt, placing them at risk for interdialytic weight gain and fluid overload. They may also eat less animal protein, which may contribute to low albumin levels, a strong predictor of hospitalization.[43,47] In qualitative studies, people on hemodialysis have described nonadherence to dietary restrictions due to food insecurity[48] and stretching medications to pay for food.[49] In a recent mixed methods study, clinicians and caregivers of people on hemodialysis described the pathway from "socioeconomic disadvantages" and "financial worry" to "skipping meals" to exacerbation of ESKD and other comorbidities as "a perfect storm" resulting in hospitalization.[50]

We are not aware of research linking housing instability with proximal predictors of hospitalization among people on hemodialysis. In one case series of people on hemodialysis

experiencing homelessness in Canada, all of 11 people had unplanned dialysis initiations ("crash starts"). Most attended hemodialysis treatments consistently but navigated barriers to obtaining arteriovenous fistula access.[51] Pre-dialysis nephrology care is associated with decreased mortality and hospital length-of-stay upon dialysis initiation.[52] Additionally, people that initiate dialysis via a catheter instead of an arteriovenous fistula are at increased risk of infection- and access-related hospitalization.[53]

Substance use disorder is associated with missed hemodialysis treatments. In a prospective cohort study with 114 black participants from one dialysis facility, participants who used cocaine missed an average of 15 treatments during follow up compared to 4 missed treatments among participants who did not use cocaine ($p = 0.0008$). Interestingly, participants who used cocaine were more likely to be dialyzed on a Tuesday/Thursday/Saturday schedule. The researchers did not specify how cocaine use was ascertained in the sample.[54] In a retrospective cohort study (n = 739), participants who reported "use of illicit drugs" were more likely to skip at least 3% of scheduled hemodialysis treatments (adjusted OR, 3.96; 95% CI, 2.16 – 7.24). Again, authors did not specify how "use of illicit drugs" was ascertained, but they reported it for 16% of the sample.[55] In a separate, large retrospective cohort study (n = 182,536), participants with documented "alcohol or drug abuse" on the CMS 2728 were more likely to miss treatments (adjusted OR, 1.68; 95% CI, 1.64 – 1.73).[56] People who miss treatments may receive inadequate dialysis and experience fluid overload and cardiac arrythmias due to electrolyte imbalance.[57]

COVID-19 and Other Confounding Variables

Though the World Health Organization's Commission on the Social Determinants of Health framework and existing research support a causal association between exposures and outcomes of interest in the present study, multiple confounding variables could bias estimates

of association given the study's observational design and sampling approach. That is, characteristics or circumstances that influenced participants' likelihood of exposure to food insecurity, housing instability, or substance use disorder may have also impacted their hospitalization risk or quality of life. Due to lack of random selection, those factors were not evenly distributed across research participants. We identified confounding variables from the literature and accounted for them in statistical analyses. However, we balanced data collection to address confounding with the very real issues of respondent burden and survey fatigue in this population, and residual confounding is a potential study limitation.

Additionally, the COVID-19 pandemic and policies to address it introduced threats to the study's internal validity. We collected data from participants receiving hemodialysis treatment at outpatient dialysis facilities in Washington D.C. and across 7 counties in Maryland and northern Virginia. We collected exposure and quality of life data during the second year of the COVID-19 pandemic. Due to the study's prospective cohort design, data collection for the hospitalization outcome spanned the pandemic's second and third years (February 2021 through June 2022). By early 2021, local governments had lifted stay-at-home orders and the federal government had provided funding for emergency rental assistance and "emergency allotments" to state supplemental nutrition assistance programs.[58] These policies may have impacted food insecurity and housing stability rates in the study sample. COVID-19 infection rates in D.C., Maryland, and Virginia declined in the summer of 2021 and peaked in the winter of 2021 – 2022 (https://coronavirus.jhu.edu/). Despite changes to dialysis facility operations to prevent COVID-19 transmission, community infection rates and infection rates among people on hemodialysis were highly correlated. However, COVID-19 hospitalization rates in 2020 were at least 3-fold higher among Medicare beneficiaries with chronic kidney disease compared to those

without it.[1] We discuss approaches to address specific COVID-19-related threats to validity in Chapters 3 and 4.

Significance

This dissertation study can begin to inform changes to healthcare policy and practice. The Centers for Medicare and Medicaid Services' (CMS) traditional reimbursement model pays dialysis facilities a capitated rate per hemodialysis treatment session. Over the last decade, CMS has experimented with various value-based programs that tie a percentage of the capitated rate to health indicators for the entire population of people in the facility. CMS ties up to 2 percent of the capitated rate to a dialysis facility's performance on health indicators compared to national benchmarks via the End-Stage Renal Disease Quality Incentive Program.[59] More recently, CMS implemented the End-Stage Renal Disease Treatment Choices Model which incentivizes home dialysis and kidney transplantation via a performance scoring method like the Quality Incentive Program but with larger payment penalties.[17]

CMS accounts for case-mix in prospective payments and value-based payment programs to counter the incentive to "cherry pick" healthy people or "lemon drop" complex ones. CMS increases the capitated rate for people with specific comorbidities, adjusts standardized health indicators in the Quality Incentive Program for nursing home status, and stratifies performance benchmarks in the End-Stage Renal Disease Treatment Choices Model by the proportion of people in a facility who are eligible for Medicare and Medicaid. However, CMS does not adjust capitated payment, performance scoring, or payment penalties for people with complex social needs who may require more support to meet benchmarks.[51] For example, housing instability presents a major barrier to home dialysis. Dialysis facilities caring for people experiencing housing instability may receive payment penalties for relatively low home modality use in the End-Stage Renal Disease Treatment Choices Model, particularly if dual eligibility is a poor proxy

for the burden of social determinants of health.[60] This lack of adjustment for social determinants of health may also explain why dialysis facilities in residentially segregated communities are more likely to receive payment penalties in the Quality Incentive Program.[61] Value-based programs that penalize dialysis facilities in divested communities may perpetuate a cycle of poor quality care, subsequent payment penalties, and even less resources. Those facilities likely require *more* resources to pay for care coordination and social worker time, not less. Research that examines the impact of social determinants of health on outcomes for people on hemodialysis may inform policy changes to reverse this cycle.

CMS also mandates specific practices within individual dialysis facilities through its Conditions for Coverage (https://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/ESRD). CMS requires interdisciplinary teams to generate plans of care for every patient and reassess them annually if a patient is "stable" and monthly if a patient is "unstable". The dietician performs a nutrition assessment, and the social worker completes a psychosocial assessment. Providers are required to physically assess each patient and monitor specific labs (e.g., albumin) monthly. However, CMS does not provide interpretive guidance on the dietary or psychosocial assessment tools that interdisciplinary teams should use or guide providers to assess social determinants of health. Moreover, we are not aware of interventions to address food insecurity, housing instability, or substance use disorder if people were to raise those issues during routine assessments. This dissertation study demonstrates the need for a systematic approach to eliciting and addressing contextual risk factors among people on hemodialysis. We discuss specific policy and practice changes in Chapter 5.

Innovation

The current approach to improving health outcomes is informed by conceptual frameworks that do not incorporate patient context. From the national to the individual patient

level: CMS, regional End-Stage Renal Disease Networks, dialysis organizations, dialysis facilities, and clinicians invest tremendous effort and resources toward reducing hospitalizations and improving patient outcomes. Though they do not always articulate the frameworks that guide their work, they typically apply established quality improvement frameworks (e.g. the Donabedian Model or Plan-Do-Study-Act cycles) or health behavior change models. None of these conceptual frameworks guides clinicians to explore the broader context of individual lived experiences. This may explain why quality improvement interventions do not consistently reduce health disparities (and may widen them).[62]

In contrast, this dissertation study builds upon a heuristic that the same exposures that mediate the relationship between socioeconomic position and ESKD incidence may influence outcomes among people on hemodialysis. Therefore, it will advance research and clinical practice by demonstrating the relevance of understudied, contextual risk factors that may contribute to high-cost healthcare utilization and poor quality of life in the hemodialysis population. Clinicians in the healthcare system cannot likely change individual's socioeconomic position. However, they may be able to improve health outcomes *equitably* – not only by changing dialysis facility process or assessing motivation to change health behaviors; but by helping people on hemodialysis address contextual factors like food insecurity, housing instability, and substance use.

Summary

If structural racism and social determinants of health influence patient outcomes, then clinicians must reconsider their practice and the scope of the healthcare system. In many ways the systems that support (or fail) people with ESKD present a microcosm and an opportunity to explore solutions for the broader healthcare system through health services research. Clinicians caring for people with ESKD confront some of the most "wicked questions" in healthcare: How

do we understand and eliminate persistent racial health disparities in ESKD (or the United States)? How do we pay for and distribute healthcare services? How do we define (and who should define) what quality healthcare is? This dissertation proposal describes research to "contextualize" (in the language of Link and Phelan) risk factors for hospitalization and poor quality of life among people on hemodialysis. It may contribute to ongoing dialogue about the role and scope of the healthcare system in the United States.

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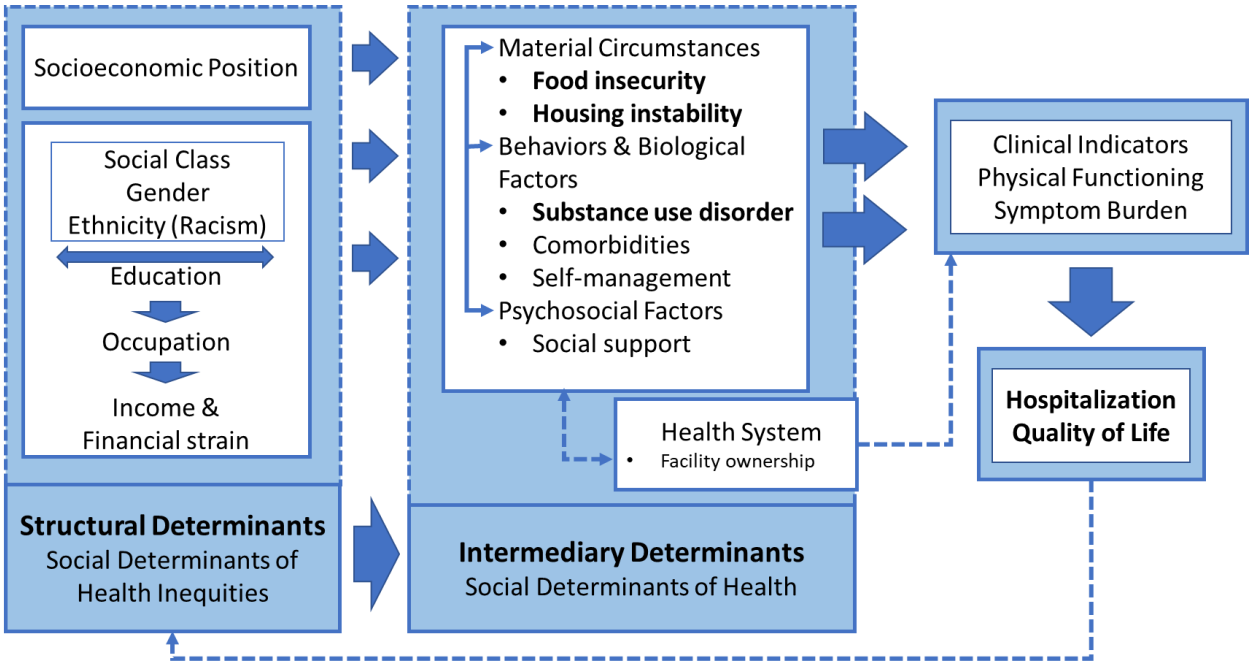
Tables and Figures

Table 1.1: Mortality and Hospitalization by Renal Replacement Therapy[1]

Modality	Mortality Rate	5-Year Survival	Hospitalization Rate
Kidney Transplant	46.8/1000 person-years	Living donor: 93% Deceased donor: 82.7%	0.65/person-yer
Peritoneal Dialysis	134.9/1000 person-years	46.5%	1.47/person-year
Hemodialysis	159.3/1000 person-years	41.7%	1.64/person-year

Figure 1.1: Adaptation of World Health Organization Conceptual Framework for Action on the Social Determinants of Health [42]



CHAPTER 2: Context Matters: A Qualitative Synthesis of Adherence Literature for People on Hemodialysis

Abstract

Background: People with end-stage kidney disease treated with hemodialysis in the U.S. have persistently higher rates of nonadherence compared to people in other developed countries. Nonadherence is associated with increased risk of death and higher medical expenditure. There is an urgent need to address it with feasible, effective interventions as the prevalence of people on hemodialysis in the U.S. continues to grow. However, published adherence interventions demonstrate limited long-term efficacy.

Methods: We conducted a synthesis of qualitative studies on adherence to hemodialysis treatment, medications, and fluid and dietary restrictions to identify gaps in published adherence interventions, searching PubMed, CINAHL, PsychInfo, Embase, and Web of Science databases. We analyzed qualitative data with a priori codes derived from the World Health Organization's adherence framework and subsequent codes from thematic analysis.

Results: We screened 1775 articles and extracted qualitative data from 12. The qualitative data revealed 20 factors unique to hemodialysis across the World Health Organization's five dimensions of adherence. Additionally, two overarching themes emerged from the data: (1) adherence in the context of individuals' whole lives and (2) dialysis treatment as a double-edged sword. Patient-level factors reflected in the qualitative data extended beyond knowledge about hemodialysis treatment or motivation to adhere to treatment. People described a profound grieving process over loss of their "old self" that impacted adherence. They also navigated complex challenges that could be exacerbated by social determinants of health as they balanced treatment, life tasks, and social roles.

Conclusions: This review adds to the growing evidence that one-size-fits-all approaches to improving adherence among people on hemodialysis are inadequate. Adherence may improve

when routine care incorporates patient context and provides ongoing support to people and families as they navigate the logistical, physical, and psychological hardships of living with dialysis.

Introduction

The number of people living with end-stage kidney disease (ESKD) in the U.S. may surpass one million by the year 2030.[1] Hemodialysis remains the primary kidney replacement therapy.[2] People with ESKD receiving hemodialysis in the U.S. have a 33% increased risk of death compared to those in Europe and a nearly 4-fold increase compared to people on hemodialysis in Japan.[3] Relatively higher rates of nonadherence to hemodialysis treatment, medications, or fluid and dietary restrictions may explain some of this disparity.[4,5] In a recent analysis from the Dialysis Outcomes and Practice Pattern Study, nearly 25% of people on hemodialysis in the U.S. missed at least one dialysis treatment in a 4-month period, compared to less than 1% in Japan.[6] People on hemodialysis in the U.S. also report skipping their phosphate binders more frequently than people on hemodialysis in other developed countries.[7] In addition to mortality, nonadherence is associated with increased hospitalization and medical expenditure.[8] Given the increasing prevalence of people on hemodialysis in the U.S. and the persistence and costliness of nonadherence, there is an urgent need to address it with feasible, effective interventions.

Published interventions addressing adherence among people on hemodialysis, however, demonstrate limited long-term efficacy.[9-11] A recent systematic review and meta-analysis by Murali and colleagues included 33 randomized controlled trials (RCTs) evaluating hemodialysis treatment, medication, or fluid and dietary restriction adherence interventions.[10] Many adherence interventions were informed by health behavior change models like Social Cognitive Theory or the Health Belief Model, though partially applied. Nearly all focused on the patient level despite recognition of the burden of social determinants of health in the hemodialysis population.[12] Of the 12 that demonstrated efficacy, only two sustained positive effects at 12 months. The mechanisms underlying the positive effects were not clear and did not directly align with the theory guiding intervention development.[13,14] Additionally, in meta-analysis there

was no association between intervention efficacy and the role or expertise of individuals delivering the interventions, the underlying theory, or the type of intervention (e.g. educational or psychological).[10]

Given that current adherence research has not clarified the mechanisms underlying interventional effects and that positive changes are frequently not sustained, further exploration of the qualitative data is needed. Qualitative research that explores the perspectives of people on hemodialysis about adherence may point to gaps in existing interventions. Analogous to meta-analysis, qualitative synthesis is a method to integrate qualitative data from different studies that address the same research question. The product of a qualitative synthesis may be a new conceptual model or theory that explains an outcome of interest. Researchers have conducted qualitative syntheses to develop conceptual models for medication adherence among people with chronic kidney disease. However, one synthesis excluded people on kidney replacement therapy [15] and one included people across all chronic kidney disease stages and on hemodialysis or peritoneal dialysis.[16] Perspectives about adherence across all domains of the ESKD treatment regimen among people on hemodialysis remain largely unknown. Therefore, the aim of this review was two-fold: (1) to synthesize qualitative data about adherence to hemodialysis treatment, medications, or fluid and dietary restrictions, and (2) to apply findings to existing theoretical frameworks to inform the development of effective, person-centered interventions.

Methods

Below, we report our qualitative synthesis per the 21-item ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) checklist.[17]

We conducted a "best fit" framework synthesis of qualitative data as described by Carroll and colleagues.[18] The "best fit" framework synthesis consists of clarifying a research question that can be answered by qualitative research, conducting a systematic review of qualitative literature, and completing a thematic analysis of qualitative data extracted from included studies. The thematic analysis consists of deductive and inductive processes. The result is a new, tailored conceptual framework supported by qualitative data and a transparent, more replicable synthesis.

We conducted a literature search for publications in the English language to answer the research question: How do adults on hemodialysis experience adherence to hemodialysis treatment? Relevant search terms and medical subject headings were identified with support from an informationist (Supplemental Material). We searched PubMed, CINAHL, PsychInfo, Embase, and Web of Science databases. We did not restrict the search by publication date. Two authors (SS and KT) independently completed title and abstract screening and resolved discrepancies through discussion. One author (KT) screened full text articles.

We adopted an inclusive approach during title and abstract screening to reduce the likelihood of missing relevant literature. After removing duplicates, peer-reviewed studies were included for full text review if researchers applied qualitative methods and the study sample included adults on hemodialysis. We included qualitative or mixed methods studies for full text review that explored individuals' experiences on hemodialysis even if they did not explicitly address adherence in the title or abstract. Despite calls for standard measures of hemodialysis treatment adherence, none currently exist.[19] Conceptually, adherence could apply to any recommended treatment, and articles reporting perspectives on less common indicators of adherence (e.g., vascular access cleaning at home) were included in the full text review.

Studies were excluded upon full text review if the qualitative data did not address adherence among people on hemodialysis. If studies included other chronic diseases or dialysis modalities, we excluded them when we could not ascertain whether people on hemodialysis were the source of qualitative data. After deliberation, we also excluded studies if the sample was not U.S.-based. Though some factors related to hemodialysis treatment adherence may be universal (e.g., fatigue) others are unique to setting (e.g., accessibility of hemodialysis services). We anticipated that by including only U.S.-based studies, we would achieve saturation on "universal" experiences while identifying factors in the social, economic, and treatment domains that were unique to the U.S. Lastly, we excluded one study that reported results (i.e., codes derived from qualitative data) but did not report qualitative data (i.e. representative quotes).[20]

Finally, we conducted a quality appraisal per criteria from Carroll and colleagues.[21] Quality appraisal methods for qualitative research are subject to debate.[22] Researchers disagree on quality criteria and note that any appraisal is limited by the comprehensiveness of study reporting. Additionally, quality appraisal checklists for qualitative studies have demonstrated limited interrater reliability perhaps due to the subjective nature of certain criteria.[23] Given these issues, Carroll and colleagues have demonstrated that an assessment of "the auditability and transparency of the methods of each study" is an empirical, pragmatic, and likely sufficient form of appraisal. Adequately reported studies described at least two out of the following four elements: Study question and design, sampling approach, data collection methods, and data analysis methods (Table 1).[21] We concluded that a simpler quality appraisal approach would reduce the likelihood of excluding studies that were not clearly reported but might contain rich and relevant qualitative data.

The following data were extracted from included studies: Author name, date of publication, research question, study design, sampling strategy, data collection and analysis

methods, interview or focus group questions, and participant quotes. We also extracted conclusions that authors drew directly from participant quotes. We did not extract primary study results (i.e., concepts and conceptual models) because the unit of analysis in the "best fit" framework synthesis method is primary qualitative data (i.e., participant quotes)[24] .

Thematic Analysis

Two authors (MH and KT) conducted a thematic analysis[25] to synthesize qualitative data from included studies, using f4analyze software, version 3.1.1. The initial codebook consisted of the World Health Organization's (WHO) five adherence dimensions. In its 2003 report, the WHO described adherence as a "multidimensional phenomenon", determined by social and economic, health care system, condition-related, therapy-related, and patient-related dimensions.[26] For example, factors in the social and economic dimension include poverty, food insecurity, and social support. Broader theories, like Social Cognitive Theory, can explain adherence behavior with concepts from the WHO adherence framework. Additionally, Murali and colleagues used the WHO adherence framework to categorize RCTs in their systematic review and meta-analysis of hemodialysis treatment adherence interventions.[10]

One author (KT) completed initial coding (deductive process). Both authors independently reviewed the qualitative data and created a list of new codes and potential themes emerging from it (inductive process). The codebook and codebook structure were refined iteratively via discussion of the codes' conceptual definitions, explanatory power, and overarching themes. One author (KT) then re-coded the data using the refined codebook. A third author (SS) separately coded qualitative data from 20% of the articles to assess the coherence of each code and thoroughness of coding overall. Disagreements were resolved via discussion.

Results

Our search queries yielded 1775 unique articles. 12 studies were included in the "best fit" framework synthesis (Figure 2.1). Table 2.1 provides a summary of included articles as well as the results of our quality appraisal. All studies were adequately reported with one study [27] meeting three out of four criteria and 11 studies meeting four out of four criteria.

Figure 2.2 displays a new adherence framework for patients on hemodialysis derived from the WHO adherence framework and our inductive qualitative data analysis. Table 2.2 includes examples of representative qualitative data. The qualitative data revealed 20 factors (i.e., subcodes) unique to hemodialysis across the five WHO adherence dimensions. Additionally, two overarching themes emerged from the data: (1) Adherence in the context of a person's whole life and (2) dialysis treatment as a double-edged sword.

Adherence in the context of a person's whole life

Education or comprehension was a recurring code in nearly all studies. In some cases, people on hemodialysis described how education improved adherence, particularly when it helped them anticipate how dialysis, medications, or fluid and dietary nonadherence would make them feel.[28] Some people on hemodialysis found educational information confusing.[29] However, multiple authors noted that comprehension (or lack thereof) did not ultimately determine adherence behavior. Instead, people on hemodialysis explained adherence behavior in the context of their whole lives.

People described the perpetual challenge of balancing all aspects of ESKD treatment with family or social roles and logistics. For example, people balanced their hemodialysis treatment and work schedules [30]; paying for medication refills and other non-medical expenses[31]; and fluid or dietary restrictions and the desire to socialize with friends on holidays.[27] For some people, life balance was further complicated by financial strain which could be caused

or exacerbated by employment changes due to hemodialysis.[32] People described tradeoffs between food and medications to stretch inadequate finances and challenges with dietary adherence due to the cost of food (e.g., the relative cost of salt compared to more expensive salt substitutes).[33] Financial strain also contributed to psychological stress.[34] Financial strain and food insecurity were reported in studies that sampled exclusively or predominantly Black or Hispanic people.[29,32-34]

"Transportation" and "loss of function" were additional contextual factors that could impact hemodialysis treatment attendance or adherence to medications and dietary restrictions. For example, some people described feeling too weak at home to prepare healthy meals or eat.[29] Though these subcodes appeared infrequently, we included them as distinct subcodes because of their relevance in existing adherence literature.

Some people on hemodialysis perceived the disconnect between standard education and their individual circumstances and felt that education should be more tailored. For example, they believed that dietary recommendations should account for their limited finances or their perceived good health.[33,35] Contextual barriers to adherence were not always visible to dialysis clinicians and staff.[34] Instead, people reported seeking and receiving help from family and friends. Social support existed on a spectrum with some people managing medications, transportation, or dietary restrictions in partnership with family members and others relying on them completely.[30-32] People also self-managed ESKD treatment, at times in creative ways. For example, people struggling with food insecurity described purchasing groceries for the ESKD diet at "lower quality," cheaper grocery stores.[33] Others had unique strategies to organize their medications.[31]

Treatment as a double-edged sword

People on hemodialysis across multiple studies acknowledged that adherence to dialysis treatment, medications, and fluid or dietary restrictions could prolong their lives and alleviate negative symptoms.[28-30,36] However, people also described adherence as making them feel worse physically and some questioned the benefits or rationale for treatment.[37] Dialysis left some feeling tired, hungry, or "depleted."[29] People explained that strict dietary adherence made them too weak to function.[27] Many described intense food and fluid cravings that were so strong one patient "prayed to the Lord to take that taste [of fresh fruit]" from her.[29] Faced with treatment that could make them feel better or worse, people trusted a subjective sense of "feeling sick" to guide adherence behavior.[36]

Additionally, people on hemodialysis and family members grieved the life they had before dialysis initiation. They described their grief more frequently and richly than physical symptoms. Grief impacted nonadherence when people on hemodialysis missed treatment or tested food or dietary restrictions to preserve a sense of their self before dialysis.[27] Related but distinct from this grief process were affective responses to dialysis. People described feeling afraid watching their blood leave their bodies [32] and hated or "dreaded" dialysis like a "crummy job."[35] Though dialysis was life-saving, some people felt depressed or anxious about the future. One patient stopped making plans because she did not know when she would die.[38]

For some, a sense of comradery or belonging with other people on hemodialysis and dialysis facility staff could improve adherence. People described appreciating when clinicians "jumped on their case" when they "started messing up" like they were family.[28] Others navigated dialysis as a double-edged sword by adhering just enough to preserve a sense of self and stay alive.[28]

Integrating themes and codes with behavior theory to explain nonadherence

The WHO adherence framework that informed our framework synthesis does not detail causal pathways, and all but one qualitative study in this review used a qualitative descriptive design. Therefore, our adherence framework is descriptive and does not specify how adherence factors interact. However, the same grand theories of human behavior that inform existing adherence interventions can provide guidance.

Figure 2.3 depicts how adherence factors from our framework can be integrated into Social Cognitive Theory to explain adherence behavior. It also highlights mediating factors that have not been addressed in published adherence randomized controlled trials. Researchers have applied Social Cognitive Theory to design patient-level adherence interventions addressing knowledge, self-efficacy, or goal setting. However, Social Cognitive Theory positions knowledge as a precursor for health behavior and stresses the relevance of social and economic factors and outcome expectations, which are not routinely addressed in adherence related RCTs.

In Social Cognitive Theory, our theme "adherence in the context of a person's whole life" equates to socio-structural impediments (e.g., financial strain and food insecurity) and facilitators of adherence (e.g., support from friends and family). Our theme, "dialysis as a double-edged sword" speaks to individual outcome expectations and illuminates that people on hemodialysis do not always perceive the outcomes of adherence as positive. Lastly, Social Cognitive Theory clarifies that people adhere to treatment if adherence aligns with their goals. Both themes emerging from the qualitative data clarify that common goals among people on hemodialysis include balancing treatment and competing priorities, preserving a sense of their "old selves," and minimizing symptoms. At times these goals and adherence conflict.

Lastly, adherence intervention studies and some of the qualitative studies in this review address individual components of adherence, like fluid management or treatment attendance. However, the integration of themes and codes from our adherence framework with Social Cognitive Theory demonstrates that (1) the complexity of the ESKD regimen contributes to nonadherence and (2) adherence to the regimen as a whole occurs within the context of a combination of adherence factors unique to the individual person.

Discussion

Our qualitative synthesis identified 20 distinct factors associated with adherence among people on hemodialysis. Patient-level factors reflected in the qualitative data went beyond knowledge about hemodialysis treatment or motivation to adhere to treatment. The qualitative data helped to clarify how more general experiences of life on hemodialysis, such as grief and loss, impacted adherence behavior. Additionally, the qualitative data in this review confirmed the relevance of contextual factors beyond the patient level.

Our findings aligned with existing observational nonadherence research and added richness and context to observational study findings. For example, a comparison of cost-related medication nonadherence across 12 countries found that 29 percent of people on hemodialysis in the U.S. did not purchase medications due to cost, and that this proportion "significantly exceeded that in any other country."[39] A large cohort study of nearly 200,000 people on hemodialysis from one large dialysis organization demonstrated that odds of missing a treatment increased by 20 percent when they had depression or relied on van transportation. Additionally, people on hemodialysis were nearly twice as likely to miss dialysis treatments when scheduled on holidays or patients' birthdays.[40] The qualitative data detailing their decisions to miss treatment when they felt well enough or due to competing priorities may explain this finding.

Though some of the adherence factors in our framework have been previously described, many have not been addressed in previous intervention studies. In the systematic review and meta-analysis by Murali and colleagues, nearly all studies intervened at the individual level. For example, interventions included health contracts, cognitive behavioral therapy, and educational videos.[10] However, one-size-fits-all approaches to improving discrete elements of ESKD adherence among people on hemodialysis are likely inadequate.[41] Instead, our review suggests that adherence may improve when clinicians routinely elicit individuals' goals and partner to resolve conflicts between those goals and adherence. Clinicians can develop a therapeutic alliance so people feel comfortable sharing their experience and believe that sharing will make a difference in care.[42] Rather than discrete interventions, people on hemodialysis and their families likely need ongoing support as they navigate the logistical, physical, and psychological hardships of living with hemodialysis. Regarding social and economic factors, food provision may improve adherence for those experiencing food insecurity. A food program that provided 100 percent of daily energy requirements to people living with HIV or diabetes and experiencing food insecurity reduced depressive symptoms, sacrificing of food for healthcare, and sacrificing of healthcare for food. Antiretroviral adherence significantly improved.[43] However, clinic-level changes will not remedy upstream social and economic barriers to adherence. Rather, policy changes that counter long-term community disinvestment are required.

Despite a wealth of observational and intervention research on nonadherence among people on hemodialysis, new research is needed to guide a change in course. Murali and colleagues provide excellent recommendations for future intervention trials, such as developing interventions that could be feasibly implemented in practice and controlling for confounding variables when researchers use surrogate markers of adherence.[10] Multidimensional adherence

interventions rooted in patient experience can include qualitative arms to explain why interventions work when they do. Future intervention research should also apply conceptual models that incorporate race and explicitly address racial equity. Financial strain and food insecurity were important socioeconomic factors impacting adherence that emerged from qualitative studies sampling predominantly or exclusively non-White people on hemodialysis. Multiple studies have demonstrated associations between adherence and race, such that White people on hemodialysis have higher rates of adherence across different adherence measures.[40,44] A recent perspective piece by Mokiao and Hingorani argued that residential segregation and other forms of structural racism impact food security and subsequent racial disparities in chronic kidney disease incidence and progression.[45] The qualitative data in this synthesis suggest that social determinants of health, such as financial strain and food insecurity, may partially explain racial disparities in hemodialysis treatment adherence as well.

Our framework synthesis has some limitations. Though our search strategy was robust, we may have missed relevant literature. Researchers have described challenges in identifying qualitative studies via systematic review due to limitations in article indexing for qualitative methods.[46] Additionally, our parsimonious quality appraisal criteria may have resulted in the inclusion of "lower quality" studies that could bias our findings in theory. However, via iterative thematic analysis we discarded codes that lacked explanatory value.

Researchers have applied diverse methods to deepen our understanding of nonadherence among patients on hemodialysis. Yet high rates of nonadherence in U.S. have persisted for decades, signaling that more work is needed. Interventions involving unidirectional information sharing from clinician or expert to person on hemodialysis have demonstrated limited efficacy. The findings of this qualitative synthesis support a growing call that intervention

research must incorporate contextual factors, including social determinants of health, into interventional design.

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Tables and Figures

Table 2.1: Details from Included Studies

Study	Research Aim & Design	Sample	Data Collection & Interview/Focus Group Questions (Select)	Reported Data Analysis Method	Quality Appraisal of Methods Reporting
Boehmer et al., 2021[30]	To examine patient and healthcare practices associated with higher and lower levels of illness and treatment burden Explanatory mixed methods study; qualitative arm applied qualitative descriptive design	Purposive sample of 23 patients on ICHD and home modalities scoring high or low on illness and treatment burden scales English-speaking, no cognitive impairment	Semi-structured interviews "What does your typical full day look like on your dialysis days?" "What do you find are the biggest problems of being on dialysis?"	Grounded theory	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Chenitz et al., 2014[28]	To explore patient attitudes about dialysis, health beliefs related to missed treatments, barriers and facilitators to attendance Qualitative descriptive study	Purposive sample of 15 nonadherent and 15 adherent patients on ICHD On ICHD ≥ 6 months, ≥ 18 y/o, English-speaking	Semi-structured interviews "Can you tell me about what helps you make it to your treatments?" "If you were able to redesign the system, what would you like to see changed to make it easier for you to get dialysis"	Grounded theory	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Clark-Cutaia et al., 2019[33]	To explore barriers to following the hemodialysis diet Qualitative descriptive study	Purposive sample of 30 patients on ICHD enrolled in RCT, selected for "racial and economic and diversity" ICHD ≥ 3months, ≥ 18 y/o	Telephone interviews "What are the things that get in the way of eating a healthy diet?" "How does money influence whether or not you are able to follow the hemodialysis diet?"	Qualitative analysis per Crabtree and Miller (1999)	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Karolich and Ford, 2010[35]	To explore how older adults with ESKD attach meaning to their illness,	Purposive sample of 10 adults on ICHD scoring high	Semi-structured interviews	Interview responses grouped according to	✓ Study question & design ✓ Sampling approach

Study	Research Aim & Design	Sample	Data Collection & Interview/Focus Group Questions (Select)	Reported Data Analysis Method	Quality Appraisal of Methods Reporting
	and how that meaning is related to illness comprehension and management Concurrent mixed methods study; qualitative arm applied qualitative descriptive design	or low on Orientation to Life scale ICHD ≥ 6 months, ≥ 50 y/o	"What is the main reason you come to dialysis and follow the treatment plan prescribed by your doctor?"	concepts in the Orientation to Life Scale	✓ Data collection methods ✓ Data analysis methods
Krueger, 2009[37]	To explore Hmong experiences with hemodialysis & experiences of nurses working with Hmong patients Qualitative descriptive study	3 male Hmong patients on ICHD	Interviews during dialysis treatment Questions not reported	Thematic analysis	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
O'Brien, 1990[27]	To examine relationships between social support and compliance behavior among maintenance hemodialysis patients Explanatory mixed methods study; qualitative arm applied qualitative descriptive design	33 patients on ICHD enrolled in 9-year longitudinal cohort study ICHD approximately 12-18 months, ≥18 y/o; excluded patients with diabetes, cancer, heart disease, pulmonary disease, and psychiatric conditions	Interviews guided by the "Dialysis Patient Focused Interview Guide"	Not reported	✓ Study question & design ✓ Sampling approach ✓ Data collection methods X Data analysis methods
Parker et al., 2017[31]	To explore self-management strategies and experiences of medication management among patients on hemodialysis	13 patients on ICHD ≥18 y/o, English-speaking; excluded patients living in long term care or assisted living facilities	Semi-structured interviews with 1-2 patients at a time	Thematic and framework analysis	✓ Study question & design ✓ Sampling approach ✓ Data collection methods

Study	Research Aim & Design	Sample	Data Collection & Interview/Focus Group Questions (Select)	Reported Data Analysis Method	Quality Appraisal of Methods Reporting
	Qualitative descriptive study				✓ Data analysis methods
Robinson et al., 2019[29]	To explore Black older adults' experiences living with ESKD and on dialysis Qualitative descriptive study	Purposive sample of 16 Black patients on ICHD ≥ 65 y/o, oriented to person, place, time	Interviews during dialysis treatment or at participants' homes "Tell me about your experience with end stage renal disease"	Thematic analysis	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Smith et al., 2010[36]	To describe patient experiences with fluid management to guide adherence interventions Qualitative descriptive study	Convenience sample of 19 patients on ICHD ≥ 18 y/o, English-speaking, able to give informed consent	Focus groups "What makes you feel more confident in your ability to meet your fluid goals?"	Content analysis	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Senteio and Veinot, 2014[34]	To describe the "work" of adherence among African Americans who live in high-poverty communities and how "visible" it is to healthcare providers Qualitative descriptive study	Purposive sample of 37 patients with at least two of the following: hypertension, diabetes, chronic kidney disease (including on ICHD) Participants represent gender, age, racial composition of urban population in a U.S. state	Semi-structured interviews in private locations Questions not reported	Straussian grounded theory systematic approach	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods
Tijerina, 2009[38]	To explore psychosocial, cognitive, and cultural factors that shape	Purposive sample of 26 Mexican American women on ICHD	Interviews in patients' homes Questions not reported	Thematic analysis from social	✓ Study question & design ✓ Sampling approach

Study	Research Aim & Design	Sample	Data Collection & Interview/Focus Group Questions (Select)	Reported Data Analysis Method	Quality Appraisal of Methods Reporting
	adherence behavior in Mexican American women Qualitative descriptive study	ICHD ≥ 6 months, 30-55 y/o		constructivist perspective	✓ Data collection methods ✓ Data analysis methods
Wells, 2015[32]	To explore occupational changes and perceptions experienced by Mexican Americans with ESKD and their families living with dialysis. Phenomenological design	17 Mexican American patients with ESKD and their family members Patients on ICHD ≥ 6 months	Semistructured interviews at dialysis center or patients' homes Questions not reported	Thematic analysis	✓ Study question & design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods

ICHD In-center hemodialysis

Table 2.2: Factors Impacting Adherence for People on Hemodialysis with Supporting Qualitative Data

Social and economic factors	
Financial strain	"*Sometimes I skip my medicine. It's just another day or a couple days and then I'll just go ahead instead of going to get my medicine if I am going somewhere with somebody, I will keep those $2.00 to get something I can stretch for a long time. Like the ground beef I can make something I can eat two or three times."* [Clark-Cutaia et al., 2019 [33]] *"Right now I think the cost [of medications] is astronomical for us . 'Cause I take multiple pills. The pharmacist will say, 'Do you realize how much this is?,' and I said, 'It doesn't matter.' I put it on the credit card and you gotta have it. You gotta have it. The phosphorus binders are ridiculous."* [Parker et al., 2017 [31]]
Food insecurity	*"Well I ain't gone (sic) starve myself to death. I'll do what I can to follow that diet, but if I can't afford it, then I eat what I can. It is just that simple."* [Robinson et al., 2019 [29]]
Support from friends or family	And if I look at it and the day is going by and I didn't take no pills, I go, 'Uh oh, I forget to take my pill.' 'Cause sometimes she's not around, my wife, and when she comes back and they're in there. Oh boy, does she jump on me. She jumps all over me." [Parker et al., 2017 [31]]
Support from peers	*"You know you gone (sic) feel kinda down… But you know since I been coming here everybody that waits on you is so nice and then you get used to the people you come in with. That helps a whole lot."* [Robinson et al., 2019 [29]]
Health system related	
Support from clinicians	*"They make it feel like I'm at home almost. They provide that level of comfortability. And when—and just like at home, you know, you start messing up, and they always jumping on your case."* [Chenitz et al., 2014 [28]]
Patient and family education or comprehension	*"They speak in a Latin tongue and I don't understand. I have to say, 'Wait a minute. What do you mean by that?' And they just jibber, jibber, jibber."* [Robinson et al., 2019 [29]] *"My attendance is better, way better than it was . . . Because I was told in—well, they told me, you know, that I need it, and they gave me some reasons why, you know. They said, now, you know how you was feeling before you started getting it. Just imagine if you stop getting it, you know, and it made sense."* [Chenitz et al., 2014 [28]]
Transportation to/from dialysis	*"Sometimes I have to sit and wait at least an hour and I have to call and say my ride is not here yet, which makes me late getting there, which makes me late getting on the machine, which makes me late getting off the machine. And then . . . coming to pick you up, if you're not ready when they get there, they will leave you and you'll have to sit and wait and wait and wait"* [Chenitz et al., 2014 [28]]
Condition-related factors	

Disability or loss of function	"*I can't even make up my bed. Ah, I can't sweep my floor, now I can't even ah, fix my lunch, put it on a plate and put it in the refrigerator…Some days I'm too weak to even put it in the microwave and warm it and to eat it. I feel wore out."* [Robinson et al., 2019 [29]]
Feeling/not feeling sick	*"What really helps me [adhere to a fluid restriction] is remembering what it's like to not breathe."* [Smith et al., 2010 [36]] *"I understand, they are saying that certain foods are not good for you. You know for your kidneys, but I haven't been observing that too much. I like going by trial and error. I like to go with how I feel*." [Clark-Cutaia et al., 2019 [33]] *"At first I followed the diet rigorously but I just found myself getting weaker and weaker. I found that by eating more I felt better. I don't go way off the diet though, only within the bounds of what I know I can do."* [O'Brien, 1990 [27]]
Therapy-related factors	
Life sustaining nature of dialysis	*"I don't like it, but you know, it keeps me alive, so I got to do it."* [Chenitz et al., 2014 [28]] *"The machine and that tech in there are my crutch. I know I can come in and they are going to take care of it [excess fluid]."* [Smith et al., 2010 [36]]
Treatment makes you feel worse/questioning treatment	*"The thing that bothers me is the medicine they give me to help me, but then I take them and they should make me feel better and have a better appetite, but I don't feel better, and I'm just sort of worried about that. And if the medicine that will help me doesn't help me, I don't want to take it anymore."* [Krueger, 2009 [37]]
Length of dialysis	*If you don't eat before you get up and get out, and then you're hungry when you get out, and there really isn't a place where you can get some regular food. You might go to McDonald's and all that fast food really isn't good for you."* [Clark-Cutaia et al., 2019 [33]]
Craving food or fluid	*"It's like when you're on a diet and you are not supposed to eat. When you are not supposed to drink, that's all you think about."* [Smith et al., 2010 [36]]
Complexity of treatment	*"I get stuck on one thing like trying to watch my protein or my phosphorous and I'll forget about the other stuff."* [Smith et al., 2010 [36]]
Patient-related factors	
Hating, fearing, or dreading dialysis	*"Dialysis is like a crummy job, the people here aren't nice, and the other people on dialysis are depressing. I have to drag myself here. I hate it."* [Karolich and Ford, 2010 [35]]
Depression or anxiety about the future	*"I'm always thinking what kind of life I'm gonna have. Am I going to be okay? Is dialysis really going to work for me? Before, I had a very good attitude about life, but now . . . I worry constantly."* [Tijerina, 2009 [38]]
Grief over/acceptance of loss of old self	*"All my friends. All of 'em. As soon as I got sick and had to quit drinking and wasn't hanging out in the bars and wasn't doing physical things anymore, all of 'em, they went their direction and I went my direction. I don't see anybody anymore at all, which is too bad. That's the way it worked out, but what do you do when you're no fun anymore? You don't do*

	anything fun. You're not fun. We're going to where we can have fun. Okay. I can't blame 'em. I might be the same way if I was in their situation." [Boehmer et al., 2021 [29,30]] *"It was terrible, I almost went crazy, because I couldn't accept it….but after praying and meditating with the Lord, I learned to accept it….To tell you the truth I was supposed to be a Christian, and my husband was not saved. He kinda pushed me through it, because he said, 'Now look, if I can understand it, ah, what the Lord is doing to you, why you can't understand it?"* [Robinson et al., 2019 [29]]
Balancing treatment and life	*"I would imagine, too, for some people, not me personally, but balancing work and dialysis would be hard because some employers just don't understand how important it is. I've heard horror stories of bosses who really don't know that it's a life and death situation, and they make people work, but for me personally, my employers always worked very well with whatever I had."* [Boehmer et al., 2021 [27,30]] *"Once in a while you have got to go out and have a beer and pizza with your friends. You can do it if you watch what you eat the day before, and then, too, you only have one piece of pizza and one glass of beer."* [O'Brien, 1990 [27]]
Desire for tailored treatment	*"Everybody is different. Our needs are different. You have to respond to the people who have the means and the ones that [don't] have the means. You know what I mean?"* [Clark-Cutaia et al., 2019 [33]]
Self-management strategies	*"Well what I do is the pills that have two a day, I write on the top of it '2' with a marker. And the ones that have one, I put '1' on it. They're mostly all to do with one day, two a day or one a day. So that's how I line them up and in the morning I take the ones that are two a day, I take one of each, and then at noon-time I take the rest of the other ones for one a day."* [Parker et al., 2017 [31]]

Figure 2.1: Flow Diagram of Literature Search and Selection

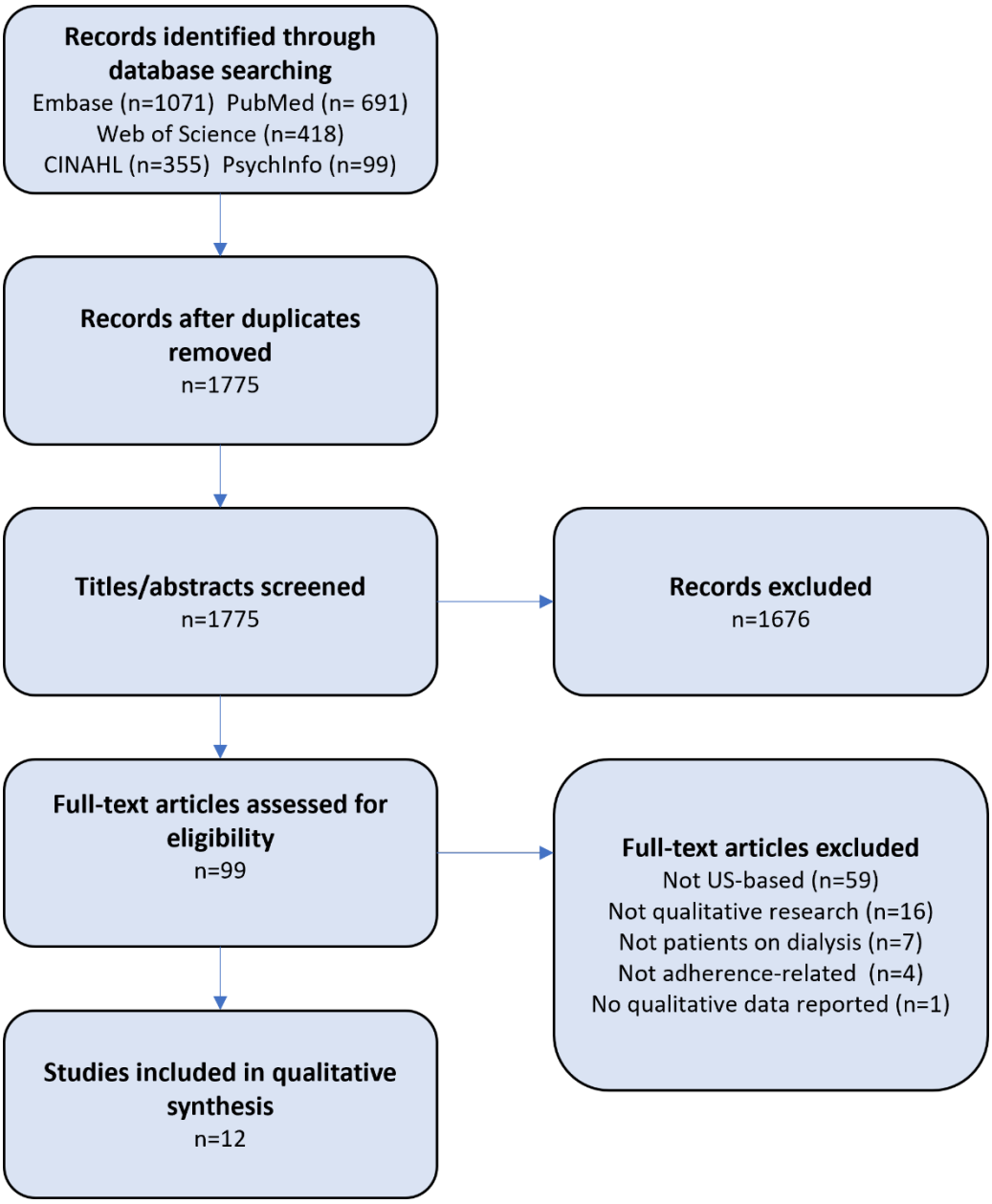
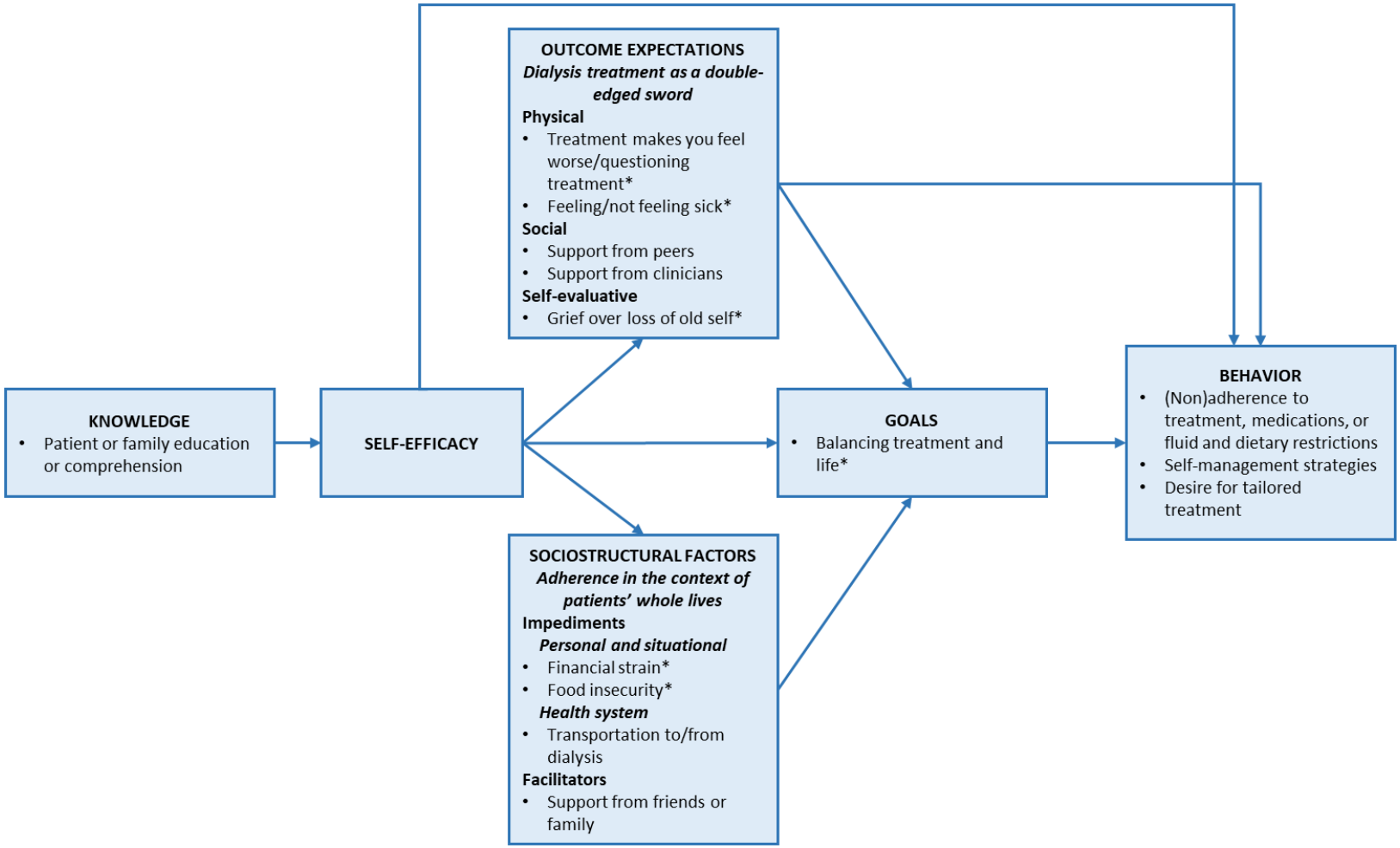


Figure 2.2: Adapted WHO Adherence Framework for People on Hemodialysis

Figure 2.3: Integration of Social Cognitive Theory and Select Adherence Factors Emerging from the Qualitative Data



Adapted from Bandura[47]

***Mediating adherence factors and relationships unaddressed in published RCTs**

CHAPTER 3: Material Need Insecurities among People on Hemodialysis: Burden, Sociodemographic Risk Factors, and Associations with Substance Use

Abstract

Background: Despite their relevance to health outcomes, previous research has not reported food insecurity and housing instability rates among adults on hemodialysis. Additionally, associations between substance use disorder and material need insecurities among people on hemodialysis have not been established. Sociodemographic risk factors in the general public may not apply to the hemodialysis population.

Methods: We enrolled a convenience sample of people receiving hemodialysis at Baltimore and Washington D.C. metropolitan area facilities. Participants completed a survey with measures of socioeconomic position, food security, housing instability, and substance use disorder. We cross referenced participant and facility zip codes with measures of area poverty and residential segregation. We examined associations between individual- and area-level sociodemographic characteristics, food insecurity, and housing instability with logistic regression models. We used Chi-squared tests to examine associations between material need insecurities and substance use disorder.

Results: People on hemodialysis who were younger, less educated, with lower incomes or experiencing financial strain were more likely to experience material need insecurities. In contrast with the general population, our study did not find an association between race and material need insecurities, though residential segregation increased risk of food insecurity for younger people and men who were predominantly Black. People on hemodialysis experiencing food insecurity were more likely to report moderate or high-risk tobacco use. A higher proportion of people experiencing food insecurity also endorsed moderate or high-risk use of cannabis and other drugs, though the association was not statistically significant.

Conclusion: Food insecurity, housing instability, and substance use are common among people on hemodialysis. Younger people on hemodialysis, particularly those living in residentially

segregated areas, are at increased risk for food insecurity. Future research should examine whether material need insecurities perpetuate health disparities among people on hemodialysis.

Introduction

Food insecurity and housing instability are material need insecurities associated with worse chronic disease outcomes[1] including progression of chronic kidney disease.[2,3] Food insecurity is defined as "a limited or uncertain availability of nutritionally adequate and safe foods"[4] and housing instability is characterized by "housing that is high-cost, overcrowded, or dangerous."[5] Food insecurity and housing instability may be persistent but are often transient,[6,7] resulting from stressors to household budgets as seen at the start of the COVID-19 pandemic.[8] For people with end-stage kidney disease, hemodialysis may be another such stressor due to employment and income loss related to thrice-weekly treatment.[9] Despite their relevance to health outcomes, previous research has not reported the burden of food insecurity and housing instability among adults on hemodialysis.

Additionally, sociodemographic risk factors for food insecurity or housing instability among people on hemodialysis remain unclear. In the U.S. general population, Black and Hispanic households and households with incomes below 185% of the federal poverty level are more likely to experience food insecurity.[10] U.S. Census Household Pulse Surveys indicate that a higher proportion of Black and Hispanic respondents faced challenges paying for housing since the start of the COVID-19 pandemic.[11] However, sociodemographic risk factors for food insecurity or housing instability in the general public may not apply to the hemodialysis population. Unlike the general population, nearly all people on hemodialysis have health insurance and thrice-weekly touch points with the health care system. They are also relatively older, disproportionately Black, and living with a greater burden of multimorbidity. Moreover, area-level variables such as neighborhood poverty or residential segregation may contextualize individual-level sociodemographic differences in material need insecurities.[12,13]

Substance use disorder; defined as recurrent substance use causing clinically significant impairment, including health problems; and material need insecurities co-occur and may be mutually reinforcing.[14] Research with other patient populations (e.g., people living with HIV[15], pregnant women[16], veterans[17]) has quantified associations between substance use disorder and material need insecurities and examined the moderating effect of food insecurity on associations between substance use disorder and health behaviors.[18] Though a limited body of research has explicitly studied people on hemodialysis who use substances,[19] associations between substance use disorder and material need insecurities among people on hemodialysis have not been established.

Therefore, important gaps exist in our understanding of risk factors for clinically relevant material need insecurities among people on hemodialysis. The current study aims to address these gaps by (1) quantifying the burden of food insecurity and housing instability, (2) identifying individual and area-level sociodemographic risk factors for food insecurity and housing instability, and (3) examining associations between food insecurity, housing instability, and substance use disorder among people on hemodialysis.

Methods

We report cross-sectional analyses of baseline survey data from our prospective cohort study testing associations between food insecurity, housing instability, substance use disorder and hospitalization among people on hemodialysis. People on hemodialysis were eligible for the cohort study if they were age 18 or older, had been on chronic hemodialysis for at least three months, and could provide a high-level explanation of study purpose and procedures after informed consent. We enrolled a convenience sample of people receiving hemodialysis at Baltimore and Washington D.C. metropolitan area facilities within the same large dialysis organization. In early 2021 due to operational changes within dialysis facilities in response to

COVID-19, we identified potential participants via nephrologist referral. After dialysis facilities completed COVID-19 vaccination campaigns in spring 2021, a study team member screened interested people for eligibility in-person prior to hemodialysis treatment. Survey data collection occurred from February 2021 to December 2021.

Survey data included participant zip code, demographics, and indicators of socioeconomic status (e.g., education level and income). To assess financial strain, one item asked participants how their finances usually worked out at the end of the month. We anticipated that some participants may not want to identify their income bracket and that financial strain would be a better risk factor for material need insecurities. We cross-referenced participant zip codes with area-level poverty rates from the 2020 American Community Survey. Lastly, we obtained county-level Dissimilarity Index scores from County Health Rankings and Roadmaps (countyhealthrankings.org). The Dissimilarity Index is a measure of Black-White residential segregation and represents the proportion of the population that would have to relocate within the county for the distribution of Black and White residents to become even.

We selected validated measures that clinicians could use for screening in a healthcare setting. We assessed participants' level of food security using the U.S. Department of Agriculture (USDA) Adult Food Security Survey Module[20]; housing instability with a 2-item screener for risk of imminent homelessness developed by the U.S. Department of Veterans Affairs[21]; and substance use disorder with the World Health Organization's Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST).[22] The ASSIST is a screening tool for substance use disorder that categorizes substance use as low, moderate, or high-risk based on its impact on individuals' health. Additionally, measures of food security and substance use disorder included skip patterns to reduce response burden. Each measure demonstrated excellent internal consistency. Cronbach's alpha for the USDA Adult Food Security Survey Module was 0.92 in the

sample. The KR-20 coefficient for the dichotomous U.S. Department of Veterans Affairs screener was 0.9. Cronbach's alphas for each of the 9 substance risk scales in the ASSIST ranged from 0.73 to 0.9.

Participants had the option of completing a paper survey independently during hemodialysis treatment or scheduling a telephone interview. A study team member was available in the facility waiting room to collect completed paper surveys, clarify survey items, and check surveys for completeness. Most participants completed the survey in approximately 20 minutes. Participants received a 20$ Visa gift card. Two study team members entered survey data into separate Excel spreadsheets to ensure data entry accuracy. A third team member resolved discrepancies in data entry comparing entries to paper surveys. The Johns Hopkins Medicine Institutional Review Board and the dialysis organization's research protocol review committee approved the study.

Statistical Methods

We used Stata version 17.0 to conduct statistical analyses. We examined descriptive statistics for exposure and outcome variables. We calculated scores for food security and substance use risk from the mean of non-missing responses if participants answered at least 70% of scale items. Less than 5% of participants had a missing food security score after imputation. The rate of missing substance use risk scores varied by substance and ranged from 3.28% for amphetamine, inhalants, or sedatives use to 14.75% for alcohol use. Less than 2% of the sample had a missing homelessness risk screener. Distributions for food security and substance use risk scores were right skewed. We generated categorical variables for high, marginal, low, or very low food security using cutoffs from the USDA. We applied cutoffs from the World Health Organization to create categorical variables for low, moderate, or high-risk use of any of the nine substances included in the ASSIST, except for alcohol use. The World Health

Organization categorizes substance risk scores greater than three as moderate risk for all substances except alcohol, which has a cutoff for moderate risk at 11. We coded alcohol risk scores greater than three as moderate risk given that even lower frequency alcohol use may be harmful to people on hemodialysis. Finally, we created a binary variable for a negative or positive screen for risk of imminent homelessness as described by the U.S. Department of Veterans Affairs.

We collapsed participant subgroups with less than 20 members to improve statistical power and generated binary area-level variables with median values as cut points. We conducted chi-squared tests and bivariate logistic regression to examine associations between individual-level sociodemographic characteristics, level of food security, and risk for imminent homelessness. For area-level predictors we used a mixed effects logistic regression model to account for clustering by zip code (poverty) or dialysis facility (residential segregation). We then generated multivariate logistic regression models adjusting for age, gender, and race. We also conceptualized area-level poverty and residential segregation as structural determinants that might differentially expose demographic subgroups to material need insecurities, and we explored interactions across individual and area-level risk factors. Finally, we conducted chi-squared tests to examine associations between food insecurity or housing instability and substance use risk scores.

Results

We enrolled 322 participants across 17 dialysis facilities. 305 participants completed the survey (95% response rate). Participant ages ranged from 27 to 86 years with a mean age of 60. Men comprised 57% of the sample. 70% of the sample identified their race as Black. 5.5% of the sample identified their ethnicity as Hispanic.

Of the 293 participants who received a food security score, 13.3% reported marginal food security, 12.6% reported low food security and 9.9% reported very low food security in the previous 12 months. Participants with very low food security ate less than they felt they should or went hungry because there was not enough money for food. Of the 300 participants who completed the 2-item screener for risk for imminent homelessness, 54 (18%) reported that they did not have a home of their own where they felt safe in the last 90 days or were worried that they would not have one in the next 90 days. 60% of participants who screened positive for risk for imminent homelessness also reported marginal, low, or very low food security. Approximately 30% of those reporting marginal, low, or very low food security also screened positive for risk for imminent homelessness. Overall, 32 participants (10.5% of the sample) reported both material needs insecurities.

Table 3.1 displays frequency of marginal, low, or very low food security and positive homelessness risk screenings by sample characteristics. We refer to marginal, low, or very low food security as "food insecurity" for the remainder of this chapter. **Table 3.2** displays odds ratios of food insecurity and positive homelessness risk screening across sample subgroups, adjusted for age and gender. For each odds ratio, subgroups with the lowest risk for food insecurity serve as the referent.

Younger age was a risk factor for food insecurity and risk for imminent homelessness. Participants in the youngest age group (ages 27 – 54) had a nearly 3-fold increase in odds of food insecurity compared to participants in the oldest age group (ages 67 – 86) after adjusting for gender and race (aOR 2.65, 95% CI 1.39 – 5.03). Male participants had nearly a 50% increased odds of food insecurity after adjusting for age and race, but this association did not reach statistical significance (aOR 1.44, 95% CI 0.86 – 2.43). There was no association between gender and risk for imminent homelessness (OR 0.95, 95% CI 0.51 – 1.78). Compared to White

participants, Black participants had a 60% increased odds of food insecurity after adjusting for age and gender, but this association did not reach statistical significance (aOR 1.6, 95% CI 0.8 – 3.19). A small number of Hispanic participants were enrolled in the study (n = 17). Though Hispanic ethnicity was associated with food insecurity in bivariate analyses, the association attenuated after adjustment (aOR 1.16, 95% CI 0.82 – 4.45).

As expected, income, financial strain, and educational level were risk factors for food insecurity and screening positive for risk for imminent homelessness. For example, participants who did not graduate from high school had a 2-fold increase in odds of food insecurity and a 3-fold increase in odds of risk for imminent homelessness compared to participants with at least some college education (aOR 1.94, 95% CI 0.94 – 4.05 and aOR 3.06, 95% CI 1.2 – 7.67, respectively). Marital status was associated with food insecurity but not risk for imminent homelessness. Compared to participants who were married or cohabitating, participants who were divorced, separated, or widowed had a nearly 3-fold increased odds of food insecurity (aOR 2.79, 95% CI 1.42 – 5.47).

Black participants were more likely to live in zip codes with higher poverty rates and in more residentially segregated counties. 38% of Black participants lived in zip codes with the highest poverty rates, compared to 16% of White participants (OR Black:White 2.26, 95% CI 1.31 – 3.92). 47% of Black participants lived in more segregated counties compared to 11% of White participants (OR Black:White 4.65, 95% CI 2.42 – 8.92). Participants living in zip codes with the highest poverty rates had a 2-fold increase in odds of food insecurity compared to participants living in zip codes with the lowest poverty rates (aOR 1.95, 95% CI 0.99 – 3.84). The association between neighborhood poverty rate and risk for imminent homelessness had a similar effect size but did not reach statistical significance (aOR highest poverty rate:lowest poverty rate 1.98, 95% CI 0.67 – 5.86). In unadjusted analysis, residential segregation was associated with food

insecurity. Participants living in more segregated counties had a 70% increase in odds of food insecurity compared to those living in less segregated counties (OR 1.69, 95% CI 1.03 – 2.78). This association was attenuated after controlling for age, gender, and race (aOR 1.3, 95% CI 0.73 – 2.33).

Residential segregation moderated associations between age, gender, and food security (interaction term p-values 0.09 and 0.01, respectively). Interaction term p-values for associations between race and area-level variables were not interpretable due to the very small number of non-Black people living in more segregated areas (n=11). In supplementary analyses, we examined associations between individual-level demographic variables and material need insecurities stratified by residential segregation (**Supplementary Materials**). Participants aged less than 55 living in more segregated areas had a 3-fold increased odds of food insecurity compared to older participants after adjusting for gender and race (aOR 3.28, 95% CI 1.36 – 7.93). We did not observe this association in less segregated areas (aOR 1.2, 95% CI 0.59 – 2.46). Among participants living in more segregated areas, men had nearly a 4-fold increased risk of food insecurity compared to women after adjusting for age and race (aOR 3.66, 95% CI 1.48 – 9.05). However, men living in less segregated areas did not have increased risk for food insecurity compared to women (OR 0.84, 95% CI 0.43 – 1.61). We observed similar trends for risk for imminent homelessness, but interaction terms were not statistically significant at $p<0.05$.

Table 3.3 displays food security and risk for imminent homelessness by substance and level of substance use risk. Of the 296 participants who received a substance risk score, 92 (31%) reported substance use that presented a moderate or high risk to their health. 9 (3%) reported high-risk use of any substance (i.e., daily use, difficulty cutting back, strong urge to use). Participants most frequently reported moderate or high-risk use of tobacco (22.2%) , alcohol

(16.9%), and cannabis (11.6%). Lower food security was associated with moderate or high-risk tobacco use (X^2 5.31, p-value 0.02). A higher proportion of participants with lower food security reported moderate or high-risk use of cannabis and other drugs, but associations did not reach statistical significance (X^2 2.99, p = 0.08). There were no statistically significant associations between risk for imminent homelessness and substance use.

Discussion

To our knowledge, this study is the first to report material need insecurities and substance use disorder in a sample of adults on hemodialysis. Estimates of food insecurity were higher than the national average. Nationwide, 3.8% of households experienced very low food security in 2021.[10] Nearly 10% of people in our sample reported very low food security during the same timeframe. We cannot make direct comparisons between housing instability rates in our study sample and the general population due to differences in housing instability measures. However, 15% of respondents to the U.S. Census Household Pulse Survey reported it was "very likely" they would be evicted within the next 2 months in August of 2021.[23] Nearly 20% of people in our sample did not have a safe home of their own or were worried they may not have a safe place to live in the immediate future.

People on hemodialysis who were younger, less educated, with lower incomes or experiencing financial strain were more likely to experience material need insecurities. Hispanic people on hemodialysis may be at increased risk for food insecurity but the study lacked sufficient power to detect associations between material need insecurities and ethnicity. In contrast with the general population, our study did not find an association between race and material need insecurities, though residential segregation increased risk of food insecurity for younger men who were predominantly Black. Conceptual models of food security resilience may explain the disproportionate burden of food insecurity among younger people and socially

disadvantaged subgroups on hemodialysis. Food security resilience models position food security as a function of stressors at the micro-level (e.g., divorce) or the macro-level (e.g., COVID-19 or inflation) and individual and community-level resilience capacities.[24] Hemodialysis initiation may restrict individual food security resilience capacity through loss of income, health care costs, and strain on social support networks. The impact may be more pronounced for younger people who may not have accumulated wealth but have not aged into federal retirement programs and may not be eligible for disability programs. Additionally, residential segregation affects individual and community-level food security resilience. For people on hemodialysis living in residentially segregated areas, hemodialysis initiation may perpetuate cumulative disadvantage over the life course.[25] At the community level, community disinvestment in residentially segregated areas may result in limited access to healthy foods.[26]

The disproportionate burden of material need insecurities among younger people and men on hemodialysis in high poverty or residentially segregated areas may partially explain racial disparities in hospitalization.[27] In a recent cross-sectional study of Medicare Advantage beneficiaries aged 65 and older, food insecurity and housing instability were associated with increased all-cause hospitalizations.[28] In a small cohort study of children with end-stage kidney disease on hemodialysis or peritoneal dialysis, children experiencing food insecurity had a higher rate of unplanned hospitalizations in the 12 months prior to screening.[29] Future research should examine associations between material need insecurities and health outcomes among adults on hemodialysis.

People on hemodialysis have thrice-weekly contact with the health care system. Our findings highlight the need for person-centered health care and proactive, routine screening for material need insecurities. Additionally, we found that people on hemodialysis experiencing food insecurity were more likely to report moderate or high-risk tobacco use. A higher

proportion of people experiencing food insecurity also endorsed moderate or high-risk use of cannabis and other drugs, though the association was not statistically significant. For people on hemodialysis with material need insecurities, a comprehensive harm reduction approach can include screening for substance use. Clinicians within dialysis facilities are logistically well-positioned to intervene on material need insecurities but may lack the time, training, or resources to do so effectively. New models of care delivery, dissemination of best practices, and food and housing subsidies specifically for people on hemodialysis may help address these gaps.

This study has some important limitations. Food security, housing instability, and substance use distributions were each right skewed. We recruited participants directly from hemodialysis facilities and may not have enrolled people on hemodialysis with the highest burden of material need insecurities or substance use disorder who would be less connected to care. Lack of variability in dependent variable distributions limited statistical power to identify subgroup differences in material need insecurities and levels of substance use risk. Additionally, people on hemodialysis with Hispanic ethnicity were underrepresented in the sample. Lastly, we measured food insecurity and housing instability once, but material need insecurities change over time. Future research should repeat analyses with larger subgroup sample sizes and repeated measures.

Conclusions

In this cross-sectional analysis of people on hemodialysis in the Baltimore and Washington, D.C. metropolitan areas, self-reported food insecurity, housing instability, and substance use were common, particularly among socially disadvantaged subgroups. Future research should examine whether material need insecurities perpetuate health disparities among people on hemodialysis.

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Tables and Figures

Table 3.1: Characteristics of People on Hemodialysis by Food Security and Risk for Imminent Homelessness (n = 305) [1]

Sample Characteristics	Food Security			Risk for Imminent Homelessness		
	High N(%)[2]	Marginal, Low, or Very Low N(%)	X^2 p-value	Negative Screen N(%)	Positive Screen N(%)	X^2 p-value
Total Sample	188 (64.16)	105 (35.84)		246 (82)	54 (18)	
Age Group (years)			**0.002**			0.11
67 – 86	75 (77.32)	22 (22.68)		85 (89.47)	10 (10.53)	
55 – 66	60 (65.22)	32 (34.78)		77 (78.57)	21 (21.43)	
27 – 54	52 (53.61)	45 (46.39)		80 (80.81)	19 (19.19)	
Gender			0.09			0.99
Female	86 (69.92)	37 (30.08)		103 (82.40)	22 (17.6)	
Male	100 (60.24)	66 (39.76)		140 (82.35)	30 (17.65)	
Race			0.38			0.4
White	39 (72.22)	15 (27.78)		171 (81.82)	7 (12.73)	
Black	128 (62.44)	77 (37.56)		48 (87.27)	38 (18.18)	
Asian, AIAN, NHPI, or >1 race	15 (68.18)	7 (31.82)		18 (75)	6 (25)	
Ethnicity			**0.04**			0.45
Non-Hispanic	178 (65.68)	93 (34.32)		227 (82.55)	48 (17.45)	
Hispanic	6 (40)	9 (60)		12 (70.59)	5 (29.41)	
Income			**<0.001**			**0.04**
>=$25,000/year	73 (83.91)	14 (16.09)		79 (87.78)	11 (12.22)	
<$25,000/year	57 (53.27)	50 (46.73)		82 (76.64)	25 (23.36)	
Financial Strain			**<0.001**			**<0.001**
Some money left over	84 (84)	16 (16)		93 (93)	7 (7)	
Just enough to make ends meet	55 (64.71)	30 (35.29)		74 (84.09)	14 (15.91)	
Not enough to make ends meet	22 (35.48)	40 (64.52)		41 (63.08)	24 (36.92)	
Education Level			**0.006**			**0.03**

Sample Characteristics	Food Security			Risk for Imminent Homelessness		
	High N(%)[2]	Marginal, Low, or Very Low N(%)	X^2 p-value	Negative Screen N(%)	Positive Screen N(%)	X^2 p-value
Post-High School	74 (67.89)	35 (32.11)		98 (89.09)	12 (10.91)	
High School	89 (68.99)	40 (31.01)		105 (80.15)	26 (19.85)	
Less than High School	25 (45.45)	30 (54.55)		43 (72.88)	16 (27.12)	
Marital Status			0.06			0.36
Cohabitating or Married	74 (72.55)	28 (27.45)		90 (86.54)	14 (13.46)	
Divorced, Widowed, or Separated	54 (56.25)	42 (43.75)		77 (80.21)	19 (19.79)	
Never Married	54 (63.53)	31 (36.47)		70 (79.55)	18 (20.45)	

[1] Cell totals may not add to event total due to missing sample characteristics data

[2] All percentages correspond to row totals

Table 3.2: Adjusted Odds Ratios[1] for Lower Food Security or Positive Homelessness Risk Screen

Sample Characteristics	Food Insecurity *N = 105*			Positive Homelessness Risk Screen *N = 54*		
	Adjusted OR	**95% CI**	**p-value**	**Adjusted OR**	**95% CI**	**p-value**
Age Group (years)						
67 – 86	(ref)			(ref)		
55 – 66	1.86	0.97 – 3.6	0.06	**2.65**	**1.24 – 6.14**	**0.03**
27 – 54	**2.65**	**1.39 – 5.03**	**0.003**	2.21	0.93 – 5.22	0.07
Gender						
Female	(ref)			(ref)		
Male	1.44	0.86 – 2.43	0.17	0.95	0.51 – 1.78	0.88
Race						
White	(ref)			(ref)		
Black	1.6	0.8 – 3.19	0.18	1.38	0.57 – 3.33	0.47
Asian, AIAN, NHPI, or >1 race	1.31	0.43 – 3.96	0.64	2.21	0.65 – 7.54	0.2
Ethnicity						
Non-Hispanic	(ref)			(ref)		
Hispanic	1.16	0.82 – 4.45	0.83	0.35	0.04 – 2.92	0.33
Income						
>=$25,000/year	(ref)			(ref)		
<$25,000/year	**4.38**	**2.15 – 8.91**	**<0.001**	2.16	0.96 – 4.84	0.06
Financial Strain						
Some money left over	(ref)			(ref)		
Just enough to make ends meet	**2.82**	**1.36 – 5.87**	**0.006**	2.5	0.95 – 6.58	0.06
Not enough to make ends meet	**7.6**	**3.4 – 16.78**	**<0.001**	**5.7**	**2.16 – 15.03**	**<0.001**
Education Level						
Post-High School	(ref)			(ref)		
High School	0.87	0.48 – 1.58	0.65	2.02	0.92 – 4.46	0.08
Less than High School	1.94	0.94 – 4.05	0.08	**3.06**	**1.2 – 7.67**	**0.02**
Marital Status						

Sample Characteristics	Food Insecurity *N = 105*			Positive Homelessness Risk Screen *N = 54*		
	Adjusted OR	**95% CI**	**p-value**	**Adjusted OR**	**95% CI**	**p-value**
Cohabitating or Married	(ref)			(ref)		
Divorced, Widowed, or Separated	**2.79**	**1.42 – 5.47**	**0.003**	1.89	0.83 – 4.28	0.13
Never Married	1.52	0.78 – 3	0.22	1.63	0.72 – 3.68	0.24
% Below FPL[2]						
0% – 7.4%	(ref)			(ref)		
7.8 – 15.6%	1.47	0.77 – 2.82	0.25	2.38	0.9 – 6.29	0.08
17% – 36.3%	1.95	0.99 – 3.84	0.05	1.98	0.67 – 5.86	0.22
Dissimilarity Index[2]						
Below Median (38 – 61)	(ref)			(ref)		
Above Median (67)	1.38	0.8 – 2.4	0.25	1.27	0.56 – 2.86	0.57

[1] Multivariate logistic regression model adjusted for age, gender, and race

[2] Multivariate mixed effects logistic regression model adjusted for age, gender, and race

AIAN American Indian and Alaska Native; NHPI Native Hawaiian and Pacific Islander

FPL Federal Poverty Level

Table 3.3: Moderate or High-Risk Substance Use by Measures of Food Security and Risk for Imminent Homelessness

Substance Use	Food Security			Risk for Imminent Homelessness		
	High N(%)	Marginal, Low, or Very Low N(%)	X^2 p-value	Negative Screen N(%)	Positive Screen N(%)	X^2 p-value
Tobacco Use			**0.02**			0.93
Low Risk	139 (82.25)	65 (69.89)		174 (78.38)	35 (77.78)	
Moderate or High Risk	30 (17.75)	28 (30.11)		48 (21.62)	10 (22.22)	
Alcohol			0.71			0.21
Low Risk	137 (84.05)	74 (82.22)		181 (84.58)	33 (76.74)	
Moderate or High Risk	26 (15.95)	16 (17.78)		33 (15.42)	10 (23.26)	
Cannabis or Other Drugs			0.08			0.37
Low Risk	153 (86.44)	76 (78.35)		195 (84.78)	39 (79.59)	
Moderate or High Risk	24 (13.56)	21 (21.65)		35 (15.22)	10 (20.41)	
Any Substance			0.1			0.91
Low Risk	134 (72.43)	65 (63.11)		168 (69.42)	35 (68.63)	
Moderate or High Risk	51 (27.57)	38 (36.89)		74 (30.58)	16 (31.37)	

Supplementary Materials

Table 3.4: Odds of Food Insecurity by Demographic Risk Factors and Residential Segregation

	More Segregated[1]			Less Segregated[2]			
Sample Characteristics	**High N(%)**	**Marginal, Low, or Very Low N(%)**	**aOR[4] (95% CI)**	**High N(%)**	**Marginal, Low, or Very Low N(%)**	**aOR[4] (95% CI)**	**Interaction p-value**
Age Group (years)							
55 – 86	44 (70.97)	18 (29.03)	(ref)	91 (71.65)	36 (28.35)	(ref)	
27 – 54	20 (42.55)	27 (57.45)	3.28 (1.36 – 7.93)	32 (64)	18 (36)	1.2 (0.59 – 2.46)	**0.09**
Gender							
Female	33 (75)	11 (25)	(ref)	53 (67.09)	26 (32.91)	(ref)	
Male	30 (44.78)	37 (55.22)	3.66 (1.48 – 9.05)	70 (70.71)	29 (29.29)	0.84 (0.43 – 1.61)	**0.01**
Race							
Non-Black[3]	8 (72.73)	3 (27.27)	(ref)	46 (70.77)	19 (29.23)	(ref)	
Black	54 (56.25)	42 (43.75)	2.63 (0.58 – 11.97)	74 (67.89)	35 (32.11)	1.18 (0.59 – 2.35)	0.57

[1]County-level Dissimilarity Index above median of 61; interpretation: more than 61% of residents would have to relocate within locality for distribution of Black and White residents to become even

[2]County-level Dissimilarity Index below median of 61

[3]White, Asian, American Indian and Alaska Native, Native Hawaiian and Pacific Islander, or >1 race

[4]Multivariate logistic regression model adjusted for age, gender, and race

CHAPTER 4: Contextual Predictors of Hospitalization and Quality of Life among People on Hemodialysis

Introduction

People on hemodialysis are hospitalized frequently but some are hospitalized more than others. Structural determinants of health and variations in healthcare practice generate pronounced variation in hospitalization rates among people on hemodialysis across health service areas in the United States.[1-3] Food insecurity and housing instability are social factors that may mediate the association between structural determinants of health and hospitalization in the hemodialysis population. Additionally, people experiencing food insecurity or housing instability may use substances to cope with hunger, fatigue, or depression.[4,5] In their seminal paper on fundamental causes of disease, Link and Phelan refer to such factors as "contextual" because they form the context for exposures to more proximate risk factors of chronic disease and disease exacerbation.[6] Contextual factors that increase hospitalization risk among people on hemodialysis may also decrease health-related quality of life, a patient-reported outcome associated with acute care utilization.[7]

Food insecurity, housing instability, and substance use directly increase hospitalization risk in other chronic diseases including diabetes,[8,9] heart failure,[10] and HIV.[11] They may also impact hospitalization rates and health-related quality of life among people on hemodialysis directly or via proximate behavioral and clinical risk factors. For example, people on hemodialysis experiencing food insecurity or housing instability may stretch medications like phosphate binders to pay for basic needs.[12] They may miss or shorten hemodialysis treatments to search for work and housing or because of transportation challenges.[13] Available food may be nutritionally inadequate or may be high in salt (e.g., microwavable or convenience foods),[14] contributing to fluid retention. Therefore, behavioral risk factors theoretically related to food insecurity or housing instability include nonadherence or poor self-management of dialysis and comorbid conditions.[13,15] Related clinical risk factors include high serum phosphate, poor dialysis

adequacy, low serum albumin, iron deficiency anemia, high interdialytic weight gain, or use of a catheter for dialysis access. These same pathways could impact health-related quality of life through symptom burden and stress.

Substance use introduces complexity into associations between contextual risk factors, proximate risk factors, hospitalization, and health-related quality of life. A full exploration of these interactions is beyond the scope of this study. However, the self-management of end-stage kidney disease and substance use is likely challenging even if substance use does not meet criteria for a disorder. It is likely even more challenging in the context of food insecurity or housing instability. Documented "drug abuse" is associated with missed hemodialysis treatments.[16] Alternatively, people with chronic diseases who use drugs have described substance use as a self-management strategy. Substance use may improve motivation to manage a chronic disease or decrease symptom burden, depending on substance category. For example, cannabis use may decrease gastrointestinal symptoms and anxiety; opioids decrease pain.[17]

Despite their relevance in other chronic disease trajectories, the impact of food insecurity and housing instability on outcomes among people on hemodialysis is unclear. Documented "drug abuse" increases mortality[18] and infection-related hospitalization rates[19] among people on hemodialysis, but it is unclear how lower risk use impacts hospitalization and health-related quality of life, particularly in the context of food insecurity and housing instability. To address this gap, we conducted a study to test the effect of food insecurity, housing instability, and substance use on hospitalization risk and kidney disease-related quality of life. Food insecurity, housing instability, and substance use likely present targets for intervention to reduce acute care utilization and improve health-related quality of life among people on hemodialysis, particularly those living in disadvantaged communities.

Methods

We conducted a prospective cohort study to test associations between food security, housing instability, and substance use on hospitalization rate. Additionally, we conducted a cross-sectional analysis to test associations between the same exposure variables and kidney disease-related quality of life. The study cohort was a convenience sample of people receiving hemodialysis at 17 facilities in the Baltimore and Washington D.C. metropolitan areas from the same large dialysis organization.

Study recruitment, participant eligibility, survey measures for study exposure variables, and survey data collection were described in detail in Chapter 3. Briefly, we dichotomized level of food security as "high or marginal" and "low or very low" based on participants' scores on the U.S. Department of Agriculture Adult Food Security Survey Module. We operationalized housing instability as a positive result on the U.S. Department of Veterans Affairs brief screening instrument for imminent homelessness risk.[20] We dichotomized substance use as "low-risk" and "moderate- or high-risk" based on participants' scores on the World Health Organization's Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST).[21]

Participants completed the Perceived Kidney Disease Self-Management Scale and the Kidney Disease and Quality of Life-36 (KDQOL-36) at the same time as other survey instruments. The Perceived Kidney Disease Self-Management Scale is an 8-item likert scale that measures participants' perceptions of their own competence at dialysis self-management. Scores range from 8 to 40 with higher scores indicating greater perceived competence.[22] The KDQOL-36 is comprised of a health-related quality of life measure (the Short Form-12) and three subscales specific to dialysis and kidney disease. The subscales measure burden of kidney disease (4 items), kidney-disease related symptoms or problems (12 items), and effects of kidney disease on daily life (8 items). Short Form-12 scores are standardized with a mean of 50 and a standard

deviation of 10. Subscale scores range from 0 to 100 with higher scores representing better kidney disease-related quality of life.[23]

Participants remained in the study for 6 months after survey completion. During the study follow-up period, we collected admission and discharge dates for all hospitalizations; ICD-10 codes for hospitalization cause; the number of missed hemodialysis treatments excluding those missed due to rescheduling or hospitalization; and monthly lab values for dialysis adequacy, serum albumin, hemoglobin, and serum phosphate. A reporting function within the electronic medical record generated average pre- and post-weights across every hemodialysis treatment that participants received during the study period. We also collected comorbidities listed as "active," participant height, and vascular access type in use at the time of study enrollment.

One study team member entered hospitalization dates and other clinical data from participant electronic medical records into an Excel spreadsheet. Before collecting data, the study team member received training from a clinical information specialist on the location of data fields and reporting functions in the electronic medical record. The study team member double-entered all fields for 10% of the sample, with a data entry error rate of 1%.

Statistical Methods

We used Stata version 17.0 for all statistical analyses. Study exposures were food security, housing instability, and substance use. Primary study outcomes were all-cause hospitalization risk and kidney disease-related quality of life subscale scores.

We examined distributions for all study variables. We conducted chi-square tests and t-tests comparing sample characteristics across levels of our exposure variables to assist with selecting potential confounders. We created separate, bivariate Cox regression models to test associations between food security, risk of imminent homelessness, substance use, and all-

cause hospitalization. We censored participants at first hospitalization or upon transfer to a non-participating facility, change in dialysis modality, transplant, death, or study completion. In supplementary analyses, we repeated bivariate Cox regression models with a subset of fluid or electrolyte-related hospitalizations, identified by ICD-10 codes for fluid overload (E87.7), congestive heart failure (I50.X), or hyperkalemia (E87.5). Other ICD-10 codes for fluid or electrolyte-related hospitalizations exist (e.g., J81.X for pulmonary edema), but none were applied to hospitalizations in the study database.

For the kidney disease-related quality of life outcome, we calculated subscale scores for the KDQOL-36 per the RAND Corporation scoring manual. We examined differences in mean subscale scores by sample characteristics via t-tests. We conducted separate, bivariate linear regression of kidney disease-related KDQOL-36 subscale scores on food security, housing instability, and substance use risk.

We repeated all analyses adjusting for age and other potential confounders. Confounders were associated with exposure variables in bivariate analyses, associated with exposures in published literature, and could causally precede exposures and outcomes. Finally, we explored whether multiple exposures modified associations with primary study outcomes.

Results

322 people on hemodialysis enrolled in the study. 17 participants did not complete the study survey and 26 participants did not return a HIPAA authorization form permitting access to their medical record. We present analyses from the 288 participants with survey and clinical record data. The study cohort had a mean age of 59.8 years (+/- 12.8), 58% of the sample were male, 73% were Black, and the mean dialysis vintage was approximately 5.5 years. 39 (13%) of participants were censored before the end of the study period of which 15 (5%) died. **Table 4.1** displays sample characteristics and all-cause hospitalization rates by study exposures with p-

values for chi-squared and t-tests. Notably, participants with low or very low food security and those reporting moderate or high-risk substance use missed more hemodialysis treatments compared to unexposed groups. On average, they also perceived themselves as less competent at self-managing dialysis. There were no other statistically significant associations between food security, housing instability, or substance use and behavioral or clinical risk factors for hospitalization.

Associations with Hospitalization

During the study's 6-month follow-up period, 91 participants (31.6%) experienced a hospitalization. The maximum number of hospitalizations was five. Eight of the 91 hospitalizations (8.8% of hospitalizations) had an ICD-10 code for COVID-19. Low or very low food security, risk of imminent homelessness, and moderate or high-risk substance use were not significant predictors of all-cause hospitalization (**Table 4.2**). This lack of association persisted after controlling for participant age. 20 participants (6.9%) experienced a hospitalization due to fluid overload or hyperkalemia. In supplementary analyses, the unadjusted risk of fluid or electrolyte-related hospitalizations among participants with low or very low food security was over 2-fold higher than participants with high or marginal food security (HR 2.58, 95% CI 1.04 – 6.4). This association strengthened after controlling for age, gender, race, and documented history of diabetes (aHR 3.44, 95% CI 1.20 – 9.17) but should be interpreted with caution due to the small event rate in the sample. There were no associations between risk of imminent homelessness or substance use risk and fluid or electrolyte-related hospitalizations.

Associations with Health-Related Quality of Life

KDQOL-36 subscales demonstrated excellent internal consistency with Cronbach alphas ranging from 0.86 to 0.88. In alignment with other studies of people on hemodialysis, SF-12 scores were lower than the U.S. average across the sample (**Table 4.3**).[24] The mean of SF-12

physical component summary scores was 40.55 (+/- 8.05) and the mean of mental component summary scores was 44.75 (+/- 7.66). Food security was strongly associated with burden of kidney disease, kidney disease-related symptoms or problems, and effects of kidney disease (**Table 4.4**). On average, scores for burden of kidney disease were 20 points lower (worse) among participants with low or very low food security compared to participants with high or marginal food security. On average, scores for symptoms of kidney disease and effects of kidney disease were approximately 7 points lower (worse) for participants with moderate or high-risk substance use compared to those with low-risk substance use. There were no associations between kidney-related KDQOL-36 subscale scores and risk of imminent homelessness.

We report the frequency of co-occurring contextual risk factors in Chapter 3. Subgroup sample sizes of participants reporting more than one contextual risk factor were small, but substance use modified associations between food insecurity and kidney disease-related KDQOL-36 subscale scores (**Supplementary Materials**). Among participants with low or very low food security, those reporting moderate or high-risk substance use rated their kidney disease as less burdensome and were less bothered by the effects of kidney disease on their daily life. Combinations of contextual risk factors did not change all-cause hospitalization risk.

Discussion

To our knowledge, this study is the first to report associations between contextual risk factors and health outcomes among adults on hemodialysis. The current study found that food security, housing instability, and substance use risk had no direct effect on all-cause hospitalization risk among a cohort of people on hemodialysis in the Baltimore and Washington, D.C. metropolitan areas.

These findings differ from research with other chronic disease populations and we considered several explanations.[8,11] We found that food insecurity significantly increased fluid or

electrolyte-related hospitalization risk in supplementary analyses. Additionally, associations between contextual risk factors and hospitalization may exist at more severe levels of exposure that we were not able to adequately capture due to our sampling approach. The timing of survey completion relative to COVID-19 may have biased results toward the null. For example, our food security measure elicited perceptions of food security over the previous 12 months. Participants may have experienced food insecurity in 2020 due to COVID-19, but the exposure may have been too transient to impact hospitalization risk.[9] Regarding housing instability, the use of different housing instability measures across research studies may explain differences in findings. Similarly, housing instability may exist on a spectrum that our binary measure did not adequately capture.[26] Alternatively, contextual risk factors may not increase all-cause hospitalization risk in the highly comorbid hemodialysis population. Future studies examining the impact of contextual risk factors on hospitalization among people on hemodialysis should consider outreach to people who are less connected to care and a longer follow-up period.

Participants with low or very low food security and those reporting moderate or high-risk substance use were more bothered by kidney disease symptoms and the effect of kidney disease on their daily life. Participants with low or very low food security also found their kidney disease to be more burdensome. These findings align with and expand upon other research demonstrating strong associations between food insecurity and health-related quality of life.[25] Additionally, substance use modified the association between low or very low food security and kidney disease-related quality of life subscale scores in supplementary analyses. Given that food security, substance use, and quality of life data were collected cross-sectionally, we cannot draw conclusions about directionality. Future research should confirm and explain these findings.

This study has important practice implications. We found that low or very low food security and moderate or high-risk substance use were associated with missed hemodialysis

treatments, but clinical risk factors for hospitalization were nearly identical in exposed and unexposed groups. This is critical, because dialysis facility teams often use clinical indicators, such as monthly lab values, to gauge the success or appropriateness of patient plans of care. In the absence of clinical indicators for food insecurity or substance use, clinicians must rely on proactive screening. Additionally, people reporting food insecurity at baseline missed more hemodialysis treatments during the 6-month study follow-up period. The association between food insecurity and missed treatments presents a financial incentive for dialysis organizations to reduce the burden of food insecurity in their facilities.

This study has important limitations related to sampling and ascertainment of study exposures and outcomes. We did not explore more complex multivariate models in hospitalization analyses due to lack of statistical significance in age-adjusted models. However, residual confounding may have biased estimates of association in quality of life analyses given non-random sampling. Additionally, we recruited from dialysis facilities affiliated with large academic centers or End-Stage Renal Disease Seamless Care Organizations. Our findings may not be generalizable to people receiving hemodialysis at facilities with less robust case management or quality improvement infrastructures. Regarding study exposures, food insecurity, housing instability, and substance use exposures may have varied during the study period but were only measured at baseline. Regarding study outcomes, we manually collected hospitalization and other clinical data from the electronic health record which may have introduced information bias. Additionally, approximately 10% of the sample died or was lost to follow up during the study period, potentially introducing attrition bias. These limitations are balanced by key strengths, including access to a difficult-to-reach and vulnerable population, the prospective study design, and primary data collection using valid measures for study exposures.

Conclusion

Food insecurity, housing instability, and substance use were not associated with all-cause hospitalization in a cohort of people on hemodialysis in the Baltimore and Washington, D.C. metropolitan areas. However, food insecurity was strongly associated with hospitalizations due to fluid overload and hyperkalemia. Food insecurity and substance use were associated with missed hemodialysis treatments, lower perceived competence at dialysis self-management, and poor kidney disease-related quality of life. Dialysis facilities can begin to intervene on food insecurity now while future research continues to examine the role of contextual risk factors in health disparities among people on hemodialysis.

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Tables and Figures

Table 4.1: Sample Characteristics and All-Cause Hospitalization Rates, Stratified by Contextual Risk Factors

Sample Characteristics	Total Sample (n = 288) [1]	Food Security			Risk of Homelessness		
		High or Marginal (n = 215)	Low, or Very Low (n = 61)	p-value	Negative Screen (n = 230)	Positive Screen (n = 53)	p-value
Outcome							
>=1 All-cause hospitalization %	31.6	32.1	32.8	0.92	32.2	30.2	0.78
Exposures %							
Low or very low food security	22.1	n/a	n/a	n/a	18.1	42.6	**<0.001**
Positive homelessness risk screen	18.7	12.7	32.8	**<0.001**	n/a	n/a	n/a
Moderate or high-risk substance use	31.8	30.7	35	0.52	31.3	32	0.92
Demographic Characteristics							
Age in years, mean (SD)	59.8 (12.8)	60.9 (13.1)	56 (11.6)	**0.01**	60.1 (13.1)	57.8 (11.4)	0.26
Male %	58	56.6	61.7	0.48	58.2	56.9	0.87
Black %	73.2	73.3	74.2	0.9	72.9	74	0.87
Non-Hispanic %	94	95.69	90.2	0.1	94.6	90.4	0.25
Socioeconomic Characteristics							
Financial Strain %				**<0.001**			**<0.001**
Some money left over	38.2	48.9	9.1		43.6	15.9	
Just enough to make ends meet	34.4	35.4	30.9		35.4	31.8	
Not enough to make ends meet	27.4	15.7	60		21.	52.3	
At least high school education %	80.2	84.2	72.1	**0.03**	83	69.8	**0.03**
Marital Status %				0.34			0.28
Cohabitating or Married	35.6	38	27.6		38	26	
Divorced, Widowed, or Separated	32.7	32.2	37.9		31.7	38	
Never Married	31.6	29.8	34.4		30.3	36	
Clinical Characteristics							
Body mass index, mean(SD)	28.8 (7.7)	29.3 (7.9)	27.2 (6.8)	0.06	28.8 (7.9)	28.9 (7)	0.96
Dialysis vintage in years, mean (SD)	5.5 (5.4)	5.4 (5.3)	5.5 (6.1)	0.88	5.5 (5.6)	5 (4.4)	0.53
Documented diabetes %	56.9	57.7	55.7	0.79	59.6	45.3	0.06
Missed >=1 treatment %	48.6	45.1	62.3	**0.02**	47.4	50.9	0.64

Sample Characteristics	Total Sample (n = 288) [1]	Food Security			Risk of Homelessness		
		High or Marginal (n = 215)	Low, or Very Low (n = 61)	p-value	Negative Screen (n = 230)	Positive Screen (n = 53)	p-value
PDSMS, mean (SD)	30.7 (5.3)	31.5 (5.1)	28.1 (5.1)	**<0.001**	30.8 (5.4)	29.7 (5.1)	0.19
Average lab values, mean (SD)							
spKt/V	1.62 (0.23)	1.62 (0.22)	1.65 (0.27)	0.34	1.62 (0.23)	1.65 (0.27)	0.3
Albumin g/dL	3.89 (0.28)	3.88 (0.27)	3.94 (0.32)	0.15	3.89 (0.29)	3.95 (0.24)	0.12
Phosphorus mg/dL	5.63 (1.46)	5.61 (1.48)	5.74 (1.42)	0.51	5.64 (1.47)	5.62 (1.47)	0.95
Hemoglobin g/dL	10.82 (0.85)	10.77 (0.82)	10.98 (0.93)	0.08	10.82 (0.87)	10.83 (0.75)	0.84
IDWG kg, mean (SD)	2.38 (0.89)	2.34 (0.86)	2.54 (1.03)	0.14	2.38 (0.85)	2.4 (1.08)	0.89
Vascular access %				0.89			0.61
AV Fistula	73.4	73.4	71.7		71.7	78.4	
AV Graft	13.6	14	13.3		14.4	11.8	
Catheter	12.9	12.6	15		13.9	9.8	

[1] Cell totals may not add to event total due to missing sample characteristics data and rounding

Abbreviations: PDSMS, Perceived Dialysis Self-Management score; IDWG, Interdialytic weight gain

Table 4.1: (Continued)

Sample Characteristics	Substance Use		
	Low Risk (n = 191)	Moderate or High-Risk (n = 89)	p-value
Outcome			
>=1 All-cause hospitalization %	30.9	32.6	0.78
Exposures %			
Low or very low food security	21	24.4	0.52
Positive homelessness risk screen	17.9	18.4	0.92
Moderate or high-risk substance use	n/a	n/a	n/a
Demographic Characteristics			
Age in years, mean (SD)	60.4 (12.5)	58.4 (13.5)	0.25
Male %	56.9	59.1	0.73
Black %	69.2	80.2	0.06
Non-Hispanic %	93	95.5	0.43
Socioeconomic Characteristics			
Financial Strain %			0.14
Some money left over	42.1	29.1	
Just enough to make ends meet	31.5	40.5	
Not enough to make ends meet	26.4	30.4	
At least high school education %	81.2	78.7	0.62
Marital Status %			0.91
Cohabitating or Married	35.9	36.5	
Divorced, Widowed, or Separated	33.2	30.6	
Never Married	31	32.9	
Clinical Characteristics			
Body mass index, mean(SD)	29.1 (8)	28 (7.2)	0.28
Dialysis vintage in years, mean (SD)	5.4 (5.3)	5.5 (5.5)	0.9
Documented diabetes %	58.6	50.6	0.21
Missed >=1 treatment %	41.8	62.9	**0.001**
PDSMS, mean (SD)	31.1 (5)	29.6 (5.8)	**0.03**
Average lab values, mean (SD)			

Sample Characteristics	Substance Use		
	Low Risk (n = 191)	Moderate or High-Risk (n = 89)	p-value
spKt/V	1.63 (0.24)	1.61 (0.23)	0.57
Albumin g/dL	3.89 (0.28)	3.91 (0.27)	0.56
Phosphorus g/dL	5.64 (1.36)	5.66 (1.69)	0.91
Hemoglobin g/dL	10.79 (0.83)	10.91 (0.87)	0.28
IDWG kg, mean (SD)	2.44 (0.9)	2.26 (0.85)	0.13
Vascular access %			0.65
AV Fistula	72	75.3	
AV Graft	15.3	11.2	
Catheter	12.7	13.5	

1

Table 4.2: Hazard Ratios for All-Cause Hospitalization Comparing Levels of Food Security, Risk of Imminent Homelessness, and Substance Use Risk

Contextual Risk Factors	Unadjusted HR (95% CI)	p-value	Age-Adjusted HR (95% CI)	p-value
Food Security				
High or Marginal	(ref)		(ref)	
Low or Very Low	0.98 (0.59 – 1.61)	0.94	1.04 (0.63 – 1.74)	0.85
Risk of Homelessness				
Negative Screen	(ref)		(ref)	
Positive Screen	0.93 (0.54 – 1.6)	0.8	0.97 (0.56 – 1.69)	0.91
Substance Use				
Low Risk	(ref)		(ref)	
Moderate or High Risk	1.14 (0.73 – 1.78)	0.55	1.16 (0.74 – 1.82)	0.52

Table 4.3: Mean KDQOL-36 Scores Stratified by Level of Food Security, Risk of Imminent Homelessness, and Substance Use Risk

KDQOL-36 Subscale	Total Sample	Food Security			Risk of Homelessness		
		High or Marginal	Low or Very Low	p-value	Negative Screen	Positive Screen	p-value
Burden of Kidney Disease	46.7 (30.9)	52.16 (30.24)	29.2 (25.01)	**<0.001**	47.45 (30.47)	43.13 (33.64)	0.39
Symptoms of Kidney Disease	75.6 (18.36)	78.6 (16.91)	66.9 (18.55)	**<0.001**	75.93 (18.12)	75.54 (17.04)	0.89
Effects of Kidney Disease	65.97 (25.47)	70.15 (23.88)	52.93 (25.57)	**<0.001**	66.68 (24.72)	64.05 (28.55)	0.52
Physical Composite SF-12	40.55 (8.05)	41.18 (7.9)	38.35 (8.43)	**0.03**	40.23 (8.08	41.95 (7.97)	0.2
Mental Composite SF-12	44.74 (7.66)	45.53 (7.64)	42.35 (7.08)	**0.008**	45.35 (7.32)	42.15 (9.03)	**0.01**

KDQOL-36 Subscale	Substance Use		
	Low Risk	Moderate or High Risk	p-value
Burden of Kidney Disease	48.44 (31.26)	42.66 (30.14)	0.15
Symptoms of Kidney Disease	77.81 (17.7)	70.55 (18.85)	**0.002**
Effects of Kidney Disease	68.73 (25.3)	60.1 (25.24)	**0.009**
Physical Composite SF-12	40.89 (8.53)	39.72 (6.97)	0.29
Mental Composite SF-12	44.87 (7.7)	44.49 (7.72)	0.72

Table 4.4: Mean Differences in Kidney Disease-Related KDQOL-36 Scores Comparing Levels of Food Security, Risk of Imminent Homelessness, and Substance Use Risk

Contextual Risk Factors	Burden of Kidney Disease			
	Unadjusted	**p-value**	**Adjusted**[1]	**p-value**
Food Security		**<0.001**		**<0.001**
High or Marginal	(ref)		(ref)	
Low or Very Low	-22.96 (-31.5 – -14.43)		-20.99 (-20.36 – -11.73**)**	
Risk of Homelessness		0.39		0.5
Negative Screen	(ref)		(ref)	
Positive Screen	-4.32 (-14.12 – 5.48)		-3.6 (-14.21 – 7.01)	
Substance Use		0.15		0.06
Low Risk	(ref)		(ref)	
Moderate or High Risk	-5.78 (-13.67 – 2.11)		-8.06 (-16.53 – 0.41)	

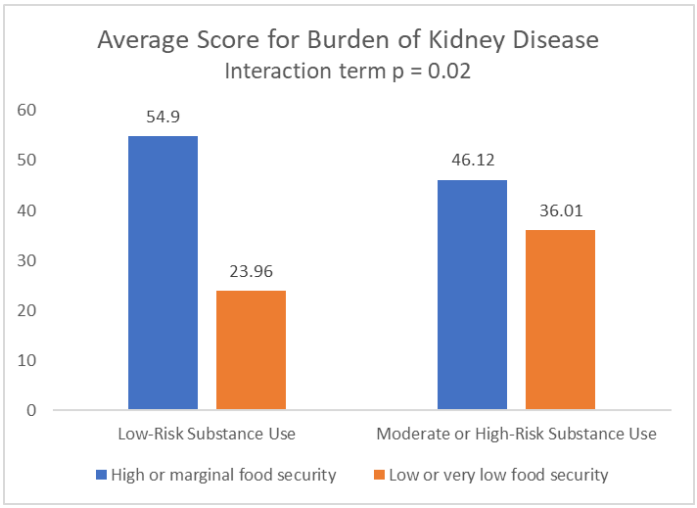
Contextual Risk Factors	Kidney Disease Symptoms and Problems			
	Unadjusted	**p-value**	**Adjusted**[1]	**p-value**
Food Security		**<0.001**		**<0.01**
High or Marginal	(ref)		(ref)	
Low or Very Low	-11.7 (-16.79 – -6.61)		-12.77 (-18.2 – -7.33)	
Risk of Homelessness		0.9		0.98
Negative Screen	(ref)		(ref)	
Positive Screen	-0.39 (-6.21 – 5.43)		0.07 (-6.16 – 6.31)	
Substance Use		**0.002**		**0.001**
Low Risk	(ref)		(ref)	
Moderate or High Risk	-7.26 (-11.89 – -2.63)		-8.59 (-13.6 – -3.58)	

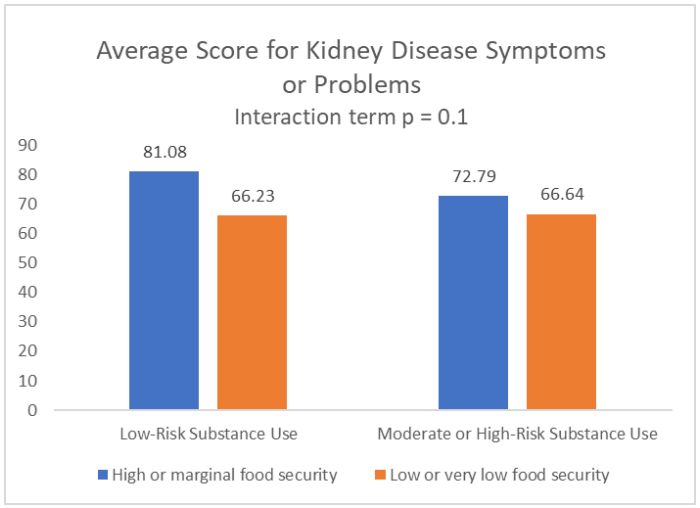
Contextual Risk Factors	Effects of Kidney Disease on Daily Life			
	Unadjusted	**p-value**	**Adjusted**[1]	**p-value**
Food Security		**<0.001**		**<0.001**
High or Marginal	(ref)		(ref)	
Low or Very Low	-17.22 (-24.35 – -10.08)		-16.35 (-23.74 – -8.97)	
Risk of Homelessness		0.52		0.46
Negative Screen	(ref)		(ref)	
Positive Screen	-2.62 (-10.72 – 5.47)		-3.12 (-11.44 – 5.19)	
Substance Use		**0.009**		**0.005**
Low Risk	(ref)		(ref)	
Moderate or High Risk	-8.63 (-15.09 – -2.17)		-9.64 (-16.33 – -2.96)	

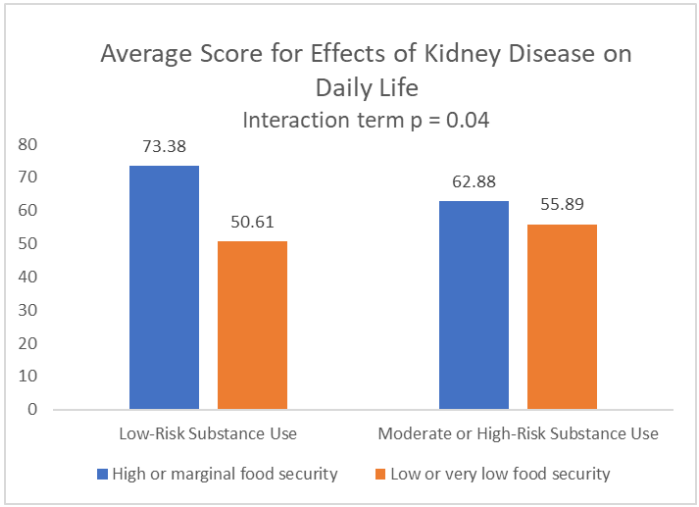
[1]Adjusted for age, gender, race, Hispanic ethnicity, education, marital status, and diabetes

Supplemental Materials

Figure 4.1: Substance Use Modifies Association Between Food Security and Kidney Disease-Related KDQOL Subscale Scores







CHAPTER 5: Key Findings and Implications

Key Findings

Material need insecurities, particularly food insecurity, impact health outcomes across the trajectory of chronic kidney disease and are common among people on hemodialysis. Though additional research can clarify causality, one interpretation of findings across Chapters 2 through 4 is that material need insecurities make dialysis self-management more challenging, leading to "treatment nonadherence," a perception of kidney disease and its symptoms as more burdensome, and increased risk for fluid overload and hyperkalemia. Via Aim 1, we learned that food insecurity, housing instability, and substance use are common among people on hemodialysis. Risk for food insecurity or housing instability was higher for younger people and those with less income or education. Additionally, residential segregation increased risk of food insecurity for younger people and men on hemodialysis. Via Aim 2, we learned that food insecurity and moderate or high-risk substance use were associated with worse kidney disease-related quality of life. People experiencing food insecurity also missed more hemodialysis treatments and were at increased risk for fluid or electrolyte-related hospitalizations.

Summary of Chapter 2 Findings

In Chapter 2, we synthesized qualitative literature on adherence among people with end-stage kidney disease on hemodialysis. We found that published adherence intervention studies did not address key adherence factors people on hemodialysis described in the qualitative literature. Adherence intervention studies addressed individual components of adherence, like fluid management or hemodialysis treatment attendance. However, our qualitative synthesis demonstrated that the complexity of the end-stage kidney disease regimen contributed to nonadherence. Additionally, people on hemodialysis adhere to the regimen as a whole within the context of a combination of adherence factors unique to them.

The qualitative data revealed 20 adherence factors unique to hemodialysis across the World Health Organization's five dimensions of adherence. We organized these factors into two overarching themes: (1) adherence in the context of patients' whole lives and (2) dialysis treatment as a double-edged sword. Financial strain increased the perpetual challenge of balancing all aspects of end-stage kidney treatment with social roles and logistics. For example, people on hemodialysis experiencing financial strain described tradeoffs between food and medications and challenges with dietary adherence due to the cost of food (e.g., the relative cost of salt compared to more expensive salt substitutes). Financial strain also contributed to psychological stress. Financial strain and food insecurity were reported in studies that sampled exclusively or predominantly Black or Hispanic patients.

We concluded that adherence may improve when routine care incorporates patient context and provides ongoing support to patients and families as they navigate the logistical, physical, and psychological hardships of living with hemodialysis. These findings supported our conceptual model and hypothesis that social disadvantaged subgroups on hemodialysis may experience a higher burden of material need insecurities.

Summary of Chapter 3 Findings

In Chapter 3, we examined associations between individual and area-level sociodemographic characteristics, material need insecurities, and substance use disorder among people on hemodialysis. We found that self-reported food insecurity, housing instability, and moderate- or high-risk substance use were common. 13.3% of participant reported marginal food security, 12.6% reported low food security and 9.9% reported very low food security in the previous 12 months. Participants with very low food security ate less than they felt they should or went hungry because there was not enough money for food. 18% reported that they did not have a home of their own where they felt safe in the last 90 days or were worried that they

would not have one in the next 90 days. 31% reported substance use that presented a moderate or high risk to their health.

People on hemodialysis who were younger, less educated, with lower incomes or experiencing financial strain were more likely to experience material need insecurities. Hispanic people on hemodialysis were at increased risk for food insecurity but the study lacked sufficient power to detect associations between material need insecurities and ethnicity. In contrast with the general population, our study did not find an association between race and material need insecurities, though residential segregation moderated associations between age, gender, and food insecurity. Food insecurity was associated with moderate or high-risk tobacco use. A higher proportion of participants with food insecurity reported moderate or high-risk use of cannabis and other drugs, but associations did not reach statistical significance.

We concluded that people on hemodialysis may have a high burden of material need insecurities due to employment and income loss and strain on social support networks related to hemodialysis initiation. The impact may be more pronounced for younger people who may not have accumulated wealth but have not aged into federal retirement programs and may not be eligible for disability programs. These findings aligned with our conceptual model.

Summary of Chapter 4 Findings

In Chapter 4, we examined associations between contextual risk factors and hospitalization and quality of life among people on hemodialysis. We described food insecurity, housing instability, and substance use as contextual risk factors because they theoretically formed the context for patients' exposures to more proximate risk factors of disease exacerbation.

Food security, housing instability, and substance use had no direct effect on all-cause hospitalization risk in unadjusted and age-adjusted analyses. These findings differed from

research with other chronic disease populations, and we explored possible explanations via supplemental analyses. We found that food insecurity markedly increased fluid or electrolyte-related hospitalization risk but interpreted findings with caution due to the low event rate in the sample. Notably, food insecurity and moderate or high-risk substance use were associated with missed hemodialysis treatments and lower perceived competence at dialysis self-management but were not associated with clinical risk factors for hospitalization.

Food insecurity and substance use were associated with kidney disease-related quality of life subscale scores. Compared to participants with high or marginal food security, those with low or very low food security more frequently described kidney disease as burdensome. They were more bothered by kidney disease symptoms or problems and the effects of kidney disease on their daily life. Participants with moderate or high-risk substance use were also more bothered by kidney disease symptoms or problems and the effects of kidney disease on daily life compared to those with low-risk substance use. There were no associations between subscale scores and housing instability.

We concluded that food insecurity, housing instability, and moderate or high-risk substance use did not "show up" in the clinical indicators that dialysis facility teams use to evaluate plans of care. Therefore, dialysis facility teams lack signals to screen for and address contextual risk factors, particularly food insecurity which was strongly associated with kidney disease-related quality of life. However, the association between food insecurity and missed treatments may present a financial incentive for dialysis organizations to reduce the burden of food insecurity in their facilities.

Implications and Future Steps

This dissertation study establishes a foundation for future nursing and health services research to eliminate health disparities in chronic kidney disease. It can inform practice changes

within nephrology practices and dialysis organizations, particularly those participating in new payment models. It can also inform ongoing debate about how to leverage dialysis reimbursement policies to incentivize health equity.

Research Implications

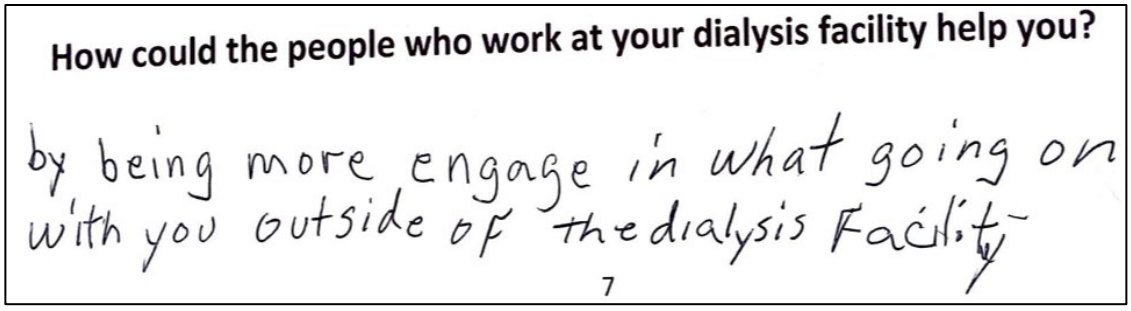
Based on dissertation findings, two overarching areas for future research emerge: (1) continued observational studies to establish causality between structural and social determinants of health and health outcomes among people on hemodialysis and (2) development and testing of interventions to ameliorate the downstream effects of structural and social determinants of health.

In Chapter 3, we found that younger people on hemodialysis were at increased risk for food insecurity in more segregated neighborhoods, but not in less segregated neighborhoods. These findings suggested that food insecurity and other social factors might explain age and racial disparities in hospitalization rates.[1,2] In Chapter 4, we found a strong association between food insecurity and fluid or electrolyte-related hospitalizations but had small event rates in food security subgroups. Future research can confirm and build upon these findings with different sampling and measurement approaches.

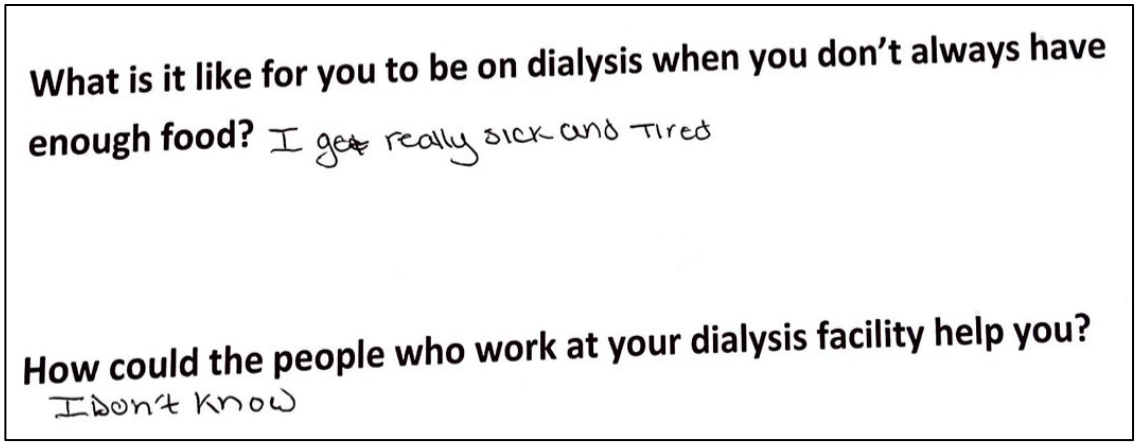
First, future research should test associations between more severe exposures (i.e., very low food security, more severe housing instability or homelessness, and substance use disorder) and health outcomes. Though nearly one-third of our sample had some level of food insecurity, housing instability, or substance use disorder, we did not reach people on hemodialysis who were disconnected from care and may rely more on acute care services. Researchers can partner with dialysis facility social workers, local emergency departments, and community organizations to engage them in research. Second, future research should measure exposures longitudinally to distinguish between chronic and transient material need insecurities and

substance use disorder. Research teams from ongoing cohort studies like the Chronic Renal Insufficiency Cohort Study (cristudy.org) or the Dialysis Outcomes and Practice Patterns Study (dopps.org) can consider integrating related measures into existing surveys. Lastly, we structured our study aims to explore material need insecurities and substance use as mediating variables in established associations between structural determinants of health inequities like residential segregation and health outcomes. However, we lacked sufficient power to test mediation directly due to small sample sizes within subgroups of interest. In particular, very few non-Black participants received dialysis in more segregated neighborhoods. Future studies can target more integrated communities to test whether material need insecurities cause racial disparities in mortality and hospitalization among younger people on hemodialysis.

In preparation for future intervention research, optional open-ended survey items asked participants experiencing food insecurity or housing instability to suggest ways dialysis facility teams could help. One participant responded:



However, participants commonly responded that they “didn’t know”:



These responses suggest a disconnect between people on hemodialysis and clinical teams within dialysis facilities. It is likely the product of multiple factors at the macro, meso, and micro levels of health care that position dialysis facilities as "the place where people get dialysis" rather than a patient-centered medical home. Qualitative research methods like grounded theory could describe and begin to explain how interactions across health care levels perpetuate the disconnect. From this deeper understanding, diverse teams (e.g., people on hemodialysis, family members, clinicians, administrators, researchers, etc.) could co-create and test interventions to address material need insecurities among people on hemodialysis.

Policy Implications

Ten percent of people in our sample had thrice-weekly contact with the healthcare system and still went hungry at some point in the previous year because they did not have enough money for food. Policy and practice changes to alter the structure and process of healthcare delivery could produce a more acceptable outcome. We focus on two policies in this section: (1) the Kidney Care Choices Model and (2) the End-Stage Renal Disease Quality Incentive Program.

As mandated by the Social Security Amendments of 1972, a diagnosis of ESKD confers Medicare eligibility to any individual who is eligible for Social Security benefits. While there is a

payer mix of public and private insurers, Medicare is the primary insurer for most people on hemodialysis, paying 80 percent of outpatient dialysis costs.[3] In 2008, Congress passed the Medicare Improvements for Patients and Providers Act, mandating that the Centers for Medicare and Medicaid Services create a case mix-adjusted prospective payment system for all dialysis-related care. The prospective payment system, also known as the "bundle", took effect January 2011.[4] The following year, CMS implemented a value-based care program, called the End-Stage Renal Disease Quality Incentive Program. Via the Quality Incentive Program, CMS can reduce bundled payments to a dialysis facility by up to 2% based on its performance on quality indicators relative to national benchmarks.[5] Payment penalties take effect during a "payment year," two years after baseline performance measurement. Finally, in 2019 the Trump administration authorized substantial changes to Medicare reimbursement for kidney disease via executive order. The optional Kidney Care Choices Model incentivized kidney care providers to coordinate care from late-stage chronic kidney disease through kidney transplant. The mandatory End-Stage Renal Disease Treatment Choices Model also incentivized home dialysis modalities and kidney transplant via dialysis facility reimbursement penalties similar to the Quality Incentive Program.

Through the Kidney Care Choices Model, nephrology practices, dialysis facilities, and transplant centers can form accountable care organizations that coordinate beneficiaries' nephrology care from later stages of chronic kidney disease through kidney transplant. They are accountable for Medicare Part A and B spending through different cost sharing options and are therefore incentivized to reduce hospitalizations. Kidney Care Choices Model participants (i.e., kidney-specific accountable care organizations) are well-positioned to screen people with chronic kidney disease for material need insecurities and substance use disorder, partner with

local organizations to address social needs, and enroll eligible people with kidney disease in income-based programs like supplemental nutrition assistance.

As efforts to prevent late-stage chronic kidney disease and improve access to kidney transplant continue, we will need policies that support socially disadvantaged people on hemodialysis and the facilities that care for them. Dialysis facilities in residentially segregated areas are more likely to receive payment penalties via the Quality Incentive Program. For this reason and in recognition of health disparities in kidney disease, CMS is considering development of a facility-level equity score as part of the Quality Incentive Program.[6] However, our study suggests that equity scores may not be meaningful at the facility-level, in part due to lack of racial integration within dialysis facilities. In residentially segregated areas, a small denominator of White people on hemodialysis within individual facilities may thwart comparisons. Additionally, racial disparities are generated by place (i.e., social context), not race.[7] Equity scores that compare outcomes among non-White people in segregated areas to non-White people at the national level would again disadvantage facilities in disinvested neighborhoods with more complex social issues. CMS should consider approaches that hold regional-level entities accountable for health equity <u>across</u> instead of <u>within</u> dialysis facilities. Regional-level entities could redistribute resources from facilities with more people on hemodialysis with private insurance to those with more dual eligibility. Additionally, regional entities would have adequate subgroup sample sizes for comparison.

Additionally, CMS can consider different quality metrics within the Quality Incentive Program to promote health equity. CMS assesses the quality of care within dialysis facilities with clinical and laboratory indicators. We found that people on hemodialysis experiencing food insecurity, housing instability, and substance use disorder had nearly identical values on quality indicators compared to unexposed groups. However, people on hemodialysis with food

insecurity had substantially lower scores for kidney disease-related quality of life. If future research confirms that patient-reported outcome measures are better indicators of the burden of social determinants of health than clinical indicators, CMS can incentivize dialysis facilities to collect and report patient-reported outcome measures as they consider how to integrate them into value-based programs.

At the practice level, our findings should motivate large dialysis organizations to intervene on food insecurity. We believe the timing is right, now. Successful quality improvement interventions require a measure that clinicians believe is valid, an evidence base for how to improve, and consideration for the "people side" of change across organizational levels.[8] The U.S. Department of Agriculture Adult Food Security Survey Module is a valid measure that facility teams could use to track and compare performance. It is also a simple screening tool that clinicians could integrate into practice. For example, dialysis facility nurses could screen people on hemodialysis for food insecurity on the same schedule as monthly lab draws. Additionally, dialysis organizations can access the growing evidence base for food insecurity intervention in health care settings[9] with support from CMS and their regional End-Stage Renal Disease Networks. COVID-19 raised awareness about our collective vulnerability to food insecurity and the vulnerability of people on hemodialysis.[10] Our dissertation findings can strengthen stakeholders' political will to address material need insecurities among people on hemodialysis as a step toward eliminating health disparities across the trajectory of chronic kidney disease.

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CURRICULUM VITAE

Kathryn S. Taylor, RN, MPH

PROFESSIONAL DATA

Johns Hopkins University School of Nursing
525 N. Wolfe St.
Baltimore, MD 21205

EDUCATION

Year	Degree	Institution	Location
2022 (expected)	Doctor of Philosophy	Johns Hopkins University School of Nursing	Baltimore, MD
2011	Master of Public Health	Johns Hopkins Bloomberg School of Public Health	Baltimore, MD
2007	Bachelor of Science in Nursing	Johns Hopkins University School of Nursing	Baltimore, MD
2004	Bachelor of Arts (psychology)	Loyola University in Maryland	Baltimore, MD

CURRENT LICENSE AND CERTIFICATION

Year	Source	Type	License
2007 - present	Maryland Board of Nursing	Registered nurse	#R178294

PROFESSIONAL EXPERIENCE

Year	Position	Institution	Location
2018 – present	PhD Student	Johns Hopkins University School of Nursing	Baltimore, MD
2016 - 2017	Corporate Vice President of Quality	Fresenius Kidney Care	Waltham, MA
2012 – 2016	Senior Research Program Manager	Johns Hopkins Medicine Armstrong Institute for Patient Safety and Quality	Baltimore, MD
2009 – 2010	Research Nurse	Johns Hopkins Center for Tuberculosis Research	Baltimore, MD
2007 – 2016	Nurse Clinician	Johns Hopkins Hospital	Baltimore, MD

HONORS AND AWARDS

2022	American Society of Nephrology Kidney STARS (Students and Residents) Award
2021	Discovery and Innovation Award, Johns Hopkins School of Nursing
2020	Predoctoral Clinical Research Training (TL1) Award, Johns Hopkins Institute for Clinical and Translational Research
2020	Nurse Faculty for the Future Education and Leadership Fellow

RESEARCH

Sponsored Projects

01/2021 – 04/2023	Contextual Predictors of Hospitalization and Quality of Life among Patients on Hemodialysis, Ruth L. Kirschstein Individual Predoctoral National Research Service Award, National Institute of Nursing Research; Principal investigator

SCHOLARSHIP

Publications

1. **Taylor, K. S.**, Umeukeje, E. M., Santos, S. R., McNabb, K. C., Crews, D. C., & Hladek, M. D. (2022) *Context Matters: A Qualitative Synthesis of Adherence Literature for People on Hemodialysis.* Manuscript under review.
2. **Taylor, K. S.**, Hladek, M. D., Elias, S. D., Jenkins, E., Robinson, K. N., Smith, O. W., & Szanton, S. L. (2022) Lessons from COVID-19: Time for shared decision-making in nursing practice. *Journal of Advanced Nursing*.
3. **Taylor, K**., & Crews, D. C. (2021). Toward antiracist reimbursement policy in end-stage kidney disease: From equality to equity. *Journal of the American Society of Nephrology*, *32*(10), 2422-2424.
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Abstracts

2022 **Taylor, K. S.**, Santos, S., Perrin, N. A., & Crews, D. C. *Individual and Community-Level Risk Factors for Food Insecurity among Patients on Hemodialysis.* Poster accepted to American Society of Nephrology Kidney Week

2022 **Taylor, K. S.**, Umeukeje, E. M., Santos, S., McNabb K. S., Crews, D. C., & Hladek, M. D. *A "Best Fit" Framework Synthesis to Guide Adherence Interventions for Patients on Hemodialysis.* Poster accepted to American Society of Nephrology Kidney Week

2020 **Taylor, K. S.**, Chu, N., Rosello, E., Kunwar, S., Butz, P., Norman, S., Crews, D., Greenberg, K., Segev, D., Shafi, T., McAdams-DeMarco, M. *Uremic Symptoms: A Patient-Reported Outcome that is Associated with Access to Kidney Transplantation and Waitlist Mortality among Kidney Transplant Candidates.* Oral presentation (prerecorded due to COVID-19) presented at the American Transplant Congress

2020 **Taylor, K. S.** *Contextual Predictors of Hospitalization and Quality of Life among Patients on Hemodialysis.* Poster presentation (accepted but subsequently cancelled due to COVID-19) at Translational Science: 2020

2019 Gross, D., Bettencourt, A.F., Singleton, A., **Taylor, K.**, Francis, L., & Bower, K. (2019, May). *What is Parent Engagement in Early Childhood Education? Depends Who You Ask.* Paper presented at the annual meeting of the Society for Prevention Research, San Francisco, CA.

2012 Berenholtz, S. Goeschel, C., Lubomski, L., Rosen, M., Pronovost, P., **Taylor, K.** & Weaver, S. *Translating Successful Improvement Programs.* Poster presented at the Office of Healthcare Quality Healthcare Acquired Infection Data Summit.

Presentations

National

2014 **Taylor, K. S.** Preventing Blood Stream Infection – What We Can Learn from the Hospital Experience, Fresenius Medical Care North America Medical Directors' Symposium, Atlanta, GA (Invited)

EDITORIAL ACTIVITIES

Manuscript Review

2019	Heart, Lung, and Circulation

EDUCATIONAL ACTIVITIES

Classroom Instruction

Johns Hopkins University School of Nursing

Spring 2020	Teaching Assistant, NR.210.609 Philosophical, Theoretical and Ethical Basis of Advanced Nursing Practice, Master's Entry Nursing Program
Fall 2019	Teaching Assistant, 210.606.8101 Biostatistics for Evidence-based Practice, Doctorate of Nursing Practice Program
Fall 2018 – Fall 2020	Lecturer, 120.501.0101 Professionalism for Nursing in Health Care, Master's Entry Nursing Program
Spring 2019	Lecturer, 110.891 Responsibilities & Activities of the Nurse Scientist, PhD Program
Fall 2018	Teaching Assistant, 210.804.8101 Organizational and Systems Leadership for Quality Care, Doctorate of Nursing Practice Program
Summer 2018	Teaching Assistant, 210.608.0101 The Research Process and Its Application to Evidence-Based Nursing, Master's Entry Nursing Program

Clinical Instruction

Fall 2019 – Fall 2020, Fall 2022	NR.120.522 Public Health Nursing, Master's Entry Nursing Program

ACADEMIC SERVICE

Johns Hopkins University School of Nursing

2021	Research Chair, PhD Student Organization
2020	Fellow, Nurse Faculty for the Future Leadership Practicum
2018	Member, Master of Science in Nursing Organizational Leadership and Management Taskforce
2018 – 2019	Social Chair, PhD Student Organization