Background: Patients with end-stage kidney disease treated with hemodialysis in the U.S. have persistently higher rates of nonadherence compared to patients 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 patients 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 patients' 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. Patients described a profound grieving process over loss of their "old selves" 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 patients on hemodialysis are inadequate. 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 dialysis. New research is urgently needed to guide a change in course.

Disclosures: K. Taylor reports the following: Other Interests or Relationships: I was the Corporate Vice President of Quality for Fresenius Kidney Care (FKC) from September 2016 through December 2017. I am currently a PhD student/candidate at the Johns Hopkins University School of Nursing. I do not currently have any financial interests, relationship, or commitment with Fresenius Kidney Care. D. Crews reports the following: Consultancy: Yale New Haven Health Services Corporation Center for Outcomes Research and Evaluation (CORE); Research Funding: Somatus, Inc.; Baxter International; Honoraria: Maze Therapeutics; Advisory or Leadership Role: Editorial Board--Journal of Renal Nutrition, Clinical Journal of the American Society of Nephrology, Journal of the American Society of Nephrology; Associate Editor, Kidney360; Co-Chair, Bayer HealthCare Pharmaceuticals Inc. Patient and Physician Advisory Board Steering Committee for Disparities in Chronic Kidney Disease Project; Advisory Group, Health Equity Collaborative, Partner Research for Equitable System Transformation after COVID-19 (PRESTAC), Optum Labs; and Other Interests or Relationships: Board of Directors, National Kidney Foundation of Maryland/Delaware; Nephrology Board, American Board of Internal Medicine; Council of Subspecialist Societies, American College of Physicians. The remaining authors have nothing to disclose.

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Author Contributions: Kathryn Taylor: Conceptualization; Formal analysis; Methodology; Writing - original draft; Writing - review and editing Ebele Umeukeje: Writing - review and editing Sydney Santos: Formal analysis; Writing - review and editing Katherine McNabb: Writing - review and editing Deidra Crews: Writing - review and editing Melissa Hladek: Formal analysis; Methodology; Supervision; Writing - review and editing

Data Sharing Statement: There are no data underlying this work.

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

Kathryn S. Taylor\textsuperscript{a}; Ebele M. Umeukeje\textsuperscript{b}; Sydney R. Santos\textsuperscript{c}, Katherine C. McNabb\textsuperscript{a}; Deidra C. Crews\textsuperscript{d}; Melissa D. Hladek\textsuperscript{a}

\textsuperscript{a} Johns Hopkins University School of Nursing, Baltimore, Maryland, United States

\textsuperscript{b} Division of Nephrology, Vanderbilt University Medical Center, Nashville, TN

\textsuperscript{c} Behavioral Biology, Johns Hopkins University, Baltimore, Maryland, United States

\textsuperscript{d} Division of Nephrology, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland

Corresponding Author: Kathryn Taylor, RN, MPH

Johns Hopkins University School of Nursing

525 N. Wolfe St.

Baltimore, Maryland 21205 United States

Tel: (302)245-2641

E-mail: ktaylo45@jhmi.edu
Key Points

- Qualitative research that explores hemodialysis patient perspectives about adherence may point to gaps in existing adherence interventions.
- Patients’ goals included balancing treatment and competing priorities, preserving a sense of their “old selves,” and minimizing symptoms.
- Adherence may improve when clinicians routinely elicit patients’ goals and partner to resolve conflicts between those goals and adherence.

Abstract

**Background** Patients with end-stage kidney disease treated with hemodialysis in the U.S. have persistently higher rates of nonadherence compared to patients 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 patients 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 patients’ 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. Patients 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 patients on hemodialysis are inadequate. 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 dialysis. New research is urgently needed to guide a change in course.
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) Patients with ESKD receiving hemodialysis in the U.S. have a 33% increased risk of death compared to similar patients in Europe and a nearly 4-fold increase compared to patients 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 hemodialysis patients in the U.S. missed at least one dialysis treatment in a 4-month period, compared to less than 1% of patients in Japan. (6) U.S. hemodialysis patients also report skipping their phosphate binders more frequently than patients in other developed countries. (7) In addition to mortality, nonadherence is associated with increased hospitalization and medical expenditure. (8) Given the increasing prevalence of hemodialysis patients 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 patients 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 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. Despite recognition of the burden of social determinants of health in the hemodialysis population,
nearly all adherence interventions focused on the patient level (i.e., fixed and modifiable characteristics of individual patients).(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 necessary components for sustained improvement, further exploration of the qualitative data is needed. Qualitative research about adherence that explores the perspectives of patients on hemodialysis in the U.S. 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 patients with chronic kidney disease. However, one synthesis excluded patients on kidney replacement therapy (15) and one included patients across all chronic kidney disease stages and on hemodialysis or peritoneal dialysis.(16) Hemodialysis patient perspectives on adherence across all domains of the ESKD treatment regimen remain largely unknown. Therefore, the aim of this review was two-fold: (1) to synthesize qualitative data from patients on hemodialysis in the U.S. 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, patient-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 adult hemodialysis patients experience adherence to hemodialysis treatment? We intentionally framed the research question broadly to capture a wide range of adherence factors from the literature. 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 adult hemodialysis patients. We included qualitative or mixed methods studies for full text review that explored patient experiences on dialysis 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. Conceptually, adherence could apply to any recommended treatment, and articles reporting patient 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 patients on hemodialysis. If studies included other chronic diseases or dialysis modalities, we excluded them when we could not ascertain whether hemodialysis patients were the source of qualitative data. 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).
Finally, we conducted a quality appraisal per criteria from Carroll and colleagues. Quality appraisal methods for qualitative research are subject to debate. 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. 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). 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).

**Thematic Analysis**

Two authors (MH and KT) conducted a thematic analysis 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 I). Table I 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 II displays a new adherence framework for patients on hemodialysis derived from the WHO adherence framework and our inductive qualitative data analysis. Table II 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 patients’ whole lives and (2) dialysis treatment as a double-edged sword.

**Adherence in the context of patients’ whole lives**

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

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

“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 patients described feeling too weak at home to prepare healthy meals or eat. Though these subcodes appeared infrequently, we included them as distinct subcodes because of their relevance in existing adherence literature.

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

*Treatment as a double-edged sword*
Patients across multiple studies acknowledged that adherence to dialysis treatment, medications, and fluid or dietary restrictions could prolong their lives and alleviate negative symptoms. However, patients also described adherence as making them feel worse physically and some questioned the benefits or rationale for treatment. Dialysis left some feeling tired, hungry, or “depleted.” Patients explained that strict dietary adherence made them too weak to function. 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. Faced with treatment that could make them feel better or worse, patients trusted a subjective sense of “feeling sick” to guide adherence behavior.

Additionally, patients and family members grieved the life they had before dialysis initiation. Patients described their grief more frequently and richly than physical symptoms. Grief impacted nonadherence when patients missed treatment or tested food or dietary restrictions to preserve a sense of their self before dialysis. Related but distinct from this grief process were patients’ affective responses to dialysis. Patients described feeling afraid watching their blood leave their bodies and hated or “dreaded” dialysis like a “crummy job.” Though dialysis was life-saving, some patients felt depressed or anxious about the future. One patient stopped making plans because she did not know when she would die. For some, a sense of comradery or belonging with other patients and dialysis facility staff could improve adherence. Patients described appreciating when clinicians “jumped on their case” when they “started messing up” like they were family. Other patients navigated dialysis as a double-edged sword by adhering just enough to preserve a sense of self and stay alive.

*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 III 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 patients’ whole lives” 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 patients’ outcome expectations and illuminates that patients on hemodialysis do not always perceive the outcomes of adherence as positive. Lastly, Social Cognitive Theory clarifies that patients adhere to treatment if adherence aligns with their goals. Both themes emerging from the qualitative data clarify that hemodialysis patients’ goals 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 patient.

DISCUSSION

The adherence framework for people on hemodialysis constructed via our qualitative synthesis included 20 distinct factors within five adherence domains. These factors emerged from qualitative studies sampling patients receiving hemodialysis in the United States, a country with relatively high rates of medication and treatment nonadherence. 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 adherence 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 dialysis patients 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 patients from one large
dialysis organization demonstrated that odds of missing a treatment increased by 20 percent when patients had depression or relied on van transportation. Additionally, patients were nearly twice as likely to miss dialysis treatments when scheduled on holidays or patients’ birthdays. The qualitative data detailing patients’ 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 patient level. For example, interventions included health contracts, cognitive behavioral therapy, and educational videos. However, one-size-fits-all approaches to improving individual elements of ESKD adherence among patients on hemodialysis are likely inadequate. Instead, interventions can address multiple, concurrent barriers across adherence domains.

Within the social and economic adherence domain, food provision may improve adherence for patients 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 and participant tradeoffs between medical care and food. Antiretroviral adherence significantly improved. Within the health system domain, our review suggests that adherence may improve when clinicians routinely elicit patients’ goals and partner to resolve conflicts between those goals and adherence. Clinicians can develop a therapeutic alliance so patients feel comfortable sharing their experience and believe that sharing will make a difference in care. Rather than targeting individual components of the ESKD regimen, interventions that address treatment and condition adherence domains can
provide ongoing support to patients and families as they navigate the logistical, physical, and psychological hardships of living with ESKD and hemodialysis.

Despite a wealth of observational and intervention research on nonadherence among patients 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. Adherence interventions that concurrently address barriers within multiple adherence domains can include qualitative arms to explain how 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 patients. Multiple studies have demonstrated associations between adherence and patient race, such that White patients have higher rates of adherence across different adherence measures. 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. 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 patient 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.

DISCLOSURES

K. Taylor reports the following: Other Interests or Relationships: I was the Corporate Vice President of Quality for Fresenius Kidney Care (FKC) from September 2016 through December 2017. I am currently a PhD student/candidate at the Johns Hopkins University School of Nursing. I do not currently have any financial interests, relationship, or commitment with Fresenius Kidney Care. D. Crews reports the following: Consultancy: Yale New Haven Health Services Corporation Center for Outcomes Research and Evaluation (CORE); Research Funding: Somatus, Inc.; Baxter International; Honoraria: Maze Therapeutics; Advisory or Leadership Role: Editorial Board--Journal of Renal Nutrition, Clinical Journal of the American Society of Nephrology, Journal of the American Society of Nephrology; Associate Editor, Kidney360; Co-
Chair, Bayer HealthCare Pharmaceuticals Inc. Patient and Physician Advisory Board Steering Committee for Disparities in Chronic Kidney Disease Project; Advisory Group, Health Equity Collaborative, Partner Research for Equitable System Transformation after COVID-19 (PRESTAC), Optum Labs; and Other Interests or Relationships: Board of Directors, National Kidney Foundation of Maryland/Delaware; Nephrology Board, American Board of Internal Medicine; Council of Subspecialist Societies, American College of Physicians. The remaining authors have nothing to disclose.

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AUTHOR CONTRIBUTIONS

KT conceptualized the study and wrote the original manuscript draft. KT and MH developed study design. KT, MH, and SS conducted data collection and analysis. All authors contributed to review and editing.

SUPPLEMENTAL MATERIAL

Relevant search terms and medical subject headings.
References


47. Bandura A. Health promotion by social cognitive means. Health Educ Behav. 2004 April 01;31(2):143-64.
<table>
<thead>
<tr>
<th>Study</th>
<th>Research Aim &amp; Design</th>
<th>Sample</th>
<th>Data Collection &amp; Interview/Focus Group Questions (Select)</th>
<th>Reported Data Analysis Method</th>
<th>Quality Appraisal of Methods Reporting</th>
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<tr>
<td><strong>Boehmer et al., 2021</strong>&lt;sup&gt;(30)&lt;/sup&gt;</td>
<td>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</td>
<td>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.</td>
<td>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?”</td>
<td>Grounded theory</td>
<td>✓ Study question &amp; design   ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
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<td><strong>Chenitz et al., 2014</strong>&lt;sup&gt;(28)&lt;/sup&gt;</td>
<td>To explore patient attitudes about dialysis, health beliefs related to missed treatments, barriers and facilitators to attendance. Qualitative descriptive study</td>
<td>Purposive sample of 15 nonadherent and 15 adherent patients on ICHD. On ICHD ≥ 6 months, ≥ 18 y/o, English-speaking.</td>
<td>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”</td>
<td>Grounded theory</td>
<td>✓ Study question &amp; design   ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
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<tr>
<td><strong>Clark-Cutaia et al., 2019</strong>&lt;sup&gt;(33)&lt;/sup&gt;</td>
<td>To explore barriers to following the hemodialysis diet. Qualitative descriptive study.</td>
<td>Purposive sample of 30 patients on ICHD enrolled in RCT, selected for “racial and economic and diversity”. ICHD ≥ 3months, ≥ 18 y/o</td>
<td>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?”</td>
<td>Qualitative analysis per Crabtree and Miller (1999)</td>
<td>✓ Study question &amp; design   ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
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<tr>
<td><strong>Karolich and Ford, 2010</strong>&lt;sup&gt;(35)&lt;/sup&gt;</td>
<td>To explore how older adults with ESKD attach meaning to their illness, and how that meaning is related to illness comprehension and</td>
<td>Purposive sample of 10 adults on ICHD scoring high or low on Orientation to Life scale.</td>
<td>Semi-structured interviews. “What is the main reason you come to dialysis and follow the treatment plan prescribed by your doctor?”</td>
<td>Interview responses grouped according to concepts in the Orientation to Life</td>
<td>✓ Study question &amp; design   ✓ Sampling approach ✓ Data collection methods</td>
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**TABLES**

**Table I. Details from Included Studies**
<table>
<thead>
<tr>
<th>Study</th>
<th>Research Aim &amp; Design</th>
<th>Sample</th>
<th>Data Collection &amp; Interview/Focus Group Questions (Select)</th>
<th>Reported Data Analysis Method</th>
<th>Quality Appraisal of Methods Reporting</th>
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<tr>
<td>Management</td>
<td>Concurrent mixed methods study; qualitative arm applied qualitative descriptive design</td>
<td>ICHD ≥ 6 months, ≥ 50 y/o</td>
<td></td>
<td>Scale</td>
<td>✓ Data analysis methods</td>
</tr>
<tr>
<td>Krueger, 2009(37)</td>
<td>To explore Hmong experiences with hemodialysis &amp; experiences of nurses working with Hmong patients</td>
<td>3 male Hmong patients on ICHD</td>
<td>Interviews during dialysis treatment Questions not reported</td>
<td>Thematic analysis</td>
<td>✓ Study question &amp; design</td>
</tr>
<tr>
<td>O’Brien, 1990(27)</td>
<td>To examine relationships between social support and compliance behavior among maintenance hemodialysis patients</td>
<td>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</td>
<td>Interviews guided by the “Dialysis Patient Focused Interview Guide”</td>
<td>Not reported</td>
<td>✓ Study question &amp; design</td>
</tr>
<tr>
<td>Parker et al., 2017(31)</td>
<td>To explore self-management strategies and experiences of medication management among patients on hemodialysis</td>
<td>13 patients on ICHD ≥18 y/o, English-speaking; excluded patients living in long term care or assisted living facilities</td>
<td>Semi-structured interviews with 1-2 patients at a time</td>
<td>Thematic and framework analysis</td>
<td>✓ Study question &amp; design</td>
</tr>
<tr>
<td>Robinson et al., 2019(29)</td>
<td>To explore Black older adults’ experiences living with ESKD and on dialysis</td>
<td>Purposive sample of 16 Black patients on ICHD ≥ 65 y/o, oriented to “Tell me about your experience with”</td>
<td>Interviews during dialysis treatment or at participants’ homes</td>
<td>Thematic analysis</td>
<td>✓ Study question &amp; design</td>
</tr>
<tr>
<td>Study</td>
<td>Research Aim &amp; Design</td>
<td>Sample</td>
<td>Data Collection &amp; Interview/Focus Group Questions (Select)</td>
<td>Reported Data Analysis Method</td>
<td>Quality Appraisal of Methods Reporting</td>
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<tr>
<td></td>
<td>Qualitative descriptive study</td>
<td>person, place, time</td>
<td>end stage renal disease”</td>
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<tr>
<td><strong>Smith et al., 2010(36)</strong></td>
<td>To describe patient experiences with fluid management to guide adherence interventions</td>
<td>Convenience sample of 19 patients on ICHD ≥ 18 y/o, English-speaking, able to give informed consent</td>
<td>Focus groups “What makes you feel more confident in your ability to meet your fluid goals?”</td>
<td>Content analysis</td>
<td>✓ Study question &amp; design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
</tr>
<tr>
<td><strong>Senteio and Veinot, 2014(34)</strong></td>
<td>To describe the “work” of adherence among African Americans who live in high-poverty communities and how “visible” it is to healthcare providers</td>
<td>Purposive sample of 37 participants 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</td>
<td>Semi-structured interviews in private locations Questions not reported</td>
<td>Straussian grounded theory systematic approach</td>
<td>✓ Study question &amp; design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
</tr>
<tr>
<td><strong>Tijerina, 2009(38)</strong></td>
<td>To explore psychosocial, cognitive, and cultural factors that shape adherence behavior in Mexican American women</td>
<td>Purposive sample of 26 Mexican American women on ICHD ICHD ≥ 6 months, 30-55 y/o</td>
<td>Interviews in patients’ homes Questions not reported</td>
<td>Thematic analysis from social constructivist perspective</td>
<td>✓ Study question &amp; design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
</tr>
<tr>
<td><strong>Wells, 2015(32)</strong></td>
<td>To explore occupational changes and perceptions experienced by Mexican Americans with ESKD and their families living with dialysis.</td>
<td>17 Mexican American patients with ESKD and their family members Patients on ICHD ≥ 6 months</td>
<td>Semistructured interviews at dialysis center or patients’ homes Questions not reported</td>
<td>Thematic analysis</td>
<td>✓ Study question &amp; design ✓ Sampling approach ✓ Data collection methods ✓ Data analysis methods</td>
</tr>
<tr>
<td>Study</td>
<td>Research Aim &amp; Design</td>
<td>Sample</td>
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<td>Phenomenological design</td>
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<td>methods</td>
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**ICHD** In-center hemodialysis
Table II. Factors Impacting Adherence for People on Hemodialysis with Supporting Qualitative Data

<table>
<thead>
<tr>
<th>Social and economic factors</th>
<th>Qualitative Data</th>
</tr>
</thead>
</table>
| 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)] |

<table>
<thead>
<tr>
<th>Health system related</th>
<th>Qualitative Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support from clinicians</td>
<td>“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)]</td>
</tr>
</tbody>
</table>
| 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)] |

<table>
<thead>
<tr>
<th>Condition-related factors</th>
<th>Qualitative Data</th>
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</thead>
<tbody>
<tr>
<td>Disability or loss of function</td>
<td>“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)]</td>
</tr>
<tr>
<td>Feeling/not feeling sick</td>
<td>“What really helps me [adhere to a fluid restriction] is remembering what it’s like to not breathe.” [Smith et al., 2010 (36)]</td>
</tr>
</tbody>
</table>
"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**

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<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td>Therapy-related factors</td>
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</tr>
<tr>
<td>Life sustaining nature of dialysis</td>
<td>“I don’t like it, but you know, it keeps me alive, so I got to do it.” [Chenitz et al., 2014 (28)]</td>
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<tr>
<td></td>
<td>“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)]</td>
</tr>
<tr>
<td>Treatment makes you feel worse/questioning treatment</td>
<td>“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)]</td>
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<tr>
<td>Length of dialysis</td>
<td>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)]</td>
</tr>
<tr>
<td>Craving food or fluid</td>
<td>“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)]</td>
</tr>
<tr>
<td>Complexity of treatment</td>
<td>“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)]</td>
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<tr>
<td>Patient-related factors</td>
<td></td>
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<tr>
<td>Hating, fearing, or dreading dialysis</td>
<td>“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.” [Karoliich and Ford, 2010 (35)]</td>
</tr>
<tr>
<td>Depression or anxiety about the future</td>
<td>“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)]</td>
</tr>
<tr>
<td>Grief over/acceptance of loss of old self</td>
<td>“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)]</td>
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<td></td>
<td>“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, oh, what the Lord is doing to you, why you can’t understand it?’” [Robinson et al., 2019 (29)]</td>
</tr>
<tr>
<td>Balancing treatment and life</td>
<td>“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</td>
</tr>
</tbody>
</table>
"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)]

<table>
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<tr>
<th>Desire for tailored treatment</th>
<th>“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)]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-management strategies</td>
<td>“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)]</td>
</tr>
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Figure I. Flow diagram of literature search and selection

Records identified through database searching
Embase (n=1071) PubMed (n= 691)
Web of Science (n=418)
CINAHL (n=355) PsychInfo (n=99)

Records after duplicates removed
n=1775

Titles/abstracts screened
n=1775

Records excluded
n=1676

Full-text articles assessed for eligibility
n=99

Full-text articles excluded
Not US-based (n=59)
Not qualitative research (n=16)
Not patients on dialysis (n=7)
Not adherence-related (n=4)
No qualitative data reported (n=1)

Studies included in qualitative synthesis
n=12
Figure II. Adapted WHO Adherence Framework for People on Hemodialysis

- **Patient Related**
  - Hating, fearing, or dreading dialysis
  - Depression or anxiety about the future
  - Grief over/acceptance of loss of old self
  - Balancing treatment & life
  - Desire for tailored treatment
  - Self-management strategies

- **Social & Economic**
  - Financial strain
  - Food insecurity
  - Support from friends or family
  - Support from peers

- **Therapy Related**
  - Life sustaining nature of dialysis
  - Treatment makes you feel worse/questioning treatment
  - Length of dialysis
  - Craving food or fluid
  - Complexity of treatment

- **Condition Related**
  - Disability or loss of function
  - Feeling/not feeling sick

- **Health System Related**
  - Support from clinicians
  - Patient & family education or comprehension
  - Transportation to/from dialysis
Figure III. Integration of Social Cognitive Theory and select adherence factors emerging from the qualitative data

OUTCOME EXPECTATIONS
Dialysis treatment as a double-edged sword
Physical
• Treatment makes you feel worse/questioning treatment*
• Feeling/not feeling sick*
Social
• Support from peers
• Support from clinicians
Self-evaluative
• Grief over loss of old self*

BEHAVIOR
• (Non)adherence to treatment, medications, or fluid and dietary restrictions
• Self-management strategies
• Desire for tailored treatment

KNOWLEDGE
• Patient or family education or comprehension

SELF-EFFICACY

GOALS
• Balancing treatment and life*

SOCIOSTRUCTURAL FACTORS
Adherence in the context of patients’ whole lives
Impediments
Personal and situational
• Financial strain*
• Food insecurity*
Health system
• Transportation to/from dialysis
Facilitators
• Support from friends or family

*Mediating adherence factors and relationships unaddressed in published RCTs

Adapted from Bandura(47)
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<td>('patient compliance'/exp OR 'cooperation'/exp OR cooperat*:ti,ab,kw OR complian*:ti,ab,kw OR adher*:ti,ab,kw) AND ('chronic kidney failure'/exp OR 'end stage renal disease'/exp OR 'chronic renal disease':ti,ab,kw OR 'chronic renal insufficiency':ti,ab,kw OR 'end-stage renal disease':ti,ab,kw OR esrd:ti,ab,kw OR dialysis:ti,ab,kw OR hemodialysis:ti,ab,kw) AND ('qualitative research'/exp OR 'empirical research'/exp OR 'interview'/exp OR 'ethnographic research'/exp OR 'grounded theory'/exp OR 'narrative'/exp OR qualitative:ti,ab,kw OR 'grounded theory':ti,ab,kw OR narrative:ti,ab,kw OR historical:ti,ab,kw OR phenomenological:ti,ab,kw OR ethnographic:ti,ab,kw OR 'case study':ti,ab,kw OR narration:ti,ab,kw OR observation:ti,ab,kw OR 'focus group':ti,ab,kw)</td>
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# Relevant search terms and medical subject headings

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