NATIONAL KIDNEY
FOUNDATION®

Council of Nephrology Social Workers

The Journal of Nephrology Social Work

Volume 44 • Issue 2 • 2020

- Structural Racism and the Racial Medication Adherence Inequity
- Eye Care Utilization Among Older Insured Adults with Kidney Disease and Diabetes
- COVID-19: A Dialysis Social Worker's Response
- Stalking in Dialysis and Transplant

Free* Online CME/CE Courses

For professionals committed to continuing their education and improving patient outcomes. More discipline-specific courses than ever before...and new courses added regularly!

- Physicians
- Pharmacists
- Advanced Practitioners
- Nurses
- Dialysis Technicians
- Dietitians
- Social Workers
- Transplant Professionals

PERC

PROFESSIONAL EDUCATION RESOURCE CENTER

Take courses on a range of topics given by renowned faculty and carefully selected by the National Kidney Foundation (NKF).

Create a personalized account so you can view your completed courses in one place.

*Free for NKF members. Not a member? Join today: *kidney.org/about/membership*

kidney.org/education

NATIONAL KIDNEY FOUNDATION®

NATIONAL KIDNEY FOUNDATION®

The Journal of
Nephrology Social Work

The Journal of Nephrology Social Work is published by the Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation, Inc. Professional membership in the NKF-CNSW ($115.00 annually) includes subscriptions to *The Journal of Nephrology Social Work, RenaLink,* and selected materials as they are published by the National Kidney Foundation, Inc. Further membership information is available from the National Kidney Foundation at 888.JOIN.NKF or from the NKF-CNSW website at **www.kidney.org/cnsw** or by contacting the CNSW Publications Chair, Jeff Harder, MSW, LICSW, FNKF, at **jharder@uw.edu**

THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

Editor
TERI BROWNE, PhD, MSW, University of South Carolina College of Social Work, Columbia, SC

Publications Chair
JEFF HARDER, MSW, LICSW, FNKF, University of Washington Medical Center, Seattle, WA

Editorial Board
EMILY AVERETTE, MSW, LCSW, NSW-C, Department of Veterans Affairs, Fayetteville, NC
STEVE BOGATZ, MBA, MSW, LCSW, NSW-C, Fresenius Medical Center Central CT Dialysis, Meriden, CT
JENNIFER K. BRUNS, LMSW, CCTSW, St. John Hospital & Medical Center Transplant Social Work, Troy, MI
MARY BETH CALLAHAN, ACSW, LCSW, Dallas Transplant Institute, Dallas, TX
MAYA DOYLE, PhD, LCSW, Quinnipiac University School of Health Sciences, Department of Social Work, Hamden, CT
SHILOH D. ERDLEY, DSW, Geisinger Medical Center Outpatient Hemodialysis Unit, Danville, PA
ANNE GOMES, MSW, MPH, MPA, University at Albany School of Social Welfare, Albany, NY
JEFF HARDER, MSW, LICSW, University of Washington Medical Center, Seattle, WA
LINDA HENSON, MSW, LMSW, Fresenius Medical Care, St. Louis, MO
SURVEEN KLEIN, LCSW-BACS, MPH, Ochsner Medical Center Multi-Organ Transplant Institute, New Orleans, LA
KAYLA LEDVINA, MSW, LSW, Dialyze Direct, Highland Park, NJ
CARRIE L. MEANS, MSW, LISW, University of Iowa Hospitals and Clinics, North Liberty, IA
JOSEPH MERIGHI, MSW, PhD, University of Minnesota School of Social Work, Saint Paul, MN
KENDALL L. MOODY, MSW, Norfolk State University School of Social Work, Virginia Beach, VA
DORI MUENCH, MSW, LCSW, NSW-C, Triad Dialysis Center, High Point, NC
JERRY F. REYNOLDS II, LMSW, MSW, PhD, University of South Carolina College of Social Work, Columbia, SC
RICK RUSSO, MSW, LMSW, DaVita Riddle Dialysis Center, Media, PA
ASHLEY SAUERS, LGSW, The Comprehensive Transplant Center, Kidney Transplant, Johns Hopkins Hospital, Baltimore, MD
TAMARA ESTES SAVAGE, MSW, PhD, University of North Carolina Pembroke, Pembroke, NC
EDWARD G. SILVERHARDT, LCSW (NV), LSCSW (KS), BCD, Center for Applied Behavioral Sciences, Reno, NV
PARASKEVI THEOFILOU, PhD, University of Thessaly, Thessaly, Greece
MEGAN URBANSKI, MSW, LCSW, Temple University Health System, Philadelphia, PA
TIFFANY WASHINGTON, PhD, MSW, University of Georgia School of Social Work, Athens, GA
CAMILLE M. YUSCAK, LCSW-R, Hospice care in Westchester & Putnam, Tarrytown, NY

© 2020 National Kidney Foundation, Inc. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means now or hereafter known, electronic or mechanical, including photocopy, recording or any information storage and retrieval system, without permission in writing from the publisher.

ISSN 1532-0863

TABLE OF CONTENTS

JOIN THE *JNSW* EDITORIAL BOARD

The Journal of Nephrology Social Work Editorial Board is comprised of nephrology social work experts who engage in research, policy analysis, and clinical practice. The board members include university faculty members and social work clinicians who are leaders and innovators in the field.

The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

If you are interested in submitting your resume for consideration to become a member of the Editorial Board, please contact Teri Browne, PhD, MSW, NSW-C by email **(browne@sc.edu**) or phone (803.777.6258).

CALL FOR MANUSCRIPTS

The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

- Social Work Outcomes
- Kidney Transplant
- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
- Home Dialysis Modalities
- Professional Roles
- Rehabilitation
- HIV/AIDS
- Diversity/Discrimination Issues
- Quality of Life
- Ethics

Please email manuscripts to: **jnsw@kidney.org** Questions? Contact Editor Teri Browne, PhD, MSW, NSW-C by email (**browne@sc.edu**) or phone (803.777.6258).

INSTRUCTIONS FOR AUTHORS

The Journal of Nephrology Social Work (*JNSW*) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. *JNSW* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

ETHICAL POLICIES

Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics [**http://www.socialworkers.org/pubs/code/code.asp**]; see clause 5.02 (a)-(p) focused on research. This portion of the code pertains to conflicts of interest, research with human participants, and informed consent. Per the code, "Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary." Authors who submit manuscripts to *JNSW* must disclose potential conflicts of interest, which may include, but are not limited to, grants, remuneration in payment or in kind, and relationships with employers or outside vendors. When in doubt, authors are expected to err on the side of full disclosure. Additional information about conflicts of interest may be obtained via the International Committee of Medical Journal Editors' Uniform Requirement for Manuscripts Submitted to Biomedical Journals (URMSBJ): Ethical Considerations in the Conduct and Reporting of Research [**http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html**].

Human/Animal Rights. Regarding human rights, the NASW code is specific: "Social workers engaged in evaluation or research should carefully consider possible consequences and should follow guidelines developed for the protection of evaluation and research participants. Appropriate institutional review boards should be consulted…. Social workers should take appropriate steps to ensure that participants in evaluation and research have access to appropriate supportive services…. Social workers engaged in evaluation or research should protect participants from unwarranted physical or mental distress, harm, danger, or deprivation." In the unlikely event that animals are involved in research submitted to *JNSW*, per URMSBJ, "authors should indicate whether the institutional and national guide for the care and use of laboratory animals was followed."

Informed Consent. The practice of informed consent is mandatory for ethical research. In accordance with the NASW code, "Social workers engaged in evaluation or research should obtain voluntary and written informed consent from participants…without any implied or actual deprivation or penalty for refusal to participate; without undue inducement to participate; and with due regard for participants' well-being, privacy, and dignity. Informed consent should include information about the nature, extent, and duration of the participation requested, and disclosure of the risks and benefits of participation in the research. When evaluation or research participants are incapable of giving informed consent, social workers should provide an appropriate explanation to the participants, obtain the participants' assent to the extent they are able, and obtain written consent from an appropriate proxy. Social workers should never design or conduct evaluation or research that does not use consent procedures, such as certain forms of naturalistic observation and archival research, unless rigorous and responsible review of the research has found it to be justified because of its prospective scientific, educational, or applied value, and unless equally effective alternative procedures that do not involve waiver of consent are not feasible. Social workers should inform participants of their right to withdraw from evaluation and research at any time without penalty."

PEER REVIEW PROCESS

Manuscripts submitted to *JNSW* are peer-reviewed, with the byline removed, by at least two Editorial Board members. The review process generally takes two to three months. *JNSW* reserves the right to edit all manuscripts for clarity or length. Minor changes in style and clarity are made at the discretion of the reviewers and editorial staff. Substantial changes will only be made with the primary author's approval.

Exclusive Publication. Manuscripts are accepted for review with the understanding that the material has not been previously published, except in abstract form, and are not concurrently under review for publication elsewhere. Authors should secure all necessary clearances and approvals prior to submission. Authors submitting a manuscript do so with the understanding that, if it is accepted for publication, the copyright for the article, including the right to reproduce the article in all forms and media, shall be assigned exclusively to the National Kidney Foundation. The publisher will not refuse any reasonable request by the author for permission to reproduce any of his or her contributions to the *Journal*.

A submitted manuscript should be accompanied by a letter that contains the following language and is signed by each author: "**In compliance with the Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled _______________ to *The Journal of Nephrology Social Work* in the event this material is published.**"

To qualify as an original manuscript, the article or a version of the article must not have been published elsewhere. The author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions to the manuscript.

TYPES OF MANUSCRIPTS BEING SOUGHT

Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider manuscripts that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

Reports and Commentary. The *JNSW* welcomes manuscripts that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field, or that provide historical perspectives on renal social work. Commentaries are published with the following disclaimer: "The statements, comments, or opinions expressed in this article are those of the author, who is solely responsible for them, and do not necessarily represent the views of the Council of Nephrology Social Workers or the National Kidney Foundation."

Original Research. Full manuscript format should include: introduction, method, results, and discussion of original research. The method section needs either a declaration of IRB approval or exemption. Length should usually not exceed 15 double-spaced pages, including references.

Clinical/Research Briefs. Abbreviated manuscript format presents clinical practice experience, preliminary research findings (basic or clinical), or professional observations in a shortened report form. Length should usually not exceed six double-spaced pages.

Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

Case Studies. These detailed scenarios should illustrate a patient care situation that benefited from clinical social work intervention. Typically, they should consist of a brief clinical and psychosocial history, and a detailed intervention plan with discussion of recommendations focused toward practical application.

Letters to the Editor. Letters should be restricted to scientific commentary about materials published in the *JNSW* or to topics of general interest to professionals working in the field of renal social work.

MANUSCRIPT SUBMISSION PROCESS

Manuscript Format. Manuscripts should be formatted according to the rules laid out by the *Publication Manual of the American Psychological Association, Sixth Edition.* What follows is a brief synopsis of the broader style points used by the APA.

Manuscripts should conform to the following guidelines: Text should be double-spaced, set in 12-point type (preferably Times New Roman), and have 1-inch margins along all sides of every page. Starting with the title page, pages should be numbered in the upper, right-hand corner and should have a running head in the upper left-hand corner. The running head should be a shortened version of the manuscript's title and should be set in all uppercase letters. The first line of every paragraph in the manuscript should be indented, as should the first line of every footnote.

Order of the Manuscript Sections

1) Title page
2) Abstract
3) Text
4) References
5) Appendices (optional)
6) Author note
7) Tables
8) Figures with captions

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the APA style guide for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

Abstract. The manuscript's abstract should be set on its own page, with the word "Abstract" centered at the top of the page. The abstract itself should be a single paragraph with no indentation and should not exceed 120 words. All numbers—except for those that begin a sentence—should be typed as numerals. Running heads and page numbers should continue from the title page.

Text. The text (or body) of the manuscript should begin on a new page, after the abstract. The title of the manuscript should be set at the top of the first page, centered and double spaced. Running heads and page numbers should continue from the abstract.

References. The reference list should begin on a new page, with the word "References" centered at the top of the page. Entries should be listed alphabetically, according to the primary author's last name, and must conform to APA style, 6th edition. Running heads and page numbers should continue from the text. If you use software to format your references, please be sure that the software edits are "de-linked" before submitted (i.e., all text should be in plain text, not with software tracking). All references must have a corresponding citation in the article.

Appendices. Each appendix should begin on a new page and should be double spaced. The word "Appendix" and the identifying letter (A, B, C, etc.) should be centered at the top of the first page of each new appendix. Running heads and page numbers should continue from the references.

Author Note. *JNSW* policy is to include an author note with disclosure information at the end of the article. It should begin on a new page with the words "Author Note" centered at the top of the page. Each paragraph should be indented. Running heads and page numbers should continue from the last appendix. Consult the APA style guide for further details on the structure of an author note.

Authors must include a two-sentence disclosure. The author note should include this disclosure (source of funding, affiliation, credentials) and contact information: "address correspondence to" primary author.

Tables. All tables should be double-spaced and each should begin on a separate page. Tables are numbered sequentially according to the order in which they are first mentioned in the manuscript (Table 1., Table 2., etc.) and are given an appropriate title that is centered at the top of the page. All tables must be referenced in the manuscript. Running heads and page numbers should continue from the Author Note. Please submit all table files in high-resolution format.

If a table has been previously published, the author is required to submit a copy of a letter of permission from the copyright holder, and must acknowledge the source of the table in the manuscript's reference section.

Figures. Figures are also numbered sequentially, according to the order in which they appear in the manuscript. The convention Figure 1., Figure 2., Figure 3., etc. should be followed. In cases where the orientation of the figure is not obvious, the word TOP should be placed on the page, well outside the image area, to indicate how the figure should be set. If any figure has been previously published, the author is required to submit a copy of a letter of permission from the copyright holder, and must acknowledge the source of the figure in the manuscript's reference section. Running heads and page numbers should continue from the tables. Please submit all figure files in high-resolution format.

Each figure in the manuscript must have a caption, formatted as follows:

Figure 1. Exemplary formatting for all figure captions.

ACCEPTANCE PROCESS

If a manuscript is accepted for publication, the author will be required to send the following to the editorial office:

- An electronic copy of the final version of the manuscript. All components of the manuscript must appear within a single word processing file, in the order listed previously. Any features that track or highlight edits should be turned off; do not forget to hit the "accept all changes" function first. Do not use automatic numbering functions, as these features will be lost during the file conversion process. Formatting such as Greek characters, italics, bold face, superscript, and subscript, may be used; however, the use of such elements must conform to the rules set forth in the APA style guide and should be applied consistently throughout the manuscript.
- Art, tables, figures, and images should be high-resolution TIFF or EPS file formats only. Most other file formats (PowerPoint, JPG, GIF, etc.) are not of sufficient resolution to be used in print. The resolution for all art must be at least 300 d.p.i. A hard copy of each figure should accompany the files.
- In addition to the images that appear in your word processing file, it is also important to send the images separately as individual files. These images should be 300 d.p.i. minimum.

Structural Racism and the Racial Medication Adherence Inequity Within the End-Stage Renal Disease Population: A New Theoretical Framework

Tamara Estes Savage, PhD, MSW, College of Health Sciences, University of North Carolina at Pembroke, Pembroke, NC

Blacks or African Americans are almost four times more likely to develop end-stage kidney disease (ESKD) than Whites (United States Renal Data System (USRDS), 2019). Black or African-American ESKD patients are also less likely to manage their medications successfully compared to White ESKD patients (Browne & Merighi, 2010; Curtin, Svarstad, Keller, 1999). Few studies, however, investigate broad social issues, such as structural racism, as a fundamental cause of the inequity. Furthermore, the interaction of structural racism and societal power dynamics in the form of social and cultural capital and their effect on medication adherence inequity has not been explored. This article examines this interaction and its link to medication adherence inequity in the Black or African-American ESKD population and posits a new theoretical framework.

INTRODUCTION

End-stage kidney disease (ESKD) currently affects 746,557 people in the United States (USRDS, 2019). A disproportionate number of ESKD patients are Black or African American (USRDS, 2019). According to the U.S. Renal Data System (2019), the prevalence of ESKD per million of the population for Whites is 1,573. Comparatively, the prevalence of ESKD per million for the Black or African American population is 5,816 (USRDS, 2019). Thus, Blacks or African Americans are over 3.5 times more likely to develop ESKD than Whites (USRDS, 2019).

In addition to being disproportionally affected by ESKD, Black or African-American ESKD patients are less likely to manage their medications successfully compared to White EKRD patients (Browne & Merighi, 2010; Curtin et al., 1999; Saran et al., 2003). However, the reasons for this racial inequity are not understood beyond the identified proximal risk factors. This is particularly troubling since ESKD patients who do not adhere to their medication regimen suffer decreased quality of life, increased morbidity, and death (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & De Geest, 2007; Saran et al., 2003). Hence, medication nonadherence is an important health inequity that is worthy of further investigation.

Given the racial inequity in medication adherence in ESKD patients, the societal response to race is worth consideration. Race is a social construct devised to justify an oppressive social hierarchy that privileges Whites. Therefore, race, "… precisely captures the impact of racism" (Jones, 2000, p. 1212). However, few studies have investigated broader social issues, such as racism, or, more specifically, structural racism, and their effect on Black or African-American ESKD patients' medication adherence (Kennedy, 2009; Wells & Walker, 2012). Instead, most studies report racial differences and attribute them to micro-level patient risk factors (Andrus & Roth, 2002; Cleary, Matzke, Alexander, & Joy, 1995; Lindberg & Lindberg, 2008). Some studies go further and report the difference in race to the risk factor, SES (socioeconomic status), but do not connect SES in any meaningful way to structural racism or medication adherence, except to add it to the long list of individual risk factors (Bame, Peterson, & Wray, 1993; Curtin et al., 1999; Kalichman, Ramachandran, & Catz, 1999).

A *fundamental cause perspective* allows the expansion of inquiry beyond micro-level risk factors to a broader social condition such as structural racism. To further enrich this analysis, Bourdieu's theory of societal power provides a framework for viewing the impact of structural racism on two forms of capital: social and cultural (Bourdieu, 1986). Sequentially, structural racism affects the societal power (capital) of Black or African-American ESKD patients, and this, in turn, affects risk factors proximally related to medication adherence. Thus, this author contends that structural racism is a fundamental cause of medication nonadherence in Black or African-American ESKD patients. The following is an examination of racial inequity and the role of structural racism as fundamental causes of medication adherence inequity in the Black or African-American ESKD population. Also, structural racism is integrated with Bourdieu's conceptualization of social and cultural capital to produce a new theoretical framework. Lastly, the implications of this new integrated framework and how it clarifies the current understanding of the medication adherence inequity is discussed.

Corresponding author: *Tamara Estes Savage, PhD, MSW, College of Health Sciences, University of North Carolina at Pembroke, 1 University Drive, Pembroke, NC 28372-1510; 910.620.3002;* ***tamara.savage@uncp.edu***

THE RACIAL INEQUITY AND RACISM

Racial inequity in medication adherence for ESKD patients is well documented. For example, Curtin and colleagues (1999) found in their study of Black or African-American and White ESKD patients that only race/ethnicity was significantly associated with poor medication adherence. Specifically, 60% of Blacks or African Americans were repeatedly nonadherent compared to 34% of Whites (Curtin et al., 1999). Similarly, Saran and colleagues (2003), in their study of 8,396 ESKD patients, found that Blacks or African Americans were twice as likely as Whites to be nonadherent. Although both authors found that being Black or African American was statistically associated with medication nonadherence, neither measured racism (Curtin et al., 1999; Saran et al., 2003). However, the authors note that racism may be a factor and urge researchers to study the construct (Curtin et al., 1999; Saran et al., 2003).

The relationship between racism and a primary precursor to ESKD, hypertension, is well-established. For instance, Kressin, Orner, Manze, Glickman, & Berlowitz (2010) discovered in their sample of 806 hypertensive Blacks or African Americans that those who reported more discrimination experiences were less adherent to their hypertensive medication regimens. Similarly, Cuffe et al. (2013) found that perceived discrimination was associated with lower medication adherence in their sample of 780 Black or African-American men and women. Lastly, in a study of 134 hypertensive Black or African-American men and women, the author found a negative association between high levels of perceived racism and medication adherence (Daramola, 2008). It is evident that there is a medication adherence inequity associated with perceived discrimination in both the hypertensive population, a primary antecedent to ESKD, and by extension the ESKD population, which is not well understood.

Scholars have attempted to understand this inequity by searching for proximal risk factors. Several risk factors associated with ESKD medication nonadherence are insufficient income, lack of education, lack of access to medications, pill burden, and social support (Browne & Merighi, 2010). However, scant attention has been given to broader social conditions, such as racism, and how they may affect the inequity (Wells & Walker, 2012). More fundamental causation may exist.

Applying the idea of structural racism as a fundamental cause of medication nonadherence in Black or African-American ESKD patients is a novel way of thinking about this inequity. Structural racism is a type of racism which is systemic, in which macro-level systems result in racial inequities. (Powell, 2007; Vaught & Castagno, 2008). Macro-level systems include societal norms, institutions, ideologies, and policies. In a racialized society, these macro systems interact and result in structural racism. The process of structural racism is subtle and does not require any overt racist verbiage or acts (Bonilla-Silva, 1997; Gee & Ford, 2011; Vaught & Castagno, 2008). Instead, structural racism is embedded in society's social, cultural, and historical fabric (Bonilla-Silva, 1997; Gee & Ford, 2011). Structural racism is normalized and becomes an unquestioned fact, especially by the dominant group. In addition, the complex interaction of many macro systems makes it difficult to detect and to eliminate structural racism (Gee & Ford, 2011). The following is a discussion of structural racism as a fundamental cause of medication nonadherence.

FUNDAMENTAL CAUSE THEORY

Link and Phelan (1995) argue that broad social conditions explain health outcomes through a group of intervening mechanisms or risk factors. The authors posit that, unless these social conditions are addressed, health outcomes will remain unchanged even though the risk factors are ameliorated. This is because the fundamental cause is still present; therefore, if all the risk factors are suddenly addressed and no longer risk factors, the health outcomes will not disappear. The health outcomes will remain as long as the broader social causes remain (Link & Phelan, 1995). Link and Phelan's (1995) theory is provocative, given that much of social science research has focused on proximal risk factors with the contention that once they are eradicated, then the resultant poor health outcomes will be eliminated. There are three tenets of the fundamental cause perspective: 1) resources such as power and prestige minimize risk and serve as protection from disease; 2) fundamental causes are linked to disease through a series of intervening mechanisms; 3) these intervening mechanisms can change over time, but the relationship between the fundamental cause and the disease stays constant (Link & Phelan, 1995). The following is a discussion of the application of the three tenets to structural racism and medication adherence in the Black or African-American ESKD population.

Tenet 1: ***Power and Prestige Minimize Risk of Poor Health***

According to the first tenet of the fundamental cause theory, resources minimize the risk of poor health outcomes. Structural racism, however, inherently results in lack of resources for the oppressed group through subtle societal norms, institutional practices, governmental policies, and cultural representations which result in a racial hierarchy that privileges Whiteness and disadvantages Blackness (Gee & Ford, 2011; Powell, 2007; Vaught & Castagno, 2008). Structural racism allows the dominant group to maintain power and control of resources at the expense of the oppressed group (Gee & Ford, 2011: Powell, 2007; Vaught & Castagno, 2008). Thus, a detrimental effect of structural racism in the U.S. is that Blacks or African Americans are denied the health protection that access to resources affords. As a result, Blacks or African Americans are exposed to health risks, which result in adverse health outcomes (American Public Health Association, 2001; Nazroo, 2003; Williams & Collins, 2001).

An example related to structural racism that can be applied directly to medication adherence in Blacks or African-American ESKD patients involves access to pharmacies. The Federal Housing Administration's segregated housing policies inculcated racial housing segregation into our society (Seitles, 1998; Williams & Collins, 2001). The racially restrictive lending policies of the nation's economic institutions additionally supported and perpetuated the practice (Seitles, 1998; Williams & Collins, 2001). Even though refusing to rent or sell a residence based on race was deemed illegal by the enactment of the Civil Rights Act of 1968, residential segregation still exists (Williams & Collins, 2001). Blacks or African Americans are more highly segregated than any other minority group in the U.S. (Logan & Stults, 2011). Also, since the housing crisis in 2007, Blacks or African Americans in poor communities have been disproportionately affected by unfair lending, which does not allow residential mobility (Steil, Albright, Rugh, & Massey, 2018).

As a result of continued residential segregation and unfair lending practices by financial institutions, Blacks or African Americans are often relegated to inferior housing in polluted and impoverished environments with limited access to health-promoting resources such as pharmacies (Gee & Ford, 2011; Williams & Collins, 2001). Amstislavski, Ariel, Sheffield, Maroko, and Weedon (2012) found a dearth of pharmacies, which they called “medication deserts” in poor, often predominately segregated Black or African-American communities. The authors' study involved 408 pharmacies in 168 socio-economically diverse communities and discovered that some poor communities were “medication deserts.” The authors also ascertained that pharmacies in poor communities had significantly higher odds of being out of stock of medicine and were more likely to be independent pharmacies. The independent pharmacies offered fewer services and were not open as often or as long per day as chain pharmacies (Amstislavski et al., 2012).

Structural racism in the form of historical governmental policies and banking practices that block Blacks or African Americans from moving from segregated housing has a detrimental effect on Blacks’ or African Americans’ ability to procure medication. The effects of such macrosystems influenced by racism (structural racism) have led to inadequate pharmacies and “medication deserts.” The geographical lack of access to medication is a risk factor for medication nonadherence. This is especially true for patients with ESKD, as they have little physical energy due to their illness to travel great distances to procure medication (Browne, Merighi, Washington, Savage, Shaver, & Holland, 2019).

<u>Tenet 2:</u> Fundamental Causes are Linked to Disease Through a Series of Intervening Mechanisms.

There is a multitude of intervening mechanisms, generally referred to as “risk factors,” that are associated with medication nonadherence in ESKD patients. Two risk factors often mentioned are lack of education and low income/poverty (Bame et al., 1993; Browne & Merighi, 2010; Caraballo, Lebrón de avilés, Dávila Torres, & Burgos Calderón, 2001; Neri et al., 2011). Both risk factors are related to structural racism.

First, within our racialized society, Blacks or African Americans have often received an inferior education (Williams, 1999). As discussed earlier, historical racial segregation due to governmental policies and restrictive lending policies of banks, as well as current unfair lending, have left many Blacks or African Americans living in social isolation (Gee & Ford, 2011; Seitles 1998; Williams & Collins, 2001). As with residential segregation, Blacks or African Americans were also forced to attend segregated schools. However, Brown v. Board of Education stated that separated schools were not equal and laid the legal groundwork for school integration (Williams, 1999). However, residential segregation has continued, and so has school segregation (Williams & Collins, 2001).

Currently, most Blacks or African Americans who attend public schools tend to go to schools within their local school district in which they reside (Williams, 1999). Thus, highly segregated communities have led to highly segregated schools (Williams, 1999). Today, two-thirds of Blacks or African Americans attend schools where more than 50% of the students are Black or African American (Powell, 2007). In addition, such highly segregated schools are 14 times more likely to be high poverty schools (Powell, 2007). Second, Poverty is another result of structural racism, as Blacks or African Americans historically were not able to benefit from income-producing New Deal initiatives because of racist federal policy or buy houses in job-rich suburban areas after WWII (Katznelson, 2005). Furthermore, Southern Blacks or African Americans did not benefit from post-WWII GI Bill opportunities because of rampant discriminatory practices of Southern universities (Turner & Bound, 2003).

This entrenched poverty, consequently, has resulted in impoverished schools. The poverty rate of schools has a profound effect on the educational outcomes of students. Attending a high poverty, highly segregated school results in poor educational attainment (Powell, 2007). For instance, according to the National Assessment of Adult Literacy, 24% of Blacks or African Americans scored below the lowest level of health literacy compared to 9% of Whites (Kutner, Greenburg, Jin, & Paulson, 2006). Health literacy involves the ability to understand medical advice regarding medications, including dosage instructions and the ability to comprehend the instructions on medication bottles (Andrus & Roth, 2002). Therefore, Blacks or African Americans are less likely to have requisite health education, which enables them to adhere to their medication regimen.

Second, in our racialized society, Blacks or African Americans are positioned at the bottom with regard to income. According to the U.S. Census Bureau, the median household income for Blacks or African Americans in 2018 was $41,361, compared to $70,642 for Whites (U.S. Census Bureau (USCB), 2019). Similarly, the U.S. Census Bureau reports that, in 2018, the poverty rate for Blacks or African Americans was 20.8% compared to a rate of 8.1% for Whites (U.S. Census Bureau, 2019).

Again, historical, social segregation in the form of policy-enforced residential and educational segregation is the structurally racist antecedent to the current social isolation of Blacks or African Americans (Williams & Collins, 2001). Sequentially, residential segregation has led to educational segregation, which has led to poor educational outcomes.

Consequently, poor educational outcomes result in poor positioning for jobs (Williams, 1999). Therefore, many Blacks or African Americans are relegated to poverty. Those ESKD patients who are impoverished are at a much higher risk for medication nonadherence because they do not have the financial resources to purchase the medication they need. Also, if Blacks or African Americans live in a "medication desert" due to poverty, they do not have the financial resources to travel to pharmacies geographically distant from their residences.

<u>Tenet 3:</u> Mechanisms Can Change Over Time. However, the Relationship Between the Fundamental Cause and the Health Outcomes Remains Constant.

The third tenet of the fundamental cause perspective is that the relationship between the fundamental cause and the health outcome remains constant. This is a theoretical tenet that Link and Phelan (1995) posit that will occur over time because social conditions are so entrenched in society. Therefore, the intervening mechanisms between the fundamental cause and the health outcome may change over time given changes in technology and advancements in medicine. However, the fundamental cause will stay connected to the health outcome. Hence, the proposed relationship between structural racism as a fundamental cause of the health outcome, medication nonadherence will remain constant even as new advances are made.

BOURDIEU'S THEORY OF CAPITAL

The proposed integrated theoretical framework combines structural racism with Bourdieu's theory of capital (Bourdieu, 1986). Bourdieu's theory of capital involves the structure of the social world, specifically the effects of social class (Bourdieu, 1986; Weininger, 2005). Social class is a complex construct that involves the stratified socioeconomic hierarchy present in society (Bourdieu, 1986; Weininger, 2005). This stratification privileges some and disadvantages others. Bourdieu postulates that the privilege of those in the upper class manifests itself in the form of power, and power is embodied in various forms of capital (Bourdieu, 1986). Thus, societal members who are rich in capital inhabit a social class position, which buffers them from lack of resources and enables them to maneuver through society with less effort due to their privileged relationships with people of power and influence.

Two forms of capital explicated by Bourdieu that are salient to this integrated framework are social and cultural capital (Bourdieu, 1986; Weininger, 2005).

First, *social capital* is defined as the powerful and influential social networks to which people have access in society (Bourdieu, 1986; Weininger, 2005). Accordingly, in the U.S., the upper and upper-middle classes have social capital because they have friends and acquaintances with expert knowledge and powerful connections. Conversely, the lower classes have few, if any, powerful relationships in their social networks.

Second, *cultural capital* is defined as the cultural artifacts and ways of interacting with similarly influential members, which are valued by the ruling upper classes (Bourdieu, 1986; Weininger, 2005). Examples include language, dress, art, and education, which are personified by society's influential members. Those endowed with cultural capital have the essential cultural keys to maintain vital relationships within their social network.

STRUCTURAL RACISM'S RELATION TO BOURDIEU'S THEORY OF CAPITAL: THE INTEGRATED THEORETICAL FRAMEWORK

In the framework proposed, structural racism is related to social and cultural capital. By definition, structural racism denies Blacks or African Americans the opportunity to succeed through social institutions and policies such as residential segregation and policies and practices of banks which do not lend fairly (Gee & Ford, 2011; Seitles 1998; Williams & Collins, 2001). Opportunity is quashed through social exclusion and social isolation that results from such institutions and policies. Thus, Blacks or African Americans are excluded and isolated from the opportunity-rich influential social networks (social capital) and cultural markers (cultural capital) of the upper-class, White, dominant group. Consequently, the lack of social and cultural capital perpetuates and reinforces the lower social position of Blacks or African Americans. Since the majority of Blacks or African Americans are not part of upper-class White society, they are not afforded the same benefits that power provides, such as job promotions because of relationships with influential co-workers. As a result, the ability of Blacks or African Americans to succeed socially and economically is truncated.

Structural racism and social and cultural capital combine to influence medication adherence in ESKD patients through the same social and economic pathways described earlier. For example, structural racism leads to power differentials between Blacks or African Americans and Whites of the upper classes. Specifically, these power differentials for Blacks or African Americans manifest themselves as a lack of social and cultural capital. Without influential, powerful social networks, Blacks or African Americans are excluded from resource-rich communities, quality education, and higher incomes (Bourdieu, 1986; Weininger, 2005). Therefore, Blacks or African Americans with low incomes who live in impoverished communities and have ESKD may not have access to pharmacies that stock their many essential medications (Amstislavski et al., 2012). In addition, without a sufficient income, Blacks or African Americans with ESKD may not have the financial resources to purchase all of the necessary medications. Lastly, without quality education, they may not be able to read and understand their prescription directions (Andrus & Roth, 2002; Cleary et al., 1995; Kutner et al., 2006). All of these sequelae to structural racism and the dearth of social and cultural capital lead to medication nonadherence.

IMPORTANCE OF THE INTEGRATED THEORETICAL FRAMEWORK

The importance of this integrated theoretical framework is that it posits that medication adherence inequity amongst Blacks or African Americans is not the result of biological differences or simply a result of poor personal choices. Instead, the focus of the framework is on upstream variables that are beyond the control of Blacks or African Americans.

First, the framework situates structural racism as a fundamental cause of medication nonadherence. This is a new conceptualization of the causation of the medication adherence inequity in the Black or African-American ESKD population and a deviation from the current literature, which emphasizes proximal risk factors.

Second, the introduction of the theory of social and cultural capital in conjunction with structural racism as a fundamental cause provides a more in-depth explanation of how the medication adherence inequity occurs. The integrated framework allows discernment of the layering of disadvantage that affects the lives of Blacks or African Americans in general and Black or African-American ESKD patients in particular. Specifically, structural racism results in the lack of social and cultural capital, which results in educational and income disadvantages. These disadvantages lead to less access to resources, fewer financial resources to purchase medications. and lessened ability to understand prescription directions.

Third, this framework provides a novel pathway for the explanation of medication nonadherence in Black or African-American ESKD patients. This is a significant paradigm shift because the conversation changes when medication nonadherence is viewed as the result of structural racism. Medication nonadherence is no longer posited as an individual problem; instead, it is postulated to be a societally induced inequity. Understanding medication adherence inequity as societally induced, as opposed to individually induced, results in different implications for research, policy, and practice.

IMPLICATIONS OF THE INTEGRATED THEORETICAL FRAMEWORK

There are practice, policy, and research implications for the integrated framework. At the practice level, nephrology social workers can make an impact on racial health inequity. Nephrology social workers could form a community advisory board that could solicit direct input from Black or African-American ESKD patients to make broad community changes from their perspectives. For example, if a "medication desert" exists in a community, social workers can work in partnership with patients to address the medication access issue by appealing to local and chain pharmacies to establish a presence in the "medication desert." Also, social work provides a unique perspective regarding social justice, as we are ethically mandated to address societal injustices. Social workers could lead in the education of kidney healthcare providers regarding structural racism, as well as antiracist strategies and interventions which could be implemented at the provider/practice level.

Policy change at the agency and societal levels could be the result of this integrated framework. At the provider/practice level, social workers could begin by forming a partnership of professionals and patients. This team could review agency policies through an antiracist lens and make any needed changes. Engaging both patients and professionals in such conversations is empowering and fosters a sense of personal ownership.

At the societal level, policies could be crafted to stop residential segregation by encouraging the revitalization of poor Black or African-American communities, which would increase the tax base. The increased tax base would lead to more money flowing into school systems, which would revitalize poor schools. Incentives such as rent control and tax control could be granted to those already living in the neighborhoods, so they will not be forced out by the changes. As another example, a national living wage could be implemented, which would benefit many impoverished Blacks or African Americans, including those with ESKD.

Regarding research, the subjects of structural racism, social capital, and cultural capital have not been explored in relation to the Black or African-American ESKD population and medication adherence. Since this is a new area for exploration, both qualitative and quantitative research would be fruitful. Qualitative research could give researchers rich information, specifically on how structural racism interacts with a lack of social and cultural capital to affect medication adherence. Quantitative research would allow higher numbers of participants to be surveyed with existing surveys or new surveys generated from the qualitative interviews, which would add to the knowledge base.

CONCLUSION

In conclusion, structural racism meets the criteria as a fundamental cause of the medication inequity between Black or African-American and White ESKD patients. Furthermore, the interaction of structural racism and social and cultural capital clarifies the relationship as a fundamental cause of medication adherence. Given the postulation of this integrated framework, qualitative and quantitative research should be conducted to further our understanding of the medication inequity. Such research could hopefully lead to policy changes and changes at the practice level, which would ameliorate the inequity.

REFERENCES

American Public Health Association. (2001). Research and intervention on racism as a fundamental cause of ethnic disparities in health. *American Journal of Public Health, 91*(3), 515.

Amstislavski, P., Ariel, M., Sheffield, S., Maroko, A. R., & Weedon, J. (2012). Medication deserts: Survey of neighborhood disparities in availability of prescription medications. *International Journal of Health Geographics, 11*(1), 48.

Andrus, M. R., & Roth, M. T. (2002). Health literacy: A review. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy, 22*(3), 282–302.

Bame, S. I., Petersen, N., & Wray, N. P. (1993). Variation in hemodialysis patient compliance according to demographic characteristics. *Social Science and Medicine, 37*(8), 1035–1043.

Bonilla-Silva, E. (1997). Rethinking racism: Toward a structural interpretation. *American Sociological Review, 62*(3), 465–480.

Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of Theory of Research for the Sociology of Education* (pp. 241–258). Westport, CT: Greenwood Press.

Browne, T., & Merighi, J. (2010). Barriers to adult hemodialysis patients' self-management of oral medications. *American Journal of Kidney Diseases, 56*(3), 547–557.

Browne, T., Merighi, J., Washington, T., Savage, T., Shaver, C., & Holland, K. (2019). Nephrology social work. In Sarah Gehlert & Teri Browne (Eds.), Handbook of *Health Social Work* (3rd edition, pp. 411–440). Hoboken, NJ: John Wiley & Sons.

Caraballo, G. L., Lebrón de avilés, C., Dávila Torres, R. R., & Burgos Calderón, R. (2001). Kidney patients: Aspects related to compliance with renal treatment. *Puerto Rico Health Sciences Journal, 20*(4), 383–393. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/11845671/

Cleary, D. J., Matzke, G. R., Alexander, A. C. M., & Joy, M. S. (1995). Medication knowledge and compliance among patients receiving long-term dialysis. *American Journal of Health-System Pharmacy, 52*(17), 1895–1900.

Cuffee, Y. L., Hargraves, J. L., Rosal, M., Briesacher, B. A., Schoenthaler, A., Person, S., Hullett, S., & Jeroan, A. (2013). Reported racial discrimination, trust in physicians, and medication adherence among inner-city African Americans with hypertension. *American Journal of Public Health, 103*(11), e55–e62.

Curtin, R. B., Svarstad, B. L., & Keller, T. H. (1999). Hemodialysis patients' noncompliance with oral medications. *American Nephrology Nurses Association (ANNA) Journal, 26*(3), 307–316.

Daramola, C. O. (2008). *An Internet survey investigating relationships among medication adherence, health status, and coping experiences with racism and/or oppression among hypertensive African Americans* (Doctoral dissertation, Teachers College, Columbia University, New York, NY).

Denhaerynck, K., Manhaeve, D., Dobbels, F., Garzoni, D., Nolte, C., & De Geest, S. (2007). Prevalence and consequences of nonadherence to hemodialysis regimens. *American Journal of Critical Care, 16*(3), 222–235.

Gee, G. C., & Ford, C. L. (2011). Structural racism and health inequities: Old issues, new directions. Du Bois Review: *Social Science Research on Race, 8*(1), 115–132.

Jones, C. P. (2000). Levels of racism: A theoretical framework and a gardener's tale. *American Journal of Public Health, 86*(8), 1212–1215.

Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine, 14*(5), 267–273.

Katznelson, I. (2005). *When affirmative action was White: An untold history of racial inequality in twentieth-century America.* New York: W.W. Norton & Company.

Kennedy, B. R. (2009). Psychosocial model: Racism as a predictor of adherence and compliance to treatment and health outcomes among African Americans. *Journal of Theory Construction & Testing, 13*(1), 20–32.

Kressin, N. R., Orner, M. B., Manze, M., Glickman, M. E., & Berlowitz, D. (2010). Understanding contributors to racial disparities in blood pressure control. Circulation: *Cardiovascular Quality and Outcomes, 3*(2), 173–180.

Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy.* Washington, D.C.: National Center for Education Statistics.

Lindberg, M., & Lindberg, P. (2008). Overcoming obstacles for adherence to phosphate binding medication in dialysis patients: A qualitative study. *Pharmacy World Science, 30*, 571–576.

Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior,* (Extra Issue), 80–94.

Logan, J. R., & Stults, B. J. (2011). *The persistence of segregation in the metropolis: New findings from the 2010 census.* New York: Russell Sage Foundation.

Nazroo, J. Y. (2003). The structuring of ethnic inequalities in health: Economic position, racial discrimination, and racism. *American Journal of Public Health, 93*(2), 277–284.

Neri, L., Alma, M., Andreucci, V. E., Gallieni, M., Rey, L. A. R., Brancaccio, D., & Dialisi. M. (2011). Regimen complexity and prescription adherence in dialysis patients. *American Journal of Nephrology, 34*(1), 71–76.

Powell, J. A. (2007). Structural racism: Building upon the insights of John Calmore. *North Carolina Law Review, 86*, 791–816.

Saran, R., Bragg-Gresham, J. L., Rayner, H. C., Goodkin, D. A., Keen, M. L., Van Dijk, P. C., Piera, K. K. L., Saito, A., Fukuhara, S., Young, E. W., Held, P. J., & Port, F. K. (2003). Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the *DOPPS. Kidney International, 64*, 254–262.

Seitles, M. (1998). The perpetuation of residential racial segregation in America: Historical discrimination, modern forms of exclusion, and inclusionary remedies. *Journal of Land Use & Environmental Law, 14*, 89–114.

Steil, J. P., Albright, L., Rugh, J. S., & Massey, D. S. (2018). The social structure of mortgage discrimination. *Housing Studies, 33*(5), 759–776.

Turner, S., & Bound, J. (2003). Closing the gap or widening the divide: The effects of the GI Bill and World War II on the educational outcomes of Black Americans. *The Journal of Economic History, 63*(1), 145–177.

United States Census Bureau (USCB). (2019). *Income, poverty, and health care coverage in the United States: 2018.* Retrieved from: https://www.census.gov/newsroom/press-releases/2019/income-poverty.html

United States Renal Data System (USRDS). (2019). *USRDS annual data report: Epidemiology of kidney disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.

Vaught, S. E., & Castagno, A. E. (2008). "I don't think I'm a racist": Critical Race Theory, teacher attitudes, and structural racism. Race, *Ethnicity, and Education, 11*(2), 95–113.

Weininger, E. B. (2005). Foundations of Pierre Bourdieu's class analysis. In E.O. Wright (Ed.), *Approaches to class analysis* (pp.119–149). Cambridge, United Kingdom: Cambridge University Press.

Wells, J. R., & Walker, C. A. (2012). Factors influencing adherence in African Americans with end-stage renal disease. *Journal of Theory Construction & Testing, 16*(2), 52–56.

Williams, D. R. (1999). Race, socioeconomic status, and health. The added effects of racism and discrimination. *Annals New York Academy of Sciences, 896*(1), 173–188. doi: 10.1111/j.1749-6632.1999.tb08114.x

Williams, D. R., & Collins C. (2001). Racial residential segregation: A fundamental cause of racial disparities in health. *Public Health Reports, 116*, 404–416.

Eye Care Utilization Among Older Insured Adults with Kidney Disease and Diabetes

Allison Houston, PhD, MS, CPH, Proscenium Data Solutions, Albany, NY

Older adults have increased risk factors for chronic kidney disease (CKD), diabetes, and blindness. Frequent routine screening may help with early detection, management, and prevention of eye disease and blindness. Using data from the National Health Interview Survey (NHIS), this study examined the use of eye health service among a national sample of older insured adults with self-reported diabetes and chronic kidney disease diagnoses. This study demonstrates an important correlation in the use of eye healthcare based on diabetes status, kidney disease status, and length of a diabetes diagnosis. Given the importance of early detection of potential eye disease, encouraging people and their families to seek early and frequent eye examinations is suggested.

INTRODUCTION

Chronic kidney disease (CKD), defined by reduced glomerular filtration rate (GFR < 60 ml/min/1.73m^2) or kidney damage (National Kidney Foundation, 2002), is recognized as a common condition. According to recent estimates, in 2019, approximately 15% (37 million) of adults in the United States have CKD (Centers for Disease Control and Prevention (CDC), 2019). CKD may occur at the same time as other health problems, including diabetes (Fox et al., 2004), heart disease (Meisinger, Döring, Löwel, & KORA Study Group, 2006), high blood pressure (Horowitz, Miskulin, & Zager, 2015), and other illnesses (Fox et al., 2004; Iwagami, Caplin, Smeeth, Tomlinson, & Nitsch, 2018). In addition, due to the presence of many of these different risk factors, CKD is elevated in older adults (Prakash & O'Hare, 2009).

CKD, DIABETES, AND VISION LOSS

In 2018, 50.9 million Americans were 65 years of age or older, and this population is projected to almost double to 98 million in 2060 (Administration for Community Living, 2019). The aging of the overall U.S. population is a significant driver of some chronic multi-morbidities, including CKD and diabetes. According to current estimates, CKD affects 38% of people aged 65 years or older, but only 13% of people aged 45–64 years, and 7% 18–44 years (CDC, 2019). According to estimates from 2018 (the latest year for which such data are available), diabetes affects 26.8% of people aged 65 years or older, but only about 17.5% among people 45–64 years of age (CDC, 2020).

There is a significant correlation between CKD and diabetes. The prevalence of CKD in U.S. adults with diagnosed diabetes was 25% between 2011 and 2014 (CDC, n.d.). This may be because the prevalence of CKD tends to be significantly and progressively higher with increasing levels of serum insulin and therefore, one of the main risk factors for CKD is diabetes. Previous work in the general population of the U.S. has found that, participants with diabetes had an estimated prevalence of 25% any stage CKD (eGFR < 60 ml/min per 1.73 m^2; albumin-to-creatinine ratio ≥ 30 mg/g; or both) versus 5.3% CKD in nondiabetic subjects, respectively (Zelnick et al., 2017). Researchers have also found that the presence of CKD in people with diabetes foreshadows significantly worse prognoses and poorer health outcomes (Fox et al., 2012; Pecoits-Filho et al., 2016).

In addition to the complex relationship between CKD and diabetes, other important complications of diabetes exist. Diabetes itself is also closely associated with other comorbid conditions, particularly blindness, vision loss, and diabetic retinopathy. Diabetic retinopathy is a common complication of both type 1 and type 2 diabetes and occurs when high blood sugar levels cause damage to blood vessels in the retina (Solomon et al., 2017). According to the National Eye Institute, a division of the National Institutes of Health (NIH), diabetic retinopathy is the most common cause of vision loss among people with diabetes and a leading cause of blindness in American adults aged 20–74 years (National Eye Institute, NIH, n.d.; NIH, n.d.). It is also the leading cause of vision impairment and blindness among working-age adults in developed countries (Solomon et al., 2017)Also according to the NIH, diabetic retinopathy is the most common cause of vision loss among people with diabetes and the leading cause of vision impairment and blindness among working-age adults (NIH, n.d.). Recent statistics from the CDC indicate that among adults aged 45 and over with diagnosed diabetes, 32.2% had cataracts, and 9.2% had vision loss due to cataracts (Cha, Villarroel, & Vahratian; NCHS, 2019).

Corresponding author: *Allison Houston PhD, MS, CPH, Proscenium Data Solutions, PO Box 12641 Albany, NY 12212; 518.977.2328;* ***ahouston@yourdatamatter.com***

This association between diabetes and vision loss in older people has been identified in previous research. For example, more than three decades ago, Klein and Klein (1990) found that blindness and vision loss are common complications in the diabetic population. More recent research suggests that older Americans with diabetes are one and a half times more likely than their age-matched nondiabetic counterparts to develop vision loss and blindness (Tumosa, 2008). Diabetic retinopathy progresses slowly and may not present vision symptoms in the early stages of disease progression. Therefore, for patients with diabetes, regular eye checkups with early detection and treatment of vision-threatening retinopathy may prevent vision loss. Despite the documented increased risk for vision loss among people with diabetes in the U.S. population and the importance of routine eye examinations, the frequency of eye examinations is very low among people in the general population with diabetes (Benoit, Swenor, Geiss, Gregg, & Saaddine, 2019).

The management of kidney disease in older people remains challenging because of the interactions between age and other risk factors in kidney disease progression. The associations of CKD in older people with other comorbidities are understudied and poorly understood. Additionally, despite the documented increased risk for vision loss among people with diabetes in the U.S., national population-based data on the utilization of vision-related health services among older Americans with diabetes remain scarce. The purpose of this study is to answer three research questions concerning the relationship between diabetes and eye-care utilization among

- What proportion of older people with diabetes saw an eye doctor in the last year?
- Does time since diabetes diagnosis matter?
- What is the likelihood of seeing or talking to an eye doctor in the past year among older people with diabetes and kidney disease?

METHOD

Study design and data source

Data for this analysis are from the National Health Interview Survey (NHIS), conducted from 2010 to 2015 (Minnesota Population Center & State Health Access Data Assistance Center (SHADAC), 2012). With limitations outlined in the following, the NHIS is an important instrument for monitoring the health of the U.S. population because NHIS variables are consistently coded, well-documented, and capture a rich profile of its respondents, including many factors on health status, health conditions, and healthcare utilization. Details of the study sample and research methods have been published previously (Davern, Blewett, Lee, Boudreaux, & King, 2012).

Study population

Sociodemographic information and data related to health and health service utilization for a population of insured older American adults, aged 65 years and older (n = 80,153), were extracted for this analysis. Using complex survey sample designs, such as NHIS, can introduce unwanted bias, where the population of interest is stratified on several dimensions and oversampled within certain of these strata. This bias was minimized in the current study by employing the subpopulation option(s) and the sampling weights in the calculation of the estimates.

Main independent variables

Three independent variables of interest are weak or failing kidneys, diabetes status, and time since diabetes diagnosis. Classification for weak or failing kidneys was based on information reported in response to whether the respondent was told they had weak/failing kidneys in the past 12 months. The variable weak or failing kidneys was categorized with a binary indicator as yes (1) and no (0). Classification for diabetes was based on information reported in response to whether the respondent was ever told they had diabetes. Diabetes status was categorized as no (0), yes (1), and borderline (2). Time since diabetes diagnoses was classified as 0–2 years, 3–5years, 6–10 years, and more than 10 years.

Outcome variables

The dependent variable, eye care utilization, was based on/defined as whether the respondent saw or talked to an eye doctor in the past 12 months. The measure was assessed dichotomously: saw an eye doctor (1) and did not see an eye doctor (0).

COVARIATES

Demographic characteristics

Basic demographic characteristics (age, race/ethnicity, and gender) were included in the analyses for the purpose of adjustment. Classification for race/ethnicity was based on information reported for each respondent and was categorized into six categories (American Indians and Alaska Natives, non-Hispanic White, non-Hispanic Black, Asian/Pacific Islander, Hispanic/Latino, and other races). Non-Hispanic White is the reference category. Age was classified into two ordinal categories (65–84yrs, and 85+yrs) that captured group-specific effects in older adult populations. Gender was assessed with a binary indicator (0 = male; 1 = female). For age and gender, the lower categories served as reference.

Data analysis/analytic strategy

Data were analyzed descriptively using cross tabulations, and inferential statistics were assessed using logistic regressions. Logistic regression analyses were conducted to estimate odds ratios (OR) and p-values for the association between past-year eye doctor visits or communication and diabetes in a multivariate context, adjusting for age, sex, and race/ethnicity factors. STATA 12 survey commands were used to adjust for the complex survey design and to weight the NHIS samples to provide estimates for the U.S. population. Statistical significance was assessed as $p < 0.05$. The present study is exempted from the internal review board process because it used a secondary data source that is publicly available.

RESULTS

Figure 1 illustrates the percentage, by time, of older people who saw or talked with an eye doctor in the past 12 months since diabetes diagnosis. Percentages range from a low of 62.2% among those older people who had received a diagnosis in the past two years or less, to a high of 66.7% among those people who had received a diagnosis more than 10 years ago. Nevertheless, past-year visits or communication with an eye doctor did not achieve statistical significance. Weighted cross-tabulations analysis reveals a Pearson's chi-square F-statistic score of 2.0407 and a p-value of 0.1069 (not shown).

Table 1 shows that past-year visits or communications with eye doctors vary by diabetes status. Older people with diabetes are most likely to make such visits (65.4%), followed by those with borderline diabetes (59.3%), and those with no diabetes (56.7%). Pearson's chi-square F-statistic and p-value show that this relationship is statistically significant (69.48; $p < .0001$).

Analysis of the association between diabetes status and past-year visits or communication with eye doctors, stratified by the presence or absence of a weak or failing kidneys, is shown in **Table 2.** Unadjusted and adjusted odds ratios of the association between diabetes status and past-year visits/communications with an eye doctor were positive and statistically significant. The likelihood of past-year visits/communications with an eye doctor was highest among people with both conditions (diabetes and kidney disease). After adjusting for age, sex, and race/ethnicity, older people with diabetes who also had weak or failing kidneys were 1.640 times more likely to visit/communicate with an eye doctor than their counterparts without diabetes ($p < .0001$). Whereas older people with diabetes who did not have weak or failing kidneys were only 1.497 times more likely to visit/communicate with an eye doctor as their counterparts without diabetes ($p < .0001$). There are no age, gender, or race/ethnicity subgroup differences in this association.

DISCUSSION

The older adult population is rapidly increasing and is expected to represent 20% of the total U.S. population by 2050 (Ortman, Velkoff, & Hogan, 2014). Chronic conditions, such as diabetes, eye disease, and kidney disease, play roles in functional limitations among older adults in later years. Identifying factors such as eye disease before they occur could steer intervention and prevention efforts, reduce the incidence of functional disability, reduce the use of social services, preserve quality of life, and delay nursing home admittance. Keeping older adults healthy for as long as possible is also economically beneficial to individuals and society.

The American Diabetes Association recommends annual or biennial eye exams. However, given the close connection between aging, diabetes, and kidney disease, annual visits to eye physicians should be part of routine care for older people with risk factors for eye disease, such as diabetes and kidney failure. Previous research using population data has found that the annual frequency of eye examinations is about 50% among people in the general population with diabetes (Benoit et al., 2019). The current study found that a higher percentage of older people with diabetes (65.4%) saw an eye doctor in the past year. While 65% is an improvement compared to 50%, this finding adds to the abundant literature pointing out that systemic changes in healthcare may be needed to detect and prevent vision-threatening eye disease among people with diabetes.

Additional results suggest that having both kidney disease and diabetes increases the likelihood of past-year visits or communication with eye doctors among older U.S. adults. Results also suggest that the likelihood of seeing an eye doctor increases with the length of diabetic diagnosis. Retinal disease is a common concomitant of diabetes.

There are some limitations to our study. Using data from an existing national survey limits the types of questions available to respond to the research question because the questions pre-exist and cannot be altered, and additional questions could not be added. For example, the survey does not include questions about the specific types of diabetes, length of CKD diagnosis, and reasons for delaying medical care. Moreover, the survey did not capture whether an actual eye examination was performed during each encounter with an eye doctor.

IMPLICATIONS

Living with diabetes can be difficult, especially when it is discovered late or uncontrolled for long periods. Older people with diabetes can develop complications that cause burden to families. Health at old age is greatly influenced by long-term health history—by a long line of events in the health status of individuals and their families, and by health beliefs.

Additionally, CKD has devastating medical, social, and economic impacts for patients and their families. The rates of older patients living with CKD is also expected to grow (U.S. Renal Data System (USRDS), 2012). Concurrently, the aging process may lead to more complex medical and psychosocial impacts.

To help prevent vision loss and blindness, it is important for older people with diabetes to have a comprehensive dilated eye examination at least once a year to detect potential diabetic eye disease early. Such examinations are performed by eye doctors. The findings in this research provide supportive and consistent evidence that older insured people with diabetes alone and with both diabetes and CKD are more likely to have annual eye checkups. This is good news; however, at 65%, their utilization of such services may not be ideal. Owing mainly to the aging of the U.S. population (Varma et al., 2016), the prevalence of visual disabilities is expected to increase markedly during the next 20 years. Retinopathy progresses slowly, and even when it becomes sight threatening, it may not present symptoms involving vision. When symptoms do occur, it is often too late to restore full vision or to stop further deterioration from retinal photocoagulation. Therefore, timely observation of early changes in eye health can be important in preventing and addressing blindness before physiological changes or structural, neurological, or acquired damage to one or both eyes occur.

The prevalence of comorbidities is common among older adults with chronic health problems. Uncontrolled diabetes can be the cause of complications, such as stroke, heart attack, impaired circulation to the feet, amputations, kidney disease, and blindness. Ageing, diabetes, and hypertension are major risk factors for an increased probability of death due to CKD (Bowe et al., 2018). Consequently, collective efforts to mitigate risk factors, such as better control of hypertension and diabetes, will likely helped to abate rates of CKD. For instance, the available evidence indicates that early identification of CKD may allow physicians to aggressively modify cardiovascular risk, which, in turn, has the potential to improve patient outcomes in older people (Dukkipati, Adler, & Mehrotra, 2008).

Given the practical benefits of being able to detect and treat eye disease before it is too late, early identification of potential eye diseases and appropriate care can have a similar result as when targeting risk factors for early identification of CKD. Further studies to better explore such initiatives, as well as patterns of behavior in older populations, would be useful to improve patient care and outcomes. Studies are also needed to understand better the health-related behaviors and practices of older populations with CKD, diabetes, eye disease, and other comorbid conditions, such as hypertension.

Nephrology social workers should be included in interdisciplinary teams to ease the burdens associated with CKD-multimorbid chronic illnesses and to promote optimal outcomes for patients. Nephrology social work offers excellent opportunities to make significant differences in the lives of older people who are faced with the challenges of managing multiple conditions. Nephrology social workers can help patients self-manage both their CKD and diabetes. They can also play a critical role in encouraging individuals and their families to seek early and frequent eye examinations and help address any psychosocial barriers to these exams.

REFERENCES

Administration for Community Living. (2019). *2018 older Americans profile.* Retrieved from: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2018OlderAmericansProfile.pdf

Benoit, S. R., Swenor, B., Geiss, L. S., Gregg, E. W., & Saaddine, J. B. (2019). Eye care utilization among insured people with diabetes in the U.S., 2010–2014. *Diabetes Care, 42*(3), 427–433. doi: 10.2337/dc18-0828

Bowe, B., Xie, Y., Li, T., Mokdad, A. H., Xian, H., Yan, Y., Maddukuri, G., & Al-Aly, Z. (2018). Changes in the US burden of chronic kidney disease from 2002 to 2016: An analysis of the Global Burden of Disease Study. *JAMA Network Open, 1*(7), e184412–e184412. doi: 10.1001/jamanetworkopen.2018.4412

Centers for Disease Control and Prevention. (n.d.). *Chronic kidney disease surveillance system.* Retrieved from: http://www.cdc.gov/ckd

Centers for Disease Control and Prevention (CDC). (2020). *National Diabetes Statistics Report, 2020. Estimates of diabetes and its burden in the United States.* Retrieved September 15, 2020, from: https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf

Centers for Disease Control and Prevention (CDC). (2019). *Chronic kidney disease in the United States, 2019.* Retrieved from: https://www.cdc.gov/kidneydisease/publications-resources/2019-national-facts.html

Cha, A. E., Villarroel, M. A, & Vahratian, A.; U.S. Department of Health and Human Services (HHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS). (2019 July). Eye disorders and vision loss among U.S. adults aged 45 and over with diagnosed diabetes, 2016–2017. *NCHS Data Brief,* 344. Hyattsville, MD: National Center for Health Statistics. Retrieved from: https://www.cdc.gov/nchs/data/databriefs/db344-h.pdf

Davern, M., Blewett, L. A., Lee, B., Boudreaux, M., & King, M. L. (2012). Use of the integrated health interview series: Trends in medical provider utilization (1972–2008). *Epidemiologic Perspectives & Innovations, 9.* doi: 10.1186/1742-5573-9-2

Dukkipati, R., Adler, S., & Mehrotra, R. (2008). Cardiovascular implications of chronic kidney disease in older adults. *Drugs & Aging, 25*(3), 241–253. doi: 10.2165/00002512-200825030-00006

Fox, C. S., Larson, M. G., Leip, E. P., Culleton, B., Wilson, P. W. F., & Levy, D. (2004). Predictors of new-onset kidney disease in a community-based population. *Journal of the American Medical Association (JAMA), 291*(7), 844–850. doi: 10.1001/jama.291.7.844

Fox, C. S., Matsushita, K., Woodward, M., Bilo, H. J., Chalmers, J., Lambers Heerspink, H. J., Lee, B. J., Perkins, R. M., Rossing, P., Sairenchi, T., Tonelli, M., Vassalotti, J. S., Yamagishi, K., Coresh, J., de Jong, P. E., Wen, C. P., & Nelson, R. G. (2012). Associations of kidney disease measures with mortality and end-stage renal disease in individuals with and without diabetes: A meta-analysis. *Lancet, 38*0(9854), 1662–1673. doi: 10.1016/S0140-6736(12)61350-6

Horowitz, B., Miskulin, D., & Zager, P. (2015). Epidemiology of hypertension in CKD. *Advances in Chronic Kidney Disease, 22*(2), 88–95. doi: 10.1053/j.ackd.2014.09.004

Iwagami, M., Caplin, B., Smeeth, L., Tomlinson, L. A., & Nitsch, D. (2018). Chronic kidney disease and cause-specific hospitalisation: A matched cohort study using primary and secondary care patient data. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners, 6*8(673), e512–e523. doi: 10.3399/bjgp18X697973

Klein, B. E., & Klein, R. (1990). Ocular problems in older Americans with diabetes. *Clinics in Geriatric Medicine, 6*(4), 827–837.

Meisinger, C., Döring, A., Löwel, H., & KORA Study Group. (2006). Chronic kidney disease and risk of incident myocardial infarction and all-cause and cardiovascular disease mortality in middle-aged men and women from the general population. *European Heart Journal, 27*(10), 1245–1250. doi: 10.1093/eurheartj/ehi880

Minnesota Population Center & State Health Access Data Assistance Center (SHADAC). (2012). *Integrated health interview series: Version 5.0*. Minneapolis, MN: University of Minnesota.

National Eye Institute; National Institutes of Health (NIH). *Diabetic retinopathy data and statistics.* (n.d.). Retrieved September 15, 2020, from: https://www.nei.nih.gov/learn-about-eye-health/resources-for-health-educators/eye-health-data-and-statistics/diabetic-retinopathy-data-and-statistics

National Institutes of Health(NIH). (n.d.). *Health information: Chronic kidney disease.* Retrieved from: https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd

National Kidney Foundation (NKF). (2002). K/DOQI clinical practice guidelines for chronic kidney disease: Evaluation, classification, and stratification. *American Journal of Kidney Diseases, 39(*2 Suppl 1), S1–S266.

Ortman, J. M., Velkoff, V. A., & Hogan, H. (2014). *An aging nation: The older population in the United States* (Current Population Reports; Report Number P25-1140). Washington, D.C.: United States Census Bureau. Retrieved from: https://www.census.gov/library/publications/2014/demo/p25-1140.html

Pecoits-Filho, R., Abensur, H., Betônico, C. C. R., Machado, A. D., Parente, E. B., Queiroz, M., & Vencio, S. (2016). Interactions between kidney disease and diabetes: Dangerous liaisons. *Diabetology & Metabolic Syndrome, 8*. doi: 10.1186/s13098-016-0159-z

Prakash, S., & O'Hare, A. M. (2009). Interaction of aging and CKD. *Seminars in Nephrology, 29*(5), 497–503. doi: 10.1016/j.semnephrol.2009.06.006

Solomon, S. D., Chew, E., Duh, E. J., Sobrin, L., Sun, J. K., VanderBeek, B. L., Wykoff, C. C., & Gardner, T. W. (2017). Diabetic retinopathy: A position statement by the American Diabetes Association. *Diabetes Care, 40*(3), 412–418. doi: 10.2337/dc16-2641

Tumosa, N. (2008). Eye disease and the older diabetic. *Clinics in Geriatric Medicine, 24*(3), vii, 515–527. doi: 10.1016/j.cger.2008.03.002

U.S. Renal Data System (USRDS). (2012). *USRDS 2012 annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States.* Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.

Vajaranant, T. S., Burkemper, B., Wu, S., Torres, M., Hsu, C., Choudry, F., & McKean-Cowdin, R. (2016). Visual impairment and blindness in adults in the United States: Demographic and geographic variations from 2015 to 2050. *JAMA Ophthalmology, 134(7)*, 802–809. doi: 10.1001/jamaophthalmol.2016.1284

Varma, R., Vajaranant, T. S., Burkemper, B., Wu, S., Torres, M., Hsu, C., Choudry, F., & McKean-Cowdin, R. (2016). Visual impairment and blindness in adults in the United States: Demographic and geographic variations from 2015 to 2050. *JAMA Ophthalmology, 134*(7), 802–809. doi: 10.1001/jamaophthalmol.2016.1284

Zelnick, L. R., Weiss, N. S., Kestenbaum, B. R., Robinson-Cohen, C., Heagerty, P. J., Tuttle, K., Hall, Y.N., & de Boer, I. H. (2017). Diabetes and CKD in the United States population, 2009–2014. *Clinical Journal of the American Society of Nephrology, 12*(12), 1984–1990. doi: 10.2215/CJN.03700417

TABLE 1. **Past-year eye doctor visits/communications among older people with and without diabetes, stratified by kidney disease status, NHIS 2010–2015**

	Visits to eye doctors		
	Yes (%)	**No (%)**	**[b]F-Statistic and *p*-value[b]**
Total			F (2.00, 599.99) = 69.48
Diabetes Status[a]			*p* < .0001
No	15,397 (56.7)	12,128 (43.1)	
Yes	4,976 (65.4)	2,742 (34.6)	
Borderline	623 (59.3)	413 (40.7)	

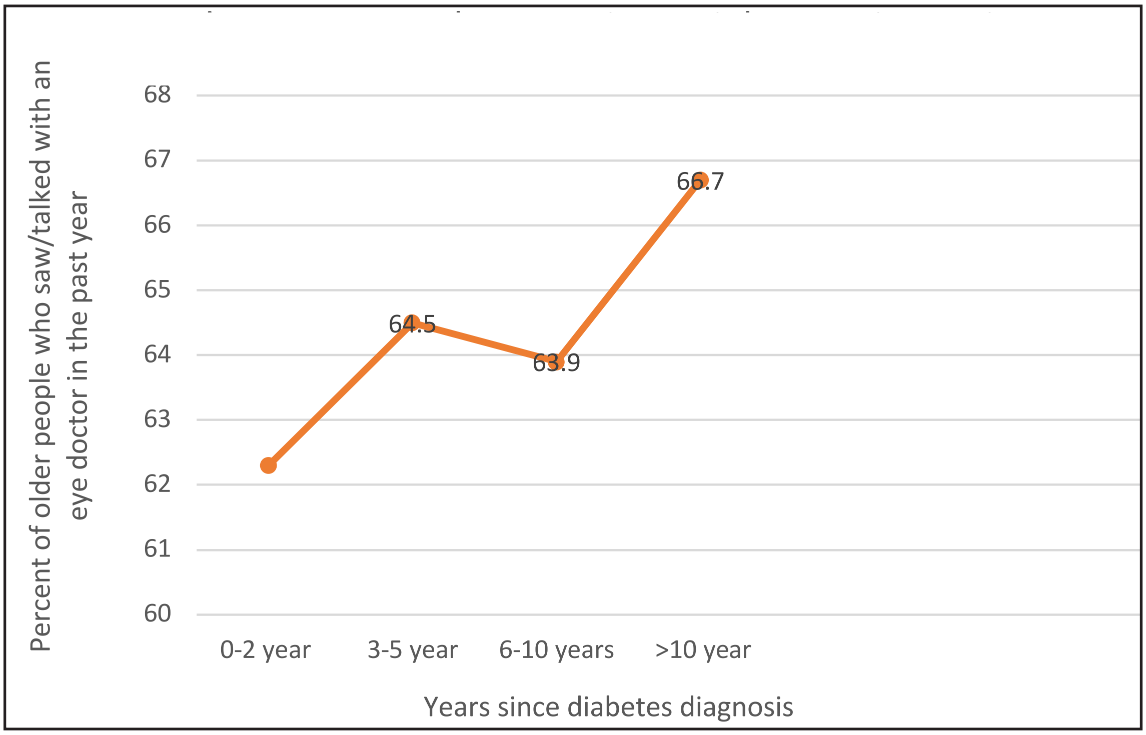
Note: **a** Sample weights are applied to the diabetes variable. **b** χ2 test; *p*-value are generated by Pearson's chi-squared F-statistic and *p*-value using SVY, tabulate, and subpopulation analysis.

TABLE 2. **Likelihood of visits to an eye doctor in the past year among older people with and without diabetes, stratified by kidney disease status and adjusted for age, sex and race/ethnicity, NHIS 2010–2015**

	Saw/Talked to an eye doctor				*Saw/Talked to an eye doctor*			
	Weak Kidney		*Weak Kidney*		*No Weak Kidney*		*No Weak Kidney*	
	Odds Ratio	***P-value***	**Odds Ratio**	***P-value***	**Odds Ratio**	***P-value***	**Odds Ratio**	***P-value***
No diabetes	1.000		1.000		1.000		1.000	
Diabetes	1.577	0.000	1.640	0.000	1.418	0.000	1.497	0.000
Borderline diabetes	1.748	0.060	1.807	0.048	1.074	0.304	1.122	0.106
Age			1.014	0.108			1.018	0.000
Sex			1.010	0.922			1.278	0.000
Race/Ethnicity			0.969	0.323			0.925	0.000
N	78964		78964		79608		79608	

Note: All analyses were weighted. Comparison groups included: non-Hispanic White, age 65–84 yrs, and male. Results from binary outcome, logistic regression is displayed.

FIGURE 1. **Percentage of older adults with last year doctor contact by year since diabetes diagnosis**



Note: F-Statistic Score = 2.0407

Practice Note: COVID-19: A Dialysis Social Worker's Response

Amber Blackshear, LCSW, Fresenius Kidney Care, Dallas, TX

Nephrology social workers commonly help their patients with life crises. With the COVID-19 pandemic, my role in supporting patients through crises has significantly expanded. I have had to keep up with the latest healthcare recommendations and understand these changes so I can accurately inform my patients about what to expect for their safety and treatment. Almost daily, new policies are added or changed, and I am often left questioning how a new policy will change the way I practice.

I began my journey as a dialysis social worker four years ago, and I never imagined I'd be living and working during a pandemic. As a matter of fact, I did not know much about nephrology social work until I relocated to Dallas. Like many states, we have been through a stay-at-home order, mask requirements, and a host of other precautionary measures. As a social worker, my job has been deemed "essential," and I have identified my best practices that are geared towards patients maintaining positive mental health.

As expected, in the weeks that passed during our stay-at-home order, a few patients reported flat affect and negative mood. I soon realized this pandemic would affect my patients in ways even they could not describe. Having chronic kidney disease affects one's personal life on a daily basis. So, it is important to remember patients' personal lives have already been interrupted due to being on dialysis, and the strains of this pandemic limit their personal lives significantly more.

To address this, I have posted signs in my clinic, so patients are aware they do not have to suffer in silence. The signs are also posted in Spanish and Vietnamese to ensure all patients have the opportunity to communicate their needs. As my social work office is not used by patients now because of social distancing, patients are offered the choice to talk with me chairside or, for more privacy, by telephone. I personally prefer to speak to patients over the phone, due to privacy reasons. I am finding it difficult to communicate effectively when I am wearing a mask and a shield as required. Most times, my patients cannot hear me unless I am speaking loudly, and I would like to be discreet as I can when communicating about sensitive topics.

While adjusting to a COVID-19 lifestyle has been challenging and stressful times for all, bringing some light to a dark time is important to me to instill in my patients. Reminding patients that family, friends, quality sleep, and self-care are things that are priceless. This has also opened the lines of communication to revisit subjects that patients previously pushed to the side, such as getting a transplant or trying home dialysis. Patients value being able to dialyze during this time, but that does not negate the fact that they would rather be at home and following social distancing orders than commuting three days a week to treatment. In addition, encouraging home therapies has been a relevant topic to revisit since patients can now see the value in seeking treatment at their home. I have taken the opportunity to revisit transplantation for eligible patients who declined the option to apply. Generally, many patients are afraid of having a transplant surgery or are just more comfortable seeking treatment at our dialysis center. So, for me, painting a picture of treatment options to consider when the pandemic stabilizes gives patients enough time to rethink their previous decisions and maybe take a risk that is worth taking. After all, if you can survive a pandemic, you can do anything!

In the meantime, day-to-day tasks are still ongoing. There have been instances of "putting out small fires," such as speaking to patients in private who falsely think another patient's absence means they have COVID-19. There is a great responsibility I feel to reduce the spread of rumors, so that none of our patients face the stigma that comes along with a high-risk diagnosis.

The silver lining during these trying times has been patients attending treatment more consistently. This has been a great time to talk to patients about improving their self-management to stay as healthy as possible (e.g., stopping smoking or improving diet). As we now know, COVID-19 is a respiratory illness and having a healthy immune system contributes to better recovery odds. Using these facts as a gateway to address smoking and dietary habits gives me the opportunity to address possible underlying issues that led to these choices.

Patients have been receptive to information from the clinic and have taken information seriously. There is also the great importance of being deliberate with the timing and subject matter of material. Thankfully, our patients have not given much resistance to new policies that are intended to keep them safe. As a nephrology social worker, I will continue to adjust my practice as we all continue to adjust to a "new normal."

Corresponding author**: Amber Blackshear, LCSW, Fresenius Kidney Care, 2613 Swiss Avenue Dallas, TX 75204;* ***amberbeatricemsw@gmail.com

Practice Note: Fear in the Shadows: Stalking in Dialysis and Transplant

Mathias E. Stricherz, EdD, New Mexico Behavioral Health Institute and New Mexico Highlands University, Las Vegas, NM;
Jane Kwatcher, MSW, LCSW, Independent Contractor and Consultant, Claremont, CA;
Charlie Thomas, MSW, LCSW, ACSW, Banner University Medical Center Phoenix, Phoenix, AZ

"Stalking is a crime that can paralyze an otherwise productive person with fear." (Madigan, n.d.)

In this article, we will provide information about stalking incidents by patients in healthcare and dialysis facilities, make recommendations, and suggest some related resources that can help nephrology social workers and their interdisciplinary colleagues. Stalking in a workplace potentially places the organization, supervisors, employees, and patients at physical or emotional risk, or can result in litigation or reduced work performance.

Stalking is defined as a course of conduct directed at a person that involves "repeated (two or more occasions) visual or physical proximity; nonconsensual communication, or verbal, written, or implied threats or a combination thereof; whereby the action would cause a reasonable person fear" (National Institute of Justice, 2007). It also is an action that is repeated more than once, rather than a single act, and induces fear in the victim (U.S. Department of Justice, 2002). Stalking can also include cyber-stalking, which targets people through social media, email, or other electronic communication.

In stalking, there is at least one person who is the target of a stalker's actions that can also include obsessive and erotic attachment. It is believed stalkers may use stalking as "power and control," similar to the postulates of rape and domestic violence perpetration. The stalker is often a silent entity who may go undetected for a considerable period of time (National Institute of Justice, 2007), and the target may not have picked up the cues that they are being stalked.

Stalking is identified with workplace "mobbing" scenarios. "Mobbing" is a term used by Dr. Heinz Leymann to describe a phenomenon he encountered while researching the social dynamics of a workplace. He states, "psychological terror or mobbing in working life involves hostile and unethical communication which is directed systematically by one or more individuals, mainly toward one individual, who, due to mobbing, is pushed into a helpless and defenseless position and held there by means of continuing mobbing activities" (Leymann.se website, n.d.). The process of "mobbing" may indeed underlie the reason that many victims of stalking may not be provided or have implemented appropriate safety plans when the agency offers protection. In and of itself, mobbing as a form of stalking may need further review within health settings, such as dialysis and transplant facilities. For example, a new employee is somewhat of a perfectionist and is subsequently ostracized by peers in the workplace. The method of ostracizing may include sabotaging workflow, gossip, ignoring, or not passing on information, and the target is not able to work with the same knowledge as their peers.

Pathe, Mullen, and Purcell (2002) discuss the dynamics of stalking along with strategies for safety and protection for the target of stalking. They suggest there has been an increase in stalking behavior in health settings, and healthcare professionals are over-represented in victimization. Other research suggests that patients who stalk their care providers may be developing a romantic attachment due to delusional beliefs or a mixture of "wounded injury belief" to "misplaced expectation" (McIvor & Petch, 2006).

In healthcare settings, when health professionals are stalked, employers and employees must focus on how the stalking target is coping and remains safe. McIvor & Petch (2006) report that stalking can increase the risk of physical violence by 25–35%, and they recommend that healthcare organizations should consider adopting formal educational programs on stalking for patients, particularly for staff in the initial stages of their career. Through education, training, policies, and processes, organizational management can be the guardian of patients and staff in dialysis and transplant facilities.

Some research indicates that stalking in healthcare settings is uniquely different than other forms of stalking (American Psychiatric Association, 2019). In healthcare settings, a stalking patient or coworker may focus on another person due to attraction that interferes with the professional's work with the stalker and has implications for the stalker's health. Multiple physical and psychological sequelae to being stalked include

Corresponding author**: Mathias E. Stricherz, EdD, New Mexico Behavioral Health Institute, 3695 Hot Springs Blvd., Las Vegas, NM 87701;* ***Mathias.Stricherz@state.nm.us

weight changes, sleep disorders, weakness, apprehension, anger, and fear (Owens, 2016). Survivors of stalking may experience long-term disruption of behavior and "normal living," with concomitant psychological trauma, including a loss of "peace of mind" and freedom, increased fear, helplessness, and depleted coping skills (Comparcini, Simonetti, Lupo, & Cicolini, 2015).

In 2015, we conducted a national survey of 274 dialysis professionals about violence in dialysis centers (Kwatcher & Stricherz, 2015). Eighty-seven respondents (32%) reported that they experienced stalking behavior or were aware of it having occurred in their dialysis center. The respondents identified a total of 92 cases of stalking. Among these cases, 52 reported incidents of stalking occurred within the past three years, 12 incidents from three to five years prior to the survey, 11 incidents from six to 10 years prior to the survey, and 17 incidents from 10 or more years prior to the survey.

Following this survey, we created a list of actions that can be taken by stalking victims and their healthcare employers/caregivers to reduce their risk when subjected to stalking behavior at dialysis or transplant facilities (see **Table 1**) (Kwatcher & Stricherz, 2015). These include changing daily schedules, changing telephone numbers, taking time off, changing travel routes, changing locks, changing jobs, and changing email addresses. If a kidney health professional is a victim of stalking, they should immediately discuss this with their employer and contact law enforcement as applicable.

TABLE 1. Actions that can be taken by stalking victims and their employers

Action	Potential PROs and CONs of the action
Change daily schedule.	PROs: Work schedule changes approved by employer may increase the protective factors for the target. CONs: May disrupt family, childcare, academics, sleep schedule, among other life areas.
Change telephone number.	PROs: Employee causes the employer to keep new number unpublished for an acceptable period, and then perhaps publish the new number when the target is safe (usually after interventions such as restraining orders or cease and desist orders). Limits/interferes with the stalker's accessibility to other patients, other employees. CONs: May impair continuity of communication within the target's professional/social sphere of influence; may require disruption of texting notifications.
Take time off from school or work.	PROs: May make stalker access to the target more difficult; may allow the victim an enhanced sense of control and efficacy. CONs: If the patient is in a college program or school there may be a loss of income from financial aid or a need to drop out of school, job coaching, or training; also: possible loss of a job; a possible change in vocational aspirations; a possible loss of avocational interests and activities; an alteration of progress with assigned tasks; possible changes to project completion deadlines.
Change travel route.	PROs: May create planning and surveillance difficulty for the stalker; may add to the target's sense of safety and efficacy. CONs: May be time-consuming; may involve additional expenses; may be an inconvenience or may result in a possible a loss of transportation (public transportation, carpool).

TABLE 1. Actions that can be taken by stalking victims and their employers, *continued*

Change locks or get a security system.	PROs: May provide maximum safety for the target; may reduce concerns regarding old keys that may have been copied by family, or the stalker, or given to trusted persons. CONs: Costly in a home or office; with a security system, some family members may be left vulnerable due to their schedules, such as "latch key kids" or impaired family members.
Change or quit job or school or location of dialysis unit.	PROs: Essentially an incognito move that, in the age of technology, may not be possible. CONs: If the patient is forced to leave the dialysis center, access to the nephrologist and staff will cause a loss of continuity in medical and interpersonal services. If the staff member has to change centers or workplace, other patients may feel the loss of a trusted caregiver.
Change email address.	PROs: Decreased access to the target. CONs: May cause a loss of communications; may require the employer to limit publication within I.T. systems; if an unknown stalker is an employee of the same workplace, this may be ineffective.
Police intervention; use of security consultant.	PROs: Places the onus for protection onto the seriousness of the perceived violence and alerts police to physical danger and awareness of possibly an active intruder or active shooter. Helps implement a plan to provide for maximum protection and quick response. Consultants can assist in identifying what may be risk factors not perceived by the agency. CONs: A police intervention with some stalkers may trigger a more violent reaction and aggressive action against the target. If police do not take the threat seriously, the victim may place their guard down and be more at risk.

Table 2 outlines recommendations that should be considered when developing policy to address stalking in healthcare facilities, such as dialysis and transplant clinics (Kwatcher & Stricherz, 2015).

TABLE 2. Recommendations for healthcare facility policies to address stalking

Policy considerations	Policy details
Zero tolerance	• Of stalking. • Toward any member of the team who does not take every part of the policy seriously. • For blaming the target of stalking for causing the stalking.
Duty to warn	• Ensure targeted staff person's safety. • Duty to warn and other related information and actions; may require advice from and contact with agency's legal representative if it is thought a threat scenario. • When grave injury or death is anticipated based on threats to kill, presence of weapons, history of threat-maker having harmed the target or others with great bodily harm, or as defined by relevant statues and codes of ethics. • All work-related stalking cases are to be reported to the facility manager and risk management without delay, i.e. as soon as threats are identified. • Management should immediately contact law enforcement.

TABLE 2. Recommendations for healthcare facility policies to address stalking, *continued*

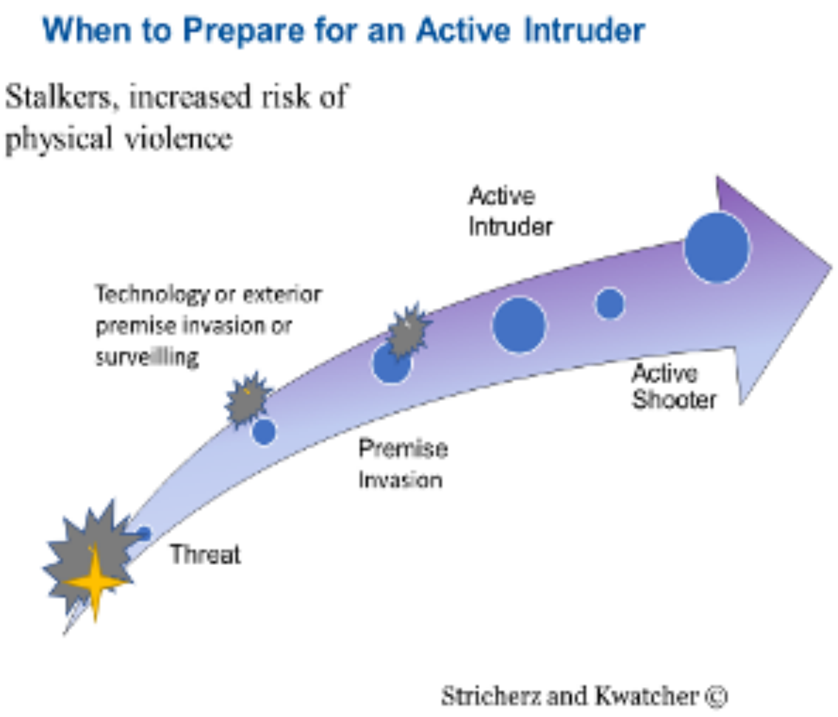
Confidentiality	• Right to privacy. • Information is available to selected staff on a need-to-know basis; the greater the type of threat (i.e., at workplace with weapon), the wider the dissemination of information about the threat should be made.
All cases to be treated with the same merit	• No judgment, discrimination, discipline, termination, or retaliation by the employer. • Assistance provided with workplace issues, such as scheduling, impact on job performance, safety nets.
Reporting	• All work-related stalking cases to be reported to the facility manager and risk management, mandatory accrediting agency reporting, and mandatory law-enforcement/security reporting requirements.
Leave for emotional or physical protection, court procedures, or other necessary actions	• Paid leave when stalking is related to employment.
Stalker identification to staff	• Post photo of the stalker in select locations, as permissible by law. • Name and description of stalker relationship to the target made known to employees, as needed, in the facility.
When agency management has permitted the target staff person to be “mobbed”	• Policy to clearly spell out what is expected of all employees. • Failure to protect and abide by safety plan will result in a disciplinary issue.
Safety plan	• Senior management works with supervisors and targeted staff person to develop a safety plan. • Risk management notified, and a safety plan is written and documented.

There are different state laws, agency policies, and supervisor practices regarding protections and accommodations for employees who are victims of crimes such as stalking. Such employees may need to meet with police and prosecutors, respond to a subpoena, testify, or take other actions because they are stalking victims. Healthcare organizations are encouraged to create and disseminate polices that address these needs. When considering stalking in healthcare settings, **Tables 1 and 2** can serve as guides for administrators about policies and protections that need to be put in place. Once a threat that is connected to a workplace is received and reported, protection of the target is incumbent upon the agency.

We postulate that all organizations should consider the potential latent potential of the perpetrator's power and control—those unrecognized consequences of the perpetrator's behavior or status, including the unrecognized consequences of management's behaviors, decisions, or status. (Merton & Merton, 1968). However, these are secondary to the direct power differential that may exist if the perpetrator's role provides access to the target on the premises, such as the perpetrator being a patient or employee of a dialysis or transplant unit.

The model in **Figure 1** illustrates when and where within the facility the perpetrator's access to a stalking target may require action. There is usually a secret or hidden period when the target is not aware of the threat or the actuality of being a target. An underlying assumption is that when stalking is identified, there is a threat, and that must be a non-negotiable trigger for the facility's response. It cannot be normalized.

FIGURE 1. Model for preparing for a continuum of active intruders



SUMMARY

Dialysis and transplant units need to be familiar with the concept of stalking and how it can affect their employees or targeted patients, as well as the vicarious impact on both employees and patients when it occurs in the unit. Centers will need to be prepared with policies to address these behaviors to protect employees and patients. Below are case examples that can be used for kidney dialysis units and in other healthcare settings to consider and discuss organizational responses that can improve employee safety. This discussion can include a root-cause analysis of each case, and use these discussion questions:

- What, if any, are the behavioral prodrome leading to violence on the continuum?
- What works?
- What needs to be done?
- When may it happen?

Within the problems and interventions in the following three cases are illustrations of some of the issues in dealing with stalking in kidney care settings. When a target first finds out or suspects they are being stalked, what can the target do, what should the agency do, and when should it be done?

Case example #1: The harried employee

The facility manager in a small town noticed a patient care technician coming to work several hours early and received reports from the facility nurse that the tech did not leave after her shift. The nurse also indicated the tech seemed to be preoccupied. The nurse asked the tech if everything was all right; she responded that everything was fine. Two days later, the nurse and manager, after talking about the tech's absent-mindedness, related their concerns to the tech. She disclosed that mysterious things had recently been happening: her car was keyed, the back door of her home was found open, and items were missing from her laundry. There were several other strange incidents in the facility parking lot, a supermarket, and the tech's home. The tech, who lived alone, was afraid at home and was not getting much sleep. The tech had not called the police because she was afraid it might get worse. She felt safer at work than at home or in the community because her coworkers were nearby.

Case example #2: "Percutere ferrum est calidum." (Strike while the iron is hot.)

A patient who had been evaluated and declined for transplant due to treatment nonadherence was admitted to a hospital where he made threatening comments about his transplant social worker. The patient responded to queries from hospital staff, "How are you doing?" with "Not well, I need a transplant, but the transplant social worker kept me off the transplant list, and now I am going to die." The patient stated multiple times, "…that since I am going to die, the social worker should die too." The patient repeated this several times.

The staff contacted a supervisor who spoke to the patient. The patient repeated his comments. The risk management department was contacted and advised there was now a duty to warn the transplant social worker. Risk management called the social worker's manager at the transplant program, and the night supervisor called the local police. The police came to the hospital and interviewed the patient who again stated, "The social worker should die since he kept me off the transplant list." The police officer filed a report of making a death threat, while the social worker's manager contacted the transplant social worker.

After receiving the call very late at night, the social worker was instructed to call the night manager at the hospital where the patient was admitted. The social worker called and was transferred to a police officer and was advised that the police officer had already filed a report. The social worker was asked if he "felt threatened," and he responded that he did. He was advised to go to the court first thing in the morning to file an Order of Protection (OOP).

In the morning, the exhausted and stressed social worker went to the local court to file paperwork, which the judge signed. The social worker delivered the OOP to his manager and hospital security department. After a discussion with management, the social worker drove to the hospital where the patient was located to deliver a copy of the OOP. The social worker called a process server, met the server in the hospital's lobby, and personally paid for the patient to be served with the OOP. This was a daunting, all-day task.

The social worker was told not to drive to the transplant center for the foreseeable future, to park in a remote area of the medical center campus, call security for an escort to the office, and to call for an escort back to the car at the end of the workday.

Within several days the social worker was notified the patient had been discharged, and a few days later, the patient arrived at the transplant clinic, which prompted the use of the "panic button" and a rapid security response. Security remained with the patient during his physician visit, where the patient was told he was terminated and had 30 days to locate another provider. The patient continued to be very ill and was re-admitted to another hospital. The social worker was advised that during the time at the new hospital the patient continued to state the "social worker needs to die too." Within six weeks, the social worker was informed the patient had died.

Case example #3: Stalking: An obsessive relationship from one-way to "no-way"

A few years ago, the 26-year old, unemployed son of a non-English speaking patient started accompanying his father to dialysis in the medical van, and stayed through his father's treatment, often waiting in the lobby. The facility's social worker, a middle-aged woman, always entered the clinic through the lobby door and said good morning to the very bashful young man. He started showing up at the lobby door just as she was coming in, and although he appeared harmless, he was making the employee uneasy. The manager felt there was not a problem, as nothing had happened. The social worker started switching cars with her husband, and altering her hours, as it was getting uncomfortable, but nothing had really "happened." Although there was another entrance to the building, the manager would not provide a key to this employee, telling her she was exaggerating. The young man started lurking in the parking lot, waiting to spot the employee pulling in, then rushing to the door. The custodian was sympathetic and provided a key for the social worker. One day as she inserted the key into the door, the young man popped out of a nearby hiding place. Fortunately, she was unharmed, and the incident was caught on the security camera and finally addressed. The family acknowledged that the young man was mentally unstable and had previous similar incidents. They agreed that he could no longer accompany his father to the clinic or be on the grounds of the facility at any time.

REFERENCES

American Psychiatric Association (APA). (2019). *Resource document on stalking, intrusive behaviors, and related phenomena by patients.* Retrieved from https://www.psychiatry.org/psychiatrists/search-directories-databases/library-and-archive/resource-documents

Comparcini, D., Simonetti, V., Lupo, R., & Cicolini, G. (2015). Nurses' experiences of stalking: A narrative review. *Professioni Infermieristiche, 68*(2), 174–182.

Kwatcher, J., & Stricherz, M. (2015). The elephant in the room: Violence in the workplace. *Nephrology News & Issues, 29*(2), 38.

Leymann.se. (n.d.) *The definition of mobbing at workplaces.* Leymann.se website. Retrieved from http://www.leymann.se/English/12100E.HTM

Madigan, L. (n.d.). *Lisa Madigan quotes.* Retrieved from https://www.brainyquote.com/quotes/lisa_madigan_880740

McIvor, R., & Petch, E. (2006). Stalking of mental health professionals: An underrecognized problem. *British Journal of Psychiatry, 188*(5), 403–404.

Merton, R. K., & Merton, R. C. (1968). Social theory and social structure. *New York: Simon & Schuster.*

National Institute of Justice (NIJ). (2007, October 24). *Overview of stalking.* Retrieved from https://nij.ojp.gov/topics/articles/overview-stalking

Owens, J. G. (2016). Why definitions matter: Stalking victimization in the United States. *Journal of Interpersonal Violence, 31*, 2196–2226.

Pathe, M. T., Mullen, P. E., & Purcell, R. (2002). Patients who stalk doctors: Their motives and management. *Medical Journal of Australia, 176*, 335–338.

Stricherz, J., & Kwatcher, M. (2015 March). *Violence in dialysis and transplant settings: Prevention, immediate, intervention, and post-incident management* [Pre-conference workshop presentation]. National Kidney Foundation Spring Clinical Meetings, Dallas, TX, United States.

U.S. Department of Justice (DOJ). (2002). *Creating an effective stalking protocol.* Washington, D.C.: U.S. Department of Justice.

HOW DO YOU ASK FOR A KIDNEY?

If you have kidney disease and need a transplant, you may not know how to ask someone to consider donating a kidney to you. Asking can feel as hard as giving. Many people won't get a transplant simply because they don't know how to ask. **We can show you how.**

WHY THINK ABOUT GIVING ONE?

You may want to know why people donate a kidney to someone. People everywhere are stepping up to help others live better lives... family, friends, even total strangers... maybe even someone close to you. **We can show you why.**

LIVING DONATION MAKES BETTER LIVES POSSIBLE.
Whether you need kidney, or want to learn more about donation, it starts with asking the National Kidney Foundation.

kidney.org/livingdonation
844.2BIGASK (844.224.4275)
bigask@kidney.org

#BigAskBigGive

NATIONAL KIDNEY FOUNDATION®

NATIONAL KIDNEY
FOUNDATION®

30 East 33rd Street
New York, NY 10016