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Council of Nephrology Social Workers

The Journal of
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- Assessment of Health-related Quality of Life in Hmong Dialysis Patients at Mayo Clinic Health System Northwest Wisconsin
- The State of Patient-Centered Outcomes Research in Chronic Kidney Disease: Perspectives from Patients, Care Partners, and Researchers
- The Importance of Kidney Disease Peer Mentor Programs During the COVID-19 Pandemic
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*The Journal of
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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.

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TABLE OF CONTENTS

5 JNSW Editorial Board Membership

5 Call for JNSW Manuscripts

6 Instructions for Authors

STUDY

9 Assessment of Health-related Quality of Life in Hmong Dialysis Patients at Mayo Clinic Health System Northwest Wisconsin
Jessica Zeman, APSW, NSW-C, Abdul Khan, MD, MBBS

STUDY

20 The State of Patient-Centered Outcomes Research in Chronic Kidney Disease: Perspectives from Patients, Care Partners, and Researchers
Samuel R. Bethel, MSW, LCSW, PhD(c), Teri Browne, MSW, PhD, Derek Forfang, Jessica Joseph, MBA, Kelli Collins Damron, MSW, Laura Brereton

PRACTICE NOTE

30 The Importance of Kidney Disease Peer Mentor Programs During the COVID-19 Pandemic
Kristy Washinger, MSN, FNP-BC, Robin Asick, MSW, LSW, NSW-C, Lynne Wright, MSW, LSW

RESEARCH

32 NKF 2021 Spring Clinical Meetings Abstracts

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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 | ■ Sexual Functioning | ■ Professional Roles |
| ■ Kidney Transplant | ■ Aging and Gerontological Issues | ■ Rehabilitation |
| ■ Pediatric Issues | ■ Disaster Preparedness | ■ HIV/AIDS |
| ■ End-of-Life Concerns | ■ Comorbid Illnesses | ■ Diversity/Discrimination Issues |
| ■ Sleep Disorders | ■ Home Dialysis Modalities | ■ 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.

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Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics [<https://www.socialworkers.org/pubs/code/code>]; 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 (URMSB): Ethical Considerations in the Conduct and Reporting of Research [<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html>].

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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.

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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."

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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.

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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.

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Order of the Manuscript Sections

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|---------------|--------------------------|
| 1) Title page | 5) Appendices (optional) |
| 2) Abstract | 6) Author note |
| 3) Text | 7) Tables |
| 4) References | 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.

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Assessment of Health-related Quality of Life in Hmong Dialysis Patients at Mayo Clinic Health System Northwest Wisconsin

Jessica Zeman, APSW, NSW-C, Abdul Khan, MD, MBBS,
Mayo Clinic Health System Department of Nephrology, Eau Claire, WI

A chronic illness, such as kidney disease, has a significant effect on an individual's perception of their quality of life (QOL). Health-related quality of life (HRQOL) is the subjective perception of an illness and treatment on the physical, psychological, and social well-being of that individual. In this study, we reviewed HRQOL in the Hmong-American (n = 22) and Non-Hmong-American (n = 40) patients receiving dialysis treatments at Mayo Clinic Health System Northwest Wisconsin (MCHS NWWI) utilizing the Kidney Disease Quality of Life-36 (KDQOL-36™) survey. Our findings indicate a discrepancy between Hmong-American and Non-Hmong-American patients in the Burden of Kidney Disease subscale score of this survey. Language barriers, traditional belief systems versus Western medical practices, lack of understanding regarding illnesses, and a cultural focus on the family as a whole instead of individuality may have a significant bearing on the differences found between Hmong-American and Non-Hmong-American patients.

INTRODUCTION

As a part of an interdisciplinary team, social workers play an integral role in enhancing and supporting the quality of life (QOL) of patients who have chronic illnesses. Social workers have the training and ability to look at patients through a holistic lens and better understand the turmoil that chronic illness diagnoses may entail. Therefore, the need for a diversified and culturally sensitive interdisciplinary team is essential when partnering with patients, especially those from minority populations, including Hmong-Americans.

Hmong-Americans today are scattered throughout the United States. They often practice a combination of traditional and modern ways of life, including managing chronic illnesses. Therefore, to treat these individual patients with a chronic disease, such as end-stage kidney disease (ESKD), it is imperative to understand their cultural practices and how they perceive their health-related quality-of-life (HRQOL) to partner with them for their medical care.

In attempts to gather information regarding Hmong-Americans and their HRQOL related to the diagnosis of ESKD, an extensive literature review was completed, but minimal information was found. This study will address the hypothesis that HRQOL is lower in the Hmong-American population who are receiving dialysis treatments than in the Non-Hmong-American population receiving dialysis treatments at Mayo Clinic Health System at Northwest Wisconsin (MCHS NWWI). The study will help address the literature gap in this area.

In this study, we will review a brief history and the traditional cultural practices of the Hmong people and look at how their illnesses are believed to have originated and how they are treated in the Hmong culture. We will examine the Kidney Disease Quality of Life-36 (KDQOL-36™) survey (Rand Healthcare, 2019) results from Hmong-American and Non-Hmong-American patients who have received dialysis treatments at MCHS NWWI. Finally, we will discuss some of the barriers Hmong-Americans have encountered and the potential reasons their KDQOL-36 scores may be lower, specifically in the area of the Burden of Kidney Disease subscale.

HISTORY

Documentation has indicated the early ancestors of the Hmong people lived in China for several centuries and began migrating to the remote mountainous regions of Vietnam, Laos, and Thailand in the 1800s (Gerdner, 2012). They had resided in small villages with multigenerational family members. Traditionally, the whole family unit would contribute to the household, while older family members cared for and provided wisdom to the younger generations through their rich oral traditions (Gerdner, 2010).

Difficult geographical terrain prevented free movement to and from urban centers with medical facilities; therefore, a journey for medical care was only undertaken in extreme, life-threatening situations. The Hmong people relied on their community leaders to provide the knowledge needed to care for those who were ill (Beghtol, 1988).

Corresponding author: Jessica Zeman, APSW, NSW-C; Mayo Clinic Health System Department of Nephrology, 1221 Whipple Street, Eau Claire, WI 54703; Zeman.jessica@mayo.edu; 715.838.3506

The Hmong people had endured decades of war trauma (Lee, 2019), most notably during the Vietnam War (Gerdner, 2010). After the United States withdrew troops from South Vietnam in 1973, neighboring Laos also came under Communist control (Reznik, Cooper, MacDonald, Benador, & Lemire, 2001). During that time, thousands of Hmong fled the war zones in both countries and crossed the dangerous Mekong river looking for safety in Thailand (Cobb, 2010). Large refugee camps were built in Thailand to provide shelter for these people (Gerdner, 2010).

The living conditions in these camps were horrific; many people succumbed to illness and death. Many elder Hmong recall appalling tales about physical and psychological trauma they endured during the ongoing wars and as refugees (Gerdner, 2010). Chronic malnutrition, lack of medical care, and lack of preventative medicine were common. Anemia was prevalent, mostly due to poor diet and parasite infections. Lice and scabies were widespread due to the proximity of the living quarters and lack of sanitary conditions (Beghtol, 1988).

Mistrust began to build between the Hmong and the U.S. government in the early 1970s. Even though many young Hmong men and boys had fought in support of the American troops, the U.S. government thought the Hmong people were “too primitive” to be given asylum at the end of the war. Initially, only prestigious Hmong leaders were allowed to enter the United States. This caused resentment among many Hmong people towards the United States. Through ongoing advocacy efforts, the Hmong leaders were able to solidify help for Hmong refugees still living in Laos and Thailand to enter the United States (Lee, 2019).

In 1976, the Indochina Migration and Refugee Assistance Act was passed. This allowed the Hmong people to begin the resettlement process to the United States (Lee, 2019). From 1976 to 1997, over 100,000 Hmong people emigrated to the United States. The last of the large refugee camps in Thailand closed in 1997, with an additional camp in Thailand relocating an additional 15,000 Hmong people to the U.S. in 2006 (Gerdner, 2010). The vast majority of Hmong people from the refugee camps settled in California, Wisconsin, and Minnesota (Johnson, 2002).

Hmong immigrants had difficulty understanding life in America. In Laos, the Hmong people had little knowledge of urban living, thus their transition to the U.S. was abrupt and traumatic (Lor, Xiong, Park, Schwei, & Jacobs, 2017). The industrial U.S.'s technology was much more advanced than many had ever known (Beghtol, 1988).

The Hmong people encountered barriers to communication, as well as understanding the American culture, community values, and expectations. This was most evident in the healthcare system (Johnson, 2002). Adapting to enormous

change in their sociocultural environment resulted in drastic misunderstandings between Western medical practices and the traditional Hmong immigrants' belief system (Helsel, Mochel, & Bauer, 2004). Compared to other refugee or immigrant groups in U.S. history, the Federal Office of Refugee Resettlement identified older Hmong immigrants as having the greatest difficulty adjusting to American life. This has been compounded by language barriers, low socioeconomic status, lack of formal education, social isolation, and lack of transportation (Gerdner, 2010).

THE CULTURE

The Hmong culture remains patriarchal in structure and is grouped into clans providing social structure (Xiong et al., 2016). There are 18 different family clans, determined by ancestral lineage; each clan has its own history, which is shared oral stories passed down through generations from their elders (Stratis Health, 2018).

In the Hmong culture, men and women typically have very distinct roles within the family structure. Traditionally the men and clan leaders make decisions about an individual's health—the individuals themselves do not make the decisions (Xiong et al., 2016). The clan leaders and other influential family members discuss the medical issues at hand and make decisions for an individual, based upon what best suits the clan as a whole (Carteret, 2012).

By tradition, the Hmong people have strong family bonds, based on a system of interdependence. Marriage and having large families are highly valued in Hmong culture (Pinzon-Perez, 2006). The birth of children is proof of the families' worth within the clan and, in accordance with their traditional belief system, an indication that the spirits are not angry with the family (Reznik et al., 2001). To this day, it remains a current practice to have multiple generations live in the same house for social and financial support (Gerdner, 2010).

THE TRADITIONAL BELIEF SYSTEM

The traditional Hmong people practice animism, the belief that spirits live on, in, and around the human body. A balance between the body and spirit is required for good health (Xiong et al., 2016). Life is seen as a continuous cycle of birth and rebirth with two worlds—the physical and spiritual—coexisting side by side (Plotnikoff, Numrich, Wu, Yang, & Xiong, 2002). The Hmong believe that death is not the end, but rather the beginning of a new cycle in the reincarnation process; souls exist in the physical world indefinitely (Pinzon-Perez, 2006).

LANGUAGE

Having a chronic medical illness as a Hmong person has been an overwhelming experience for the thousands who

emigrated from Laos and Thailand to the U.S. (Lor et al., 2017). The words “chronic illness” do not exist in the Hmong language. Therefore, it is a concept that is difficult to describe to a Hmong person (Xiong et al., 2016).

The Hmong language was not a written language until the late 1960s, when Christian missionaries developed a writing system to allow translation of the Bible; thus, the Hmong language does not include modern-day medical terms (Carteret, 2012). Words such as “diabetes,” “hypertension,” and “cancer” are nonexistent, and the physical symptoms of these illnesses are often understood as an imbalance, a disruption of the souls or spirits, or coming from evil occurrences in former lives (Plotnikoff et al., 2002).

In a culture with (until recently) no written language and minimal medical terminology in its oral language, many Hmong-Americans may lack the ability to understand and describe the human body. They may have always relied on traditional Hmong practices for support. The underlying reason for a delay in seeking early or preventative healthcare was often due to the lack of knowledge about illnesses and diseases (Vang, 2019).

Because most Hmong-Americans have significant respect for healthcare providers, they will commonly say “yes” or nod in agreement during conversations; this does not mean they agree with what is being said but are merely acknowledging the words being spoken to them. Elder Hmong-Americans are often accustomed to speaking in metaphors and telling a story to answer a question, even when asked directly by healthcare providers about specific symptoms (Carteret, 2012). This stems from their rich oral traditions and storytelling practices, dating back hundreds of years.

Many Hmong-Americans do not communicate dissatisfaction regarding the quality of their healthcare; instead, they will simply go elsewhere. They often do not feel comfortable asking questions and speaking up. Hmong-Americans may also listen attentively to healthcare providers but will often avoid eye contact (Carteret, 2012). These types of behaviors may be a cause for misunderstanding between healthcare providers and Hmong people. This misunderstanding and distrust can also stem from unfamiliarity with common practices in Western healthcare, leading to delays in seeking medical care, and poorer health outcomes.

Many Hmong-Americans also distrust medications prescribed for health issues they cannot see and often stop taking medications once they feel better because they believe the illnesses have been cured, even if that is not true (Xiong et al., 2016).

Many Hmong-Americans believe talking about a disease or hearing about bad outcomes may mean they are asking for the illness to occur, often contrary to the common practice

of Western medical providers to explain a prognosis (Reznik et al., 2001).

ILLNESSES

Illness is defined by an individual’s understanding of the process, cause, severity, and prognosis of the disease. All cultures have a belief system about the cause, diagnosis, and treatments of diseases (Reznik et al., 2001). Western medicine is typically focused on germ theory and biomedical phenomena. In comparison, many Non-Western cultures believe an illness is caused by an object intrusion, spirit possession, soul loss, or a breach of a taboo. The Hmong believe in the integrity of the physical body, that body parts which are cut or mutilated in accidents, surgery, or autopsy, will remain that way in reincarnation (Reznik et al., 2001).

Many Hmong-Americans describe an illness as the inability to get up and fulfill their daily activities (Reznik et al., 2001). When traditional Hmong-Americans decide from who or where to seek medical care for an illness, they start by evaluating the symptoms. Many feel that lack of energy and tiredness are caused by spirit loss, soul loss, or evil spirits, so a shaman is often utilized before Western healthcare providers are sought (Lor et al., 2017).

They also may believe if there are no symptoms, then the illness is cured and no longer a problem. They often base their beliefs on prior experiences—if an individual in their clan has been cured or healed by a certain treatment, then that treatment is taken into consideration by the clan leaders for healing the next person with similar symptoms (Reznik et al., 2001).

Once the clan leaders have diagnosed illness in an individual requiring help, a plan is developed for that individual by the clan leaders. They may choose to treat the illness with shaman ceremonies, herbal medicines, Western medicines, or a combination. If all else fails, that individual may be taken to the hospital; however, this was a very uncommon practice in Laos and Thailand (Beghtol, 1988).

In the traditional Hmong culture, it is believed that many illnesses are often associated with an underlying spiritual problem (Wong, Mouanoutoua, Chen, Grey, & Tseng, 2005). Spiritual diseases occur when one or more of the human souls or spirits become separated from the human body. A soul can become compromised in one of three ways (Gerdner, 2012):

- An evil spirit may invade or attach itself to a person’s body.
- An evil spirit takes a person’s spirit and tortures it.
- The person’s soul becomes dissatisfied with the current host body and leaves.

Souls can be separated from a person by accident, by a frightening event, or be taken by an angered spirit. If this occurs, the soul loss can be experienced as pain, illness, or misfortunes (Reznik et al., 2001). A shaman is the only healer who can communicate with the supernatural spirits and bring back the soul (Lor et al., 2017). The role of the shaman is to perform a spiritual ceremony to recall that soul, using ritual practices. These Hmong healers bridge the gap between the spirit world and the physical world to help resolve illnesses and bring back the good spirits to the person with the illness (Xiong et al., 2016). Other times, a shaman might say they cannot see a spiritual issue causing the illness, or it is too late to intervene, or it is too difficult to catch the wandering soul (Helsel, Mochel, & Bauer, 2004). It is widely believed that if the shaman's rituals are unable to bring back the lost soul, that individual will only get worse and die (Pinzon-Perez, 2006). The desired outcome from the shaman is to promote and maintain spiritual harmony and balance (Gerdner, 2012).

CHRONIC ILLNESS

Many Hmong-Americans, especially elders, focus on treating the illness but do not have an understanding of preventative medicine or of chronic diseases requiring daily treatments, even when symptoms are not present (Carteret, 2012). The Hmong language is very challenged in providing the words to explain this concept.

In Laos, the Hmong did not have access to modern medicine or educational opportunities to learn about the complexities of the human body. Many Hmong were unaware of the organs within the human body and what purposes those organs serve. Describing this phenomenon has become even more of a challenge due to the Hmong language's lack of words to do so (Johnson, 2002). In the present day, when healthcare providers attempt to explain a disease or illness affecting a particular organ or body part, the Hmong-American person is at a loss to understand what that means (Johnson, 2002). For example, some Hmong-American people believe that hypertension is caused by "bad blood," and diabetes is caused by personal stress or a change in the weather (Lor, 2018).

Common chronic health issues in the Hmong population include hypertension, diabetes, kidney disease, and gout. The perception of not feeling "sick" has prevented Hmong-Americans from seeking medical care or preventative measures, as well as not following prescribed medications often needed for chronic illnesses (Vang, 2019). Multiple studies have looked at health risks and disease prevalence in the Hmong culture and suggest that Hmong-Americans have higher rates of these illnesses than Caucasians (Lor, 2018).

Many Hmong-Americans have difficulty understanding and responding to chronic metabolic diseases, including diabetes and hypertension (common precursors for ESKD), for several reasons (Gerdner, 2010):

- A Hmong-American may overlook symptoms from health insufficiencies for several years, delaying treatment.
- There are very few words in the Hmong language that directly relate to these health issues.
- Hmong-American people often view their health as either "black or white." To be healthy requires a "balance." Those suffering from illnesses have attributed them to "imbalances" in souls or the spirit world.
- Western medications are "too strong," and herbal medicines are often the preferred choice.

Lifelong illnesses require lifelong work to manage and control them. Such diseases can be marginalizing, isolating, and shaming for Hmong-American people. In a culture and family system that revolves around the group as a whole, instead of individuality, being set apart from the group to manage a chronic illness can feel overwhelming and painful (Helsel, Mochel, & Bauer, 2005). This can be especially difficult for chronic illnesses that have no immediate cure or that cannot necessarily be seen by others. These feelings can have a direct connection to the Hmong-Americans' HRQOL.

QUALITY OF LIFE (QOL)

This study examines the HRQOL of Hmong-American patients compared to Non-Hmong-American patients who have chronic kidney failure requiring dialysis treatments in the same period.

Health, as defined by the World Health Organization (WHO), is a state of complete physical, mental, and social well-being, and not merely the absence of disease (Saad et al., 2015). Measuring quality of life (QOL) is essential when assessing a patient's perception of their health and is especially important for those who have a chronic illness. Health-related quality of life (HRQOL) is the subjective perception of the disease, its treatment, and its effect on the physical, psychological, and social well-being of an individual (Saad et al., 2015).

Research has indicated a plethora of explanations affecting health outcomes for Hmong-Americans, including the lack of medical attention, communication misunderstandings, unfamiliarity with standard practices in Western healthcare, and cultural aspects. This conglomeration of multifactorial issues may lead to the low reported HRQOL by Hmong-American patients. Research has also shown that

low HRQOL is a predictor of increased hospitalizations and mortality rates in this population (Schatell & Witten, 2012).

HYPOTHESIS

HRQOL is lower in the Hmong population receiving dialysis treatments than the Non-Hmong population receiving dialysis treatments at MCHS NWWI.

METHOD

The study proposal was reviewed and approved by Mayo Clinic institutional review board.

Participants

We reviewed the charts of 22 Hmong-American patients receiving dialysis treatments between November 2008 and November 2019. Nineteen patients were first-generation Hmong-Americans, and three patients were second-generation Hmong-Americans.

As a comparison group, 40 Non-Hmong-American patients were randomly selected from a total of 331 Non-Hmong-American patients from this same period (see **Table 1**).

Table 1. Demographics of Patient Samples

	Hmong-Americans	Non-Hmong-Americans
Number of patients	22	40
Age range	28–77	26–93
Mean age	58	68
Male	55%	57%
Female	45%	43%
English as primary language	36%	100%

All 62 patients receive or have received care at MCHS NWWI, a subsidiary of Mayo Clinic. MCHS NWWI has four dialysis centers: Eau Claire Luther Hospital inpatient/outpatient services, Eau Claire London Road out-patient services, Menomonie outpatient services, and Barron outpatient services. For our study's purposes, the Barron outpatient dialysis center was not included due to a lack of participants at this location.

Comorbidities

We reviewed electronic medical records of our patients to compare four chronic comorbid conditions (see **Table 2**).

Table 2. Comorbidities of Patient Samples

	Hmong-Americans	Non-Hmong-Americans
Hypertension	100%	97.5%
Diabetes	50%	52.5%
Cardiac-related issues	50%	82.5%
Gout	22.7%	25%

This data suggests similarities between Hmong-American and Non-Hmong-American patients regarding hypertension, diabetes, and gout prevalence. The biggest difference between these two groups showed a higher rate of cardiac-related issues in the Non-Hmong-American patients as compared to Hmong-American patients.

Measures

For patients with ESKD and requiring dialysis treatments, the Centers for Medicare and Medicaid Services (CMS) has integrated HRQOL measures, and mandates dialysis facilities to perform routine administration utilizing a HRQOL scale (Chow & Tam, 2014). The KDQOL-36 survey is used to meet these requirements (Cohen, Lee, Sibbel, Benner, Brunelli, & Tentori, 2019).

The KDQOL-36 survey used in this study was derived from the original 134-item KDQOL instrument, the 79-item KDQOL Short-Form survey, and the Medical Outcomes Study 12-item Short-Form survey. A 36-question survey was developed measuring HRQOL for patients receiving ESKD treatments (Peipert, Bentler, Klicko, & Hays, 2018). The KDQOL-36 survey is the preferred measurement tool for dialysis facilities because of its ease of administration with minimal burden on patients and staff to complete and score, while providing an adequate assessment of the patient's quality of life (Thaweethamcharoen et al., 2013).

The KDQOL-36 is used with people over age 18, receiving dialysis treatments for more than three months, with those who do not have cognitive impairments such as dementia or active psychosis, and is not used with non-English speakers when a translation is not available. According to the Dialysis Outcomes and Practice Patterns Study (DOPPS), this survey has proven reliable and valid for measuring patient perceptions of their health-related quality of life (Schatell & Witten, 2012).

The KDQOL-36 is divided into five distinct subscales, all measuring different aspects of quality of life: Physical, Mental, Burden of Kidney Disease, Symptoms and Problems, and Effects of Kidney Disease on Daily Life (Schatell & Witten, 2012).

The survey subscales are case-mixed adjusted, comparing age, treatment modality, gender, and diabetes diagnosis (Schatell & Witten, 2012). A numerical score, as well as ratings of “above average,” “average,” and “below average,” are provided as part of the results generated by a computer program, KDQOL Complete (KDQOL Complete, 2021). KDQOL Complete is an electronic subscription service that scores, stores, and reports KDQOL-36 survey results, allowing patient-specific information to be reviewed over time (Schatell & Witten, 2012). Patient KDQOL-36 survey results from KDQOL Complete are part of the patient’s medical records at MCHS NWWI.

During a review of patient scores from November 2008 to November 2019, there appeared to be a noticeable pattern in just one subscale area of the KDQOL-36 which prompted an in-depth analysis of patient scores, demographics, and comorbidities with Hmong-American and Non-Hmong-American patients receiving dialysis. This pattern was seen in the Burden of Kidney Disease subscale in the survey. All other subscales of the KDQOL-36 did not show any noticeable patterns.

The KDQOL-36 has been translated into 41 written languages (Rand Health Care, 2019); however, there is no written translation into the Hmong language at this time. The Hmong written language was not developed until the 1960s and many Hmong elders have never learned to read, write, or had any formal training in the written Hmong language.

The KDQOL-36 survey is required to be completed annually, so there are many patients who have completed the survey multiple times.

The benefit of reviewing multiple surveys taken by an individual patient over time allows comparison opportunities in the five subscale areas of the KDQOL-36 regarding the patient’s reported HRQOL. This also allows the interdisciplinary team to partner with the patient to provide support and resources to those who report “below average” scores. Multiple surveys over time with consistently “below average” scores from an individual patient may predict increased rates of hospitalization and mortality (Schatell & Witten, 2012).

The 22 Hmong-American patients had completed the survey collectively 64 times, and the 40 Non-Hmong-American patients had completed the survey collectively 121 times (see **Table 3**).

Table 3. KDQOL-36 Surveys: Hmong-American Patients vs. Non-Hmong-American Patients

	Number of Surveys Completed	
	Hmong-Americans <i>n</i> = 22	Non-Hmong-Americans <i>n</i> = 40
Median number of times survey was completed	2	3
% of patients who had taken survey 1x	23%	35%
% of patients who had taken survey 2x	23%	22%
% of patients who had taken survey 3x	18%	13%
% of patients who had taken survey 4x	18%	7%
% of patients who had taken survey 5 or more x	18%	23%
Total number of surveys taken	64	121

Procedure

The KDQOL-36 was translated by an in-person MCHS NWWI Hmong-language interpreter for non-English-speaking Hmong-American patients, and responses were recorded. For the eight Hmong-American patients fluent in English, the survey was provided in either written format or verbally read to them in English at the dialysis unit. Fourteen patients required assistance from an in-person Hmong interpreter to complete the survey.

As a comparison group, 40 Non-Hmong-American patients were randomly selected. These patients were either read the survey questions out loud during their dialysis treatments or completed the KDQOL-36 on their own. English was the primary language for all these patients.

Data Analysis

End-stage kidney disease (ESKD) is often caused by hypertension, diabetes, cardiac-related issues, and gout (American Kidney Fund Horizon Therapeutics, 2020); therefore, these comorbidities were included as part of the data review for both Hmong-American and Non-Hmong-American patients.

RESULTS

Burden of Kidney Disease Subscale: Surveys

Of the 64 total times the KDQOL-36 was taken by the 22 Hmong-American patients, the Burden of Kidney Disease subscale was scored “below average” collectively 37 times (57.8%) more often than any other response (see **Figure 1**).

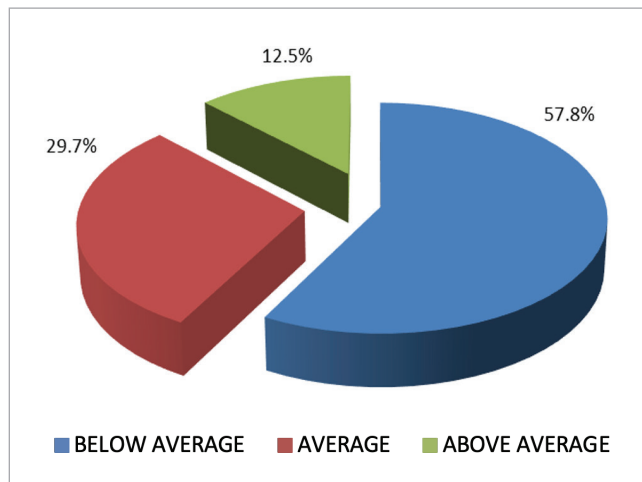


Figure 1. Burden of Kidney Disease Subscale of Hmong-American Survey Responses

The Non-Hmong-American patients completed the survey 121 times. The Burden of Kidney Disease subscale was scored “below average” collectively only 10 times (8.3%; see **Figure 2**).

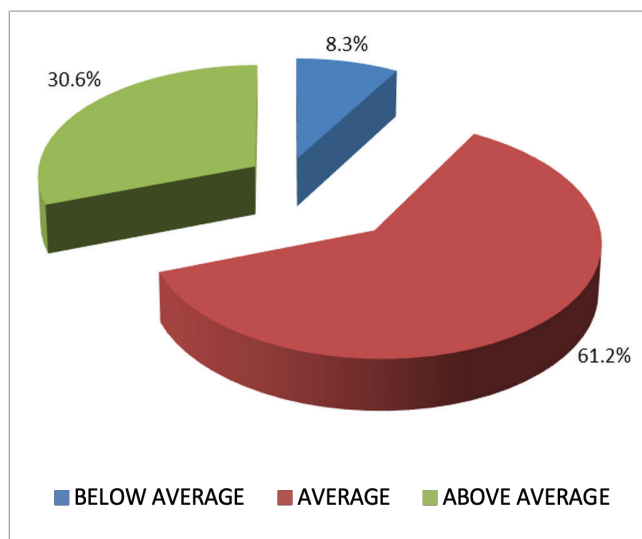


Figure 2. Burden of Kidney Disease Subscale of Non-Hmong-American Survey Responses

Comparison

Comparing the 64 Hmong-American and 121 Non-Hmong-American patient surveys reveals discrepancies in their Burden of Kidney Disease subscale scores (see **Figure 3**).

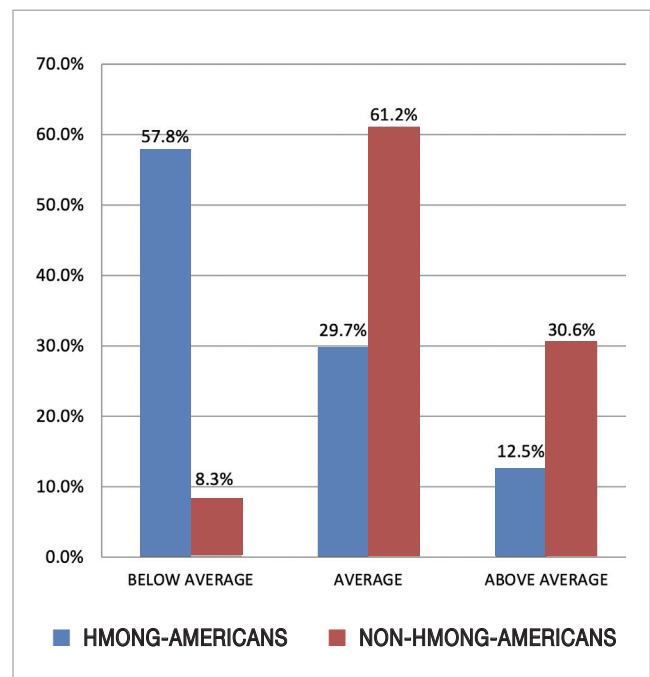


Figure 3. Burden of Kidney Disease Subscale Comparison Between Hmong-American and Non-Hmong-American Survey Responses

Burden of Kidney Disease Subscale: Patients

When looking specifically at the Burden of Kidney Disease subscale score for each individual patient over a period of time, there may be variations. The response patterns of each patient allows for comparison opportunities regarding how their reported HRQOL may change over time.

As seen in the next figure, of the 22 Hmong-American patients there are four who (18.2%) scored either “average” or “below average” in the Burden of Kidney Disease subscale during the multiple times they completed the survey.

In addition, nine (40.9%) of the Hmong-American patients consistently scored “below average” every time they completed the survey in the Burden of Kidney Disease subscale, more often than any other response for this subscale (see **Figure 4** for percentage breakdowns).

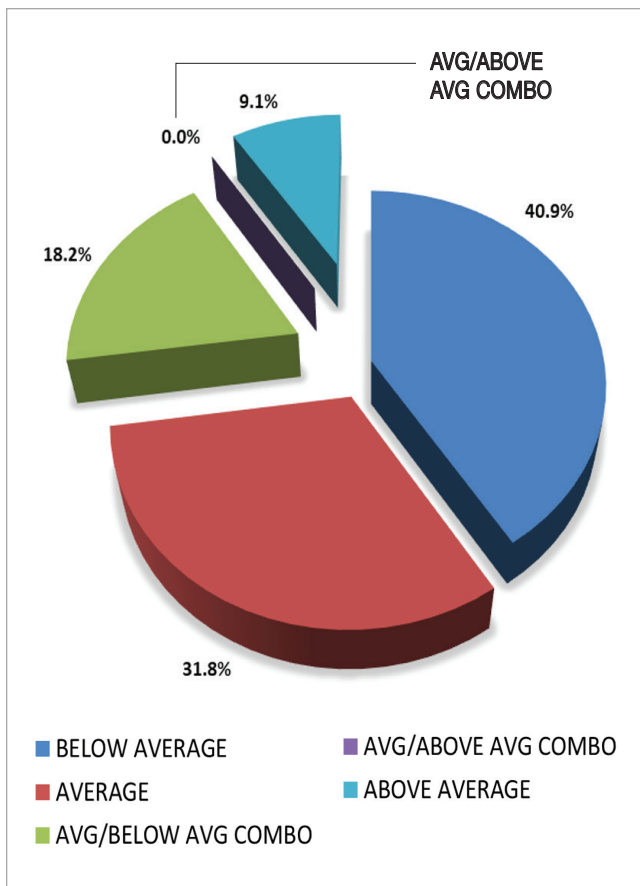


Figure 4. Burden of Kidney Disease Subscale of Hmong-American Patients

A review of the “above average” and “average” responses was completed in an attempt to parse out differences in these two groups. The two patients (9.1%) who consistently scored “above average” every time they completed the survey were both second-generation Hmong-Americans. Both spoke fluent English and completed the KDQOL-36 in English without the use of an in-person Hmong interpreter. Both were young, 32 and 28 years of age. One was female, and one was male. Both patients had been on in-center dialysis. Both patients only had hypertension listed as a comorbidity.

The four Hmong-American patients (18.2%) who consistently scored “average” every time they completed the survey were male, with their age ranging from 49 to 77 years. Two spoke fluent English and had completed the KDQOL-36 in English, and the others required the assistance of an in-person Hmong interpreter. All four of these patients had hypertension, two patients had cardiac-related issues, one patient had diabetes, and another had gout listed as a comorbidity.

In contrast, only 2 (5%) of the 40 Non-Hmong-American patients scored consistently “below average” every time they completed the survey (see **Figure 5**).

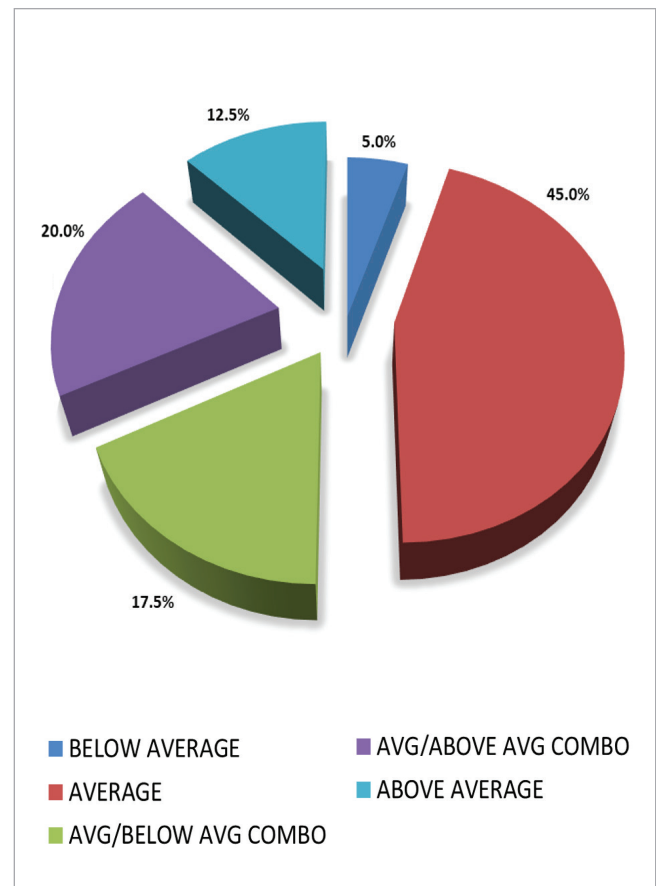


Figure 5. Burden of Kidney Disease Subscale of Non-Hmong-American Patients

With so many Non-Hmong-American patients scoring “average,” a review of the “above average” and “below average” scores was completed to determine what differentiates these groups.

The seven Non-Hmong-American patients (17.5%) who consistently scored “above average” every time they completed the survey were further reviewed. They were four females and three males between ages 26 and 93; all had hypertension listed as a comorbidity. Five of these patients had diabetes, six had cardiac-related issues, and three had gout.

The two Non-Hmong-American patients (5%) who consistently scored “below average” every time they completed the survey were further reviewed; one was male and one female, in age range 50–57. Both patients had hypertension, and neither had cardiac-related issues or diabetes. One patient had gout and the other did not. One patient had been on home hemodialysis and had been on a wide variety of different treatment modalities for decades. The other patient had been on in-center hemodialysis for less than two years.

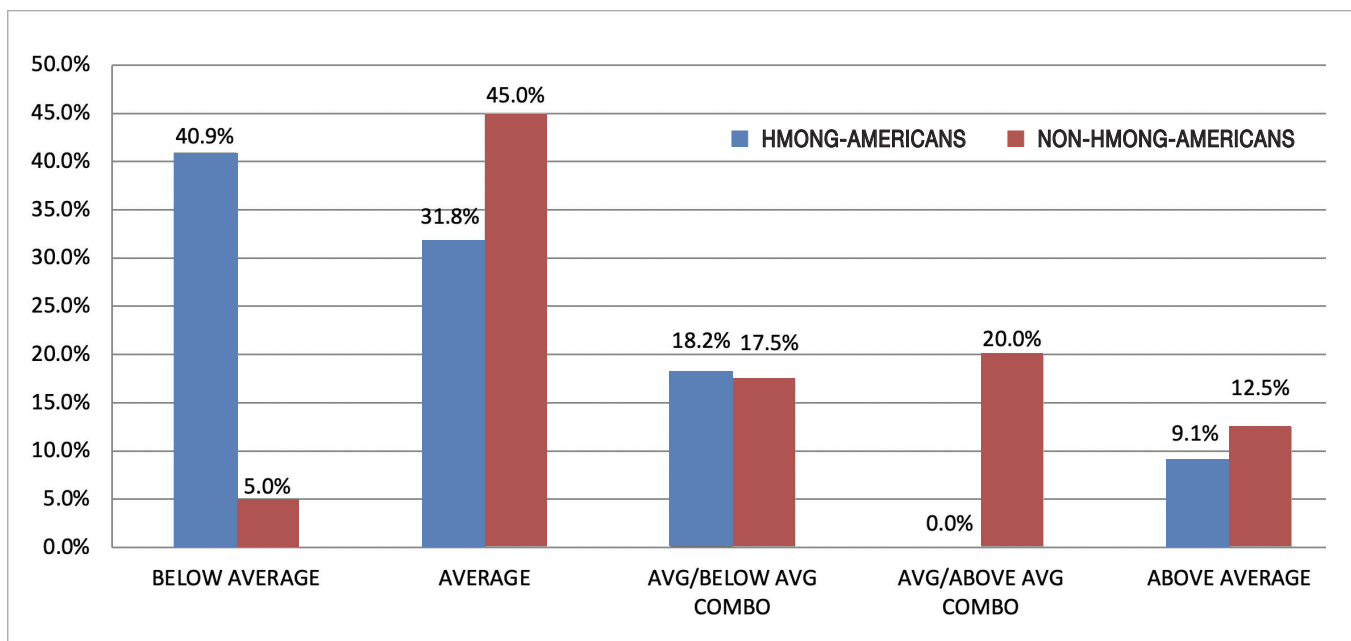


Figure 6. Burden of Kidney Disease Subscale Comparison Between Hmong-American and Non-Hmong-American Patients

Comparison

A collective comparison of the 22 Hmong-American and 40 Non-Hmong-American patients shows discrepancies in the Burden of Kidney Disease subscale with the Hmong-American patients consistently scoring “below average” most often, and the Non-Hmong-American patients consistently scoring “average” most often (see **Figure 6**).

DISCUSSION

A visual review of patient scores from November 2008 to November 2019 appears to show a noticeable pattern in the Burden of Kidney Disease subscale scores between the Hmong-American and Non-Hmong-American patients. This study has utilized 11 years of data supporting the hypothesis that HRQOL is lower in the Hmong-American population receiving dialysis treatments than the Non-Hmong-American population receiving dialysis treatments at MCHS NWWI.

This study has identified several factors that need further evaluation to better assess Hmong-American patients’ needs and help nephrology social workers and interdisciplinary teams develop ways to partner with these patients while taking into account several unique factors relevant to this population.

Social workers and interdisciplinary teams working with Hmong-American patients should remain keenly aware of the unique challenges this community may grapple with and question how HRQOL is measured to assess if the tool being used is the best option for this community.

One of the most significant challenges in evaluating the HRQOL in our Hmong-American patients receiving dialysis treatments is that the Hmong language has traditionally only been an oral language. As stated, when the Hmong language was translated into the written word in the 1960s, medical terminology was not included, making it very difficult to describe illnesses. Also, many Hmong-American elders are unable to read either the Hmong or English written languages. The KDQOL-36 is not translated into the Hmong written language, and the majority of Hmong-American patients receiving dialysis at MCHS NWWI were unable to read the Hmong or English language. And providing the Hmong-American people an accurate translation of the KDQOL-36 to study their HRQOL is difficult.

Another challenge was the complexity of the traditional Hmong spiritual belief system. Hmong-American people who follow traditional practices believe the shaman is the only one who can help heal a spiritual-related illness. These spiritual beliefs diverge considerably with traditional Western healthcare practices. Chronic diseases may not be identified and treated until much later in the disease processes, due to the importance Hmong-American people place on their traditional practices. Hmong-American people may not seek Western medical services until other healing ceremonies and traditional medicines have been tried.

The Hmong people encountered a completely different way of understanding illnesses and the human body upon their immigration to the U.S. Many Hmong-Americans lack knowledge of how the human body works, what organs are in the

human body, what functions these organs have, and the idea of biological diseases. When a Hmong-American person is faced with a chronic illness, such as ESKD, an explanation of kidney failure may be more challenging for Western health-care providers (including social workers) to describe because of this lack of basic knowledge. In addition, many Hmong-Americans are not keen on speaking about their illnesses for fear these illnesses will get worse if they are talked about.

Another challenge stems from the Hmong family system, which emphasizes the importance of group well-being over individual needs. When one member of the family cannot fulfill their role in the family due to a chronic illness, that individual may have feelings of isolation, marginalization, and shame from being set apart from their family group. These feelings may appear in the KDQOL-36 Burden of Kidney Disease subscale score, indicating their feelings of being a burden on their integrated family systems.

A final challenge to consider is the fashion in which the KDQOL-36 questions are presented. The questions on the entire KDQOL-36 survey are written in the first-person case, indicating individual dominance. The traditional Hmong culture does not focus on individuality but their clan as a whole. Their individual thoughts and responses on surveys, such as the KDQOL-36, may emphasize their isolation from their family group and may be exacerbated or not accurately reported by using a survey of this type.

Understanding the impact of health concerns on Hmong-American dialysis patients, and at the same time considering their strong family bonds and cultural practices, is key in providing accurate assessments of their HRQOL. Further research, sensitive to the culture, medical understanding, and practices of the Hmong people, is needed to address HRQOL in the Hmong-American dialysis patient population.

REFERENCES

- American Kidney Fund; Horizon Therapeutics. (2020, June 6). *Gout and kidney disease*. Retrieved from <https://www.kidneyfund.org/kidney-disease/chronic-kidney-disease-ckd/complications/gout/gout-and-kidney-disease/>
- Beghtol, M. J. (1988, March). Hmong refugees and the U.S. health system. *Cultural Survival Quarterly Magazine*. Retrieved from <https://www.culturalsurvival.org/publications/cultural-survival-quarterly/hmong-refugees-and-us-health-system>
- Carteret, M. M. (2012, January 9). *Providing healthcare to Hmong patients and families*. Retrieved from <https://www.dimensionsofculture.com/2012/01/providing-healthcare-to-hmong-patients-and-families/>
- Chow, S. K., & Tam, B. M. (2014). Is the Kidney Disease Quality of Life-36 (KDQOL-36) a valid instrument for Chinese dialysis patients? *BMC Nephrology*, *15*, 199. doi: 10.1186/1471-2369-15-199
- Cobb, T. G. (2010). Strategies for providing cultural competent health care for Hmong-Americans. *Journal of Cultural Diversity*, *17*(3), 79–82.
- Cohen, D. E., Lee, A., Sibbel, S., Benner, D., Brunelli, S. M., & Tentori, F. (2019). Use of the KDQOL-36™ for assessment of health-related quality of life among dialysis patients in the United States. *BMC Nephrology*, *20*, 112. doi: 10.1186/s12882-019-1295-0
- Gerdner, L. A. (2010). *Health and healthcare of Hmong American older adults*. Retrieved from <https://geriatrics.stanford.edu/ethnomed/hmong.html>
- Gerdner, L. A. (2012). Shamanism: Indications and use by older Hmong-Americans with chronic illness. *Hmong Studies Journal*, *13*(1), 1–22.
- Helsel, D. G., Mochel, M. R., & Bauer, R. M. (2004). Shamans in a Hmong American community. *The Journal of Alternative and Complementary Medicine*, *10*(6), 933–938.
- Helsel, D. P., Mochel, M. R., & Bauer, R. M. (2005). Chronic illness and Hmong shamans. *Journal of Transcultural Nursing*, *16*(2), 150–154.
- Johnson, S. K. (2002). Hmong health beliefs and experiences in the Western health care system. *Journal of Transcultural Nursing*, *13*(2), 126–132.
- KDQOL Complete [Computer software]. (2021). Retrieved from <https://www.kdqol-complete.org>

- Lee, M. N. M. (2019). How the Hmong have shaped the state: Hmong and Hmong-Americans in Minnesota. Retrieved from <http://www.mnopedia.org/hmong-and-hmong-americans-minnesota>
- Lor, M. P. (2018). Systematic review: Health promotion and disease prevention among Hmong adults in the United States. *Journal of Racial and Ethnic Health Disparities*, 5(3), 638–661.
- Lor, M., Xiong, P., Park, L., Schwei, R. J., & Jacobs, E. A. (2017). Western or traditional healers? Understanding decision-making in the Hmong population. *Western Journal of Nursing Research*, 39, 400–415.
- Peipert, J. D., Bentler, P. M., Klicko, K., & Hays, R. D. (2018). Psychometric properties of the Kidney Disease Quality of Life 36-item short-form survey (KDQOL-36) in the United States. *American Journal of Kidney Diseases (AJKD)*, 71(4), 461–468.
- Pinzon-Perez, H. P. (2006). Health issues for the Hmong population in the U.S.: Implications for health educators. *International Electronic Journal of Health Education*, 9, 122–133.
- Plotnikoff, G. A., Numrich, C., Wu, C., Yang, L. D., & Xiong, M. P. (2002, June). Hmong shamanism animist spiritual healing in Minnesota. *Minnesota Medicine Clinical and Health Affairs*, 85(6), 29–35.
- Rand Health Care. (2019, March). Kidney Disease Quality of Life Instrument (KDQOL). Retrieved from https://www.rand.org/health-care/surveys_tools/kdqol.html
- Reznik, V., Cooper, T., MacDonald, D., Benador, N., & Lemire, J. (2001). Hais cuaj txub kaum txub—to speak of all things: A Hmong cross-cultural case study. *Journal of Immigrant Health*, 3(1), 23–30.
- Saad, M. M., Douaihy, Y. E., Boumitri, C., Rondla, C., Moussaly, E., Daoud, M., & El Sayegh, S. E. (2015). Predictors of quality of life in patients with end-stage renal disease on hemodialysis. *International Journal of Nephrology and Renovascular Disease*, 8, 119–123.
- Schatell, M. D., & Witten, M. A. (2012). Measuring dialysis patients' health-related quality of life with the KDQOL-36. *KDQOL Complete*. <http://www.kdqol-complete.org>
- Stratis Health. (2018). Hmong in Minnesota: Common health equity issues for Hmong populations. Retrieved from <http://www.culturecareconnection.org/matters/diversity/hmong.html>
- Thaweethamcharoen, T. P., Srimongkol, W. R., Jariyayothin, P. R., Sukthinhai, N. R., Aiyasanon, N. R., Kitisriworapan, P. R., and Vasuvattakul, S. M. (2013). Patient-reported outcomes (PRO) or quality of life (QOL) studies validity and reliability of KDQOL-36 in Thai kidney disease patients. *Value in Health Regional Issues*, 2(1), 98–102.
- Vang, K. K. (2019, July). Culture and health disparities: Hmong health beliefs and practices in the United States. Retrieved from <https://sigma.nursingrepository.org/handle/10755/18275>
- Wong, C. C., Mouanoutoua, V., Chen, M. J., Gray, K., & Tseng, W. (2005). Adherence with hypertension care among Hmong-Americans. *Journal of Community Health Nursing*, 22(3), 143–156.
- Xiong, S. B., Degroote, N. M., Byington, H. M., Harder, J. M., Kaminski, K. M., & Haglund, K. P. (2016). Engaging in culturally informed nursing care with Hmong children and their families. *Journal of Pediatric Nursing*, 31(1), 102–106.

The State of Patient-Centered Outcomes Research in Chronic Kidney Disease: Perspectives from Patients, Care Partners, and Researchers

Samuel R. Bethel, MSW, LCSW, PhD(c), Teri Browne, MSW, PhD, College of Social Work, University of South Carolina, Columbia, SC; Derek Forfang, Jessica Joseph, MBA, Kelli Collins Damron, MSW, National Kidney Foundation, New York, NY; Laura Brereton, The Wilson Centre, Toronto General Hospital, Toronto, Ontario, Canada

Patient-centered outcomes research (PCOR) requires that patients and care partners be active partners throughout the entire research process. Although PCOR methodologies in health research have increased, PCOR on chronic kidney disease (CKD) remains relatively low. This project aimed to better understand the state of PCOR on CKD from the perspectives of patients, care partners, and researchers. Two National Kidney Foundation (NKF) surveys were completed by 847 CKD patients and care partners and 647 CKD researchers. Results indicate that a small minority (7%) of patient and care partner respondents were involved with kidney disease research, and less than a third (27%) of responding researchers indicated that they had involved patients and care partners in their research projects within the last five years. Despite relatively low numbers of PCOR projects on CKD, patients and care partner respondents are eager to participate in research and, likewise, CKD researchers are interested in doing PCOR. Implications include increasing PCOR on CKD and utilizing nephrology social workers to facilitate connections among CKD patients, care partners, and researchers.

INTRODUCTION

Patient-centered care in health settings, including kidney disease programs, is critically important. This approach to healthcare prioritizes patient needs, preferences, and feedback in care delivery (Epstein & Street, 2011; IOM Committee on Quality of Health Care in America, 2001). Aligned with the tenets of patient-centered care, patient-centered outcomes research (PCOR) has also increased and involves patients, care partners (a patient's family and friends involved in their care), and stakeholders partnering with researchers to perform research that is important for patients. PCOR is a research model that allows patients, care partners, and stakeholders to participate in all aspects of the research process, from research question design to disseminating results (Israel, Schulz, Parker, Becker, & Community-Campus Partnerships for Health, 2001). In the United States, the Patient-Centered Outcomes Research Institute® (PCORI®) was started in 2010 to fund research that includes patients, care partners, healthcare professionals, and stakeholders as partners (PCORI, 2017). Since their inception, evidence from PCORI-funded research projects suggests that the knowledge generated by PCOR is more meaningful to patients and communities, more attuned to patients' needs, more translational to "real-world" settings, and has a broader reach (Forsythe et al., 2019).

There have been many examples of CKD PCOR on topics such as mental health (Roumelioti et al., 2018), CKD treatment choices (Boulware et al., 2020; Green et al., 2018), medical homes (Chukwudozie et al., 2018; Hynes et al., 2019),

palliative care (Grubbs et al., 2014), patient-reported outcomes (Hanson et al., 2019; Jacobson et al., 2019; O'Lone et al., 2020), and care continuity (Lee, Cui, Tu, Chen, & Chang, 2018). However, despite this progress, PCOR on CKD remains relatively underutilized (Cukor et al., 2016). It is unclear to what extent patients with CKD and care partners are interested in and involved in the research process beyond these projects and, when they are involved in the research process, what the quality of their participation has been.

To address this literature gap and increase CKD PCOR, this study aimed to better understand how patients, care partners, and researchers experience patient-centeredness in CKD research and their CKD PCOR research priorities. The objectives of this study include understanding: how common patient and care partner involvement is in CKD research; to what degree patients and care partners are involved in the research process; the quality of experiences among patients, care partners, and researchers when including patients and care partners in research; and which research topics relevant to kidney disease are the most important among patients, care partners, and researchers. This paper also posits nephrology social workers as members of the inter-professional kidney healthcare team who can help facilitate connections among patients, care partners, and researchers interested in CKD PCOR. Social work's professional values of addressing social problems and the importance of human relationships uniquely positions nephrology social workers to help connect CKD researchers to patients and care partners experiencing CKD in their daily lives.

Corresponding author: Samuel R. Bethel, MSW, LCSW, 127 Hamilton, College of Social Work, University of South Carolina, Columbia, SC 29208; srbethel@email.sc.edu

STUDY DESIGN

Two online surveys were developed and deployed using SurveyMonkey (n.d.), one survey for patients with CKD and their care partners, and another survey for kidney disease researchers. A patient with CKD, a kidney disease researcher, and a kidney disease stakeholder organization (National Kidney Foundation (NKF)) created the surveys. The patient and care partner survey was reviewed and pilot tested by 52 patient, and care partner volunteers from NKF's Kidney Advocacy Committee (KAC). Feedback from the KAC members led to the rewording of two survey questions and a description of what is meant by "patient-centered" in the survey introduction (i.e., "Patient-centeredness refers to establishing a partnership among clinicians, patients, and their families, to ensure that healthcare decisions respect patients' preferences and that patients have the education and support they need to make decisions and participate in their own care."). These surveys were funded through a PCORI Eugene Washington Engagement Award (EAIN 3456-NKF). The University of South Carolina (Pro00058725) Institutional Review Board approved this study.

Both the researcher and patient surveys consisted of 11 questions. Survey items included seven to eight multiple-choice, two ranking questions, and two open-ended questions. Participants were also allowed to select "Other (Please explain.);" and were provided with dialogue boxes to provide additional information on the multiple-choice and ranking questions. Some questions prompted respondents to explain their responses further. The final questions in each survey were open-ended, asking, "In your opinion, what can be done to make research about CKD more patient-centered?" and "Is there anything else you want to suggest or share about patient-centered CKD research?"

In 2016, the surveys were distributed nonrandomly using a convenience sampling approach. The patient and care partner survey link was emailed to 41,593 patients and care partners in the NKF database. This database includes those who identified as a patient (including those with CKD, on dialysis, or who have received a kidney transplant), as a care partner (a family member or friend involved in a CKD patient's care), or as a living kidney donor. The researcher survey link was distributed to 28,808 kidney care professionals who subscribed to NKF's professional and clinical email Listservs. Both surveys were also advertised on NKF's social media outlets to encourage followers who met inclusion criteria to complete the surveys.

To examine the frequency of patients', care partners', and researchers' involvement in PCOR, percentages, means, and standard deviations were calculated for each survey item in SPSS (version 26; IBM, 2019). Qualitative data from the CKD patient and care partner and CKD researcher surveys

were compiled and analyzed in MAXQDA Plus 2018 (version 18.2.0; VERBI Software, 2019). Data were coded using an inductive thematic analysis approach (Braun & Clarke, 2006). The first author completed the initial coding of provisional codes, with additional open coding of emergent themes and subthemes. All authors reviewed these codes and themes, and the final coding was completed based on group consensus.

RESULTS

PATIENT AND CARE PARTNER SURVEY

Demographics/Interest in Research

Eight-hundred and forty-seven respondents completed the full patient and care partner survey. Full results from the patient and care partner survey multiple-choice questions are presented in **Table 1**. About 80% of respondents to the patient and care partner survey were patients living with kidney disease (79.46%, $n = 673$). Only 20 of the 847 respondents (2.36%) indicated that they were not interested in research. The majority of respondents indicated that they read about kidney disease research when they "happen to see it" (54.18%, $n = 460$) or that they actively seek out research to read (49.35%, $n = 419$). Respondents stated that they usually read about studies in kidney patient forums or newsletters (60.22%, $n = 501$).

Involvement in Research

Most patients and care partners (87.31%, $n = 743$) stated that they had never been involved in a research study. Among those who were involved with research and answered further questions (45%, $n = 103$), most were involved passively as research subjects, with 71.84% ($n = 74$) having clinical data collected and 38.83% ($n = 40$) participating in interviews or focus groups. A minority of patient and care partners who participated in previous research projects had an active role in the research process, with 20.39% ($n = 21$) providing feedback on research implementation materials, 14.56% ($n = 15$) informing research questions, and 10.68% ($n = 11$) helping disseminate research findings. Even fewer patients and care partners participated in the development or selection of research methods (8.74%, $n = 9$), recruiting or selecting participants (6.8%, $n = 7$), or reviewing and commenting on research findings (4.85%, $n = 5$). Nearly 50% of 101 respondents who had been involved in research projects felt that their input on a research study had a meaningful impact on the research being carried out (49.5%, $n = 50$).

A majority (86%) of 728 respondents also identified ways in which patients and care partners could best ensure that research on kidney diseases is relevant to their needs. They indicated this could be done by having patients and care partners help share information about the research results (63.05%, $n = 459$), give input into the research topic and question selection (53.98%, $n = 393$), actively participate in

the research project design, and implementation (50.69%, $n = 369$), and review research results (41.48%, $n = 302$).

CKD Research Priorities

Research priority ranking by patients and care partners is summarized in **Table 2**. Respondents were asked to rank nine CKD research topics from “most important” (1) to “least important” (9). The CKD research topic most important to patients and care partners was preventing kidney disease ($M = 3.14$, $SD = 2.55$). This is followed by keeping kidney disease from getting worse ($M = 3.25$, $SD = 1.96$), quality of life ($M = 3.58$, $SD = 1.85$), treatment options, ($M = 4.78$, $SD = 2.07$), kidney disease biology ($M = 4.76$, $SD = 2.95$), costs ($M = 5.57$, $SD = 2.38$), mental health ($M = 5.79$, $SD = 2.09$), healthcare delivery ($M = 6.08$, $SD = 2.5$) and care partner support ($M = 6.54$, $SD = 2.08$).

Open-ended Responses

Open-ended responses to the patient and care partner survey indicate that most respondents used the internet as their primary source for finding kidney disease research, including websites and social media. Respondents who had participated in research were asked to explain their answers to question six (Q6), “Did you feel your input had a meaningful impact on the research being carried out?” For those who felt that their research participation was meaningful or somewhat meaningful (71.28%, $n = 72$), three broad, explanatory themes emerged from patients and care partners: they had a clear understanding of their contribution to the research; they saw essential changes in their kidney care being implemented as a result of the research; or they felt that their perspectives as kidney disease patients and care partners were being highly respected and valued by the researchers.

For the respondents who did not feel that their research participation was meaningful or were not sure if it was (28.71%, $n = 29$), the most common open-ended response to explain their answer was that they never received any updates or communication from the research team following their involvement in the study and that the study results were never shared with them. For example, one respondent stated, “You are asked to participate, but then you never hear from the study group.” Another participant wrote, “Zero feedback. The questions asked were only ones I could answer favorably as if [it was] set up for good results for them—not constructive. No questions centered around my concerns.” One patient summarized this concern by stating plainly, “I was a guinea pig!”

Question seven on the patient and care partner survey asked, “How do you think patients and care partners can best ensure that research about kidney disease is relevant to their needs?” Among those respondents choosing the “Other (Please explain.)” response option for this question (5.08%, $n = 37$), the most frequently mentioned theme was

communication. Many respondents felt that the best way to ensure that research about kidney disease is relevant to patient and care partner needs is to create a bidirectional communication loop where patients and care partners can both learn about what is happening in the realm of CKD research while also providing feedback to researchers from their unique perspectives as CKD patients. For example, one respondent stated, “I believe patients living with the disease can best explain what it’s like to live with the disease.” Many respondents mentioned that they wished to offer feedback on the goals of a study and how study results will be disseminated. “Involvement of people LIVING WITH CKD is key to any relevant research. Too many projects are designed and managed by people who are not directly impacted by kidney disease,” one respondent wrote. Another said, “Please involve us in the ongoing studies and then remember to share the relevant findings.”

Examining the answers to the open-ended question, “What can be done to make research about kidney disease more patient-centered?” there were three themes that emerged from patients and care partners’ responses ($n = 510$): better engagement of patients and care partners in the research process; more awareness of research project opportunities; and better communication from researchers. Respondents wanted to be engaged and included in the overall research process, with one respondent stating, “Involve patients in the research design—they are in the front line, so they should play a more active role,” and another commenting, “[P]atients and caregivers are not just statistics and should be consulted in order to make research projects more applicable.”

Patients and care partners also greatly desired to learn more about ways to get involved in CKD research: “Make more information available to the patients. It is very difficult to locate information about different research projects that are being/or that will be conducted,” one patient respondent wrote. Another patient responded with, “Talk to the patients!! Don’t expect them to come to you.” Similarly, one care partner said, “My son has been on different trials, but we’ve never heard anything about them. It would be good that when he went for appointments he was told how he has helped these trials.”

Many respondents felt that dissemination of research findings to the CKD community should occur regularly and that the public should have a greater awareness of CKD. Other subthemes included a need for more information regarding alternatives to dialysis, such as kidney transplantation, artificial kidney technology, and stem cells. Patients and care partners also mentioned that they think research on chronic kidney disease should use more diverse patient populations such as pediatric patients and people with genetic kidney diseases.

RESEARCHER SURVEY

Demographics

Six-hundred and forty-seven responses were submitted to the researcher survey. Full results from the researcher survey multiple-choice questions are presented in **Table 3**. The majority of research respondents came from the disciplines of nursing (24.18%, $n = 155$), social work (22.46%, $n = 144$), dietetics (20.75%, $n = 133$), and clinical medicine (14.82%, $n = 95$).

Involvement of Patients and Care Partners in Research

Over 70% of the researcher respondents (73.18%, $n = 472$) stated that they had not worked on a research project involving patients or care partners within the past five years. Among the minority ($n = 173$) who said they had, 85.31% ($n = 122$) stated that they had merely collected patient clinical data to use as part of their studies, and 46.15% ($n = 66$) responded that patients and care partners had participated in interviews or focus groups. Even fewer researchers who had done PCOR within the past five years had worked with patients and care-partners to create research questions/topics (18.88%, $n = 27$), select research methods (4.9%, $n = 7$), create study materials (18.88%, $n = 27$), reviewed and commented on findings (6.99%, $n = 10$) or disseminate findings (4.9%, $n = 7$). When patient and care partners provided feedback on a research project (Q4), respondents stated that it most often occurred individually between researcher and patients or care partners (66.19%, $n = 92$).

Researchers (Q5, $n = 141$) most frequently stated that they recruited participants for PCOR projects among patients and care partners who were already known to them (39.72%, $n = 56$). A majority of researcher respondents who had done PCOR (68.57%, $n = 96$) felt that patient or care partner input had a meaningful impact on the research being carried out, whereas 11.43% ($n = 16$) did not and 20% ($n = 28$) were not sure. When asked (Q7) whether they or their institution promote research findings to patients or lay audiences, about half of all respondents ($n = 425$) said they or their institution do not do so (46.82%, $n = 199$). Additionally, when responding to the question (Q8) of how patients and ics can most effectively engage with CKD research, researchers ($n = 429$) responded most frequently that patients and care partners could provide their input into research topic and question selection (37.30%, $n = 160$). However, the second most frequent response to this question was, “I am not sure” (21.68%, $n = 93$).

CKD Research Priorities

When asked to rank topics most important in kidney disease research, researchers most frequently selected quality of life issues ($M = 2.53$, $SD = 1.57$), followed by preventing the onset of CKD and disease progression ($M = 2.82$, $SD = 2.26$). **Table 4** includes the average score and standard deviation for each research topic.

Open-ended Responses

Researchers who responded to the open-ended questions on the survey ($n = 284$) were asked to share their opinion about what can be done to make CKD research more patient-centered. The most salient themes that emerged from this question included: the need to compensate patients and care partners for their participation; better information for patients and care partners about the research process and research opportunities; and more funding for CKD PCOR. A final theme was the need for broader dissemination of research findings; as one respondent said, “Translate the research findings into more broad [sic], patient-centered things that they can understand and use in their everyday life.” Researchers also commented on the need behind CKD PCOR in general, as one respondent stated:

“We need to make sure that patients and family members are driving the questions we seek to answer. Often the questions that we as researchers think are most important are of little interest to patients or caregivers. While clinical research is very important, we must always ask ourselves the question, ‘How does this benefit our patients?’”

DISCUSSION

These survey findings are the first to broadly examine the state of CKD PCOR utilization from the perspective of patients, care partners, and researchers. Survey results were used as part of the first national CKD PCOR conference hosted and led by the National Kidney Foundation (NKF) (2016) and were the impetus for the first NKF PCOR research award (NKF, 2018).

Overall, these results suggest that there is much work to be done to improve CKD PCOR. Most patient and care partner respondents were not involved in CKD research, despite almost all of the patients and care partners being interested in research participation. When they were involved, it was mostly as passive participants (i.e., providing clinical data or answering survey or focus group questions), which is not in accordance with the tenets of PCOR (PCORI, n.d.). The patients’ and care partners’ answers align with the researcher responses, the majority of whom also indicated that they had not been involved in a research project that involved patients and care partners within the past five years and mainly work with patients and care partners passively when conducting research. The CKD community needs more PCOR and more examples of robust patient and care partner participation on PCOR teams (Demian, Lam, Mac-Way, Sapir-Pichhadze, & Fernandez, 2017).

The majority of patients, care partners, and researchers agree that research results are seldom disseminated in “patient-friendly” ways. Researchers are encouraged to create non-

academic summaries of their research and share them with patients and care partners, especially on the internet. Also, researchers should create lay research summaries and provide them to any patient or care partner who provided data or samples to inform them how their information was used to advance science (Huang, Lipman, & Mullins, 2017).

When researchers sought to include patients and care partners in a study, the most common recruitment method was by selecting patients and care partners known to the researchers or clinicians, according to the patient and care partner survey results. Researchers can go beyond their institutions to involve patients and care partners more broadly in CKD PCOR (Browne et al., 2020). Both respondent groups in our study also generally agreed on the top research priorities for CKD: primary prevention, treatment options, and quality of life. CKD researchers who engage in PCOR should align their research priorities with the research priorities of patients and care partners.

Many patients and care partners indicated that they believe dialysis units, transplant centers, and CKD clinics are excellent places to learn about CKD research and opportunities to become involved. Because nephrology social workers often serve as resource brokers for CKD patients in dialysis and kidney transplant clinics and work to address the psychosocial aspects of living with CKD, this finding presents a unique opportunity for the profession to potentially bridge the gap between research and the patients and care partners who are interested in consuming and participating in research.

Social workers can collaborate with their interdisciplinary colleagues or other social workers to lead research projects that involve patients and care partners in the research. Social workers are urged to also actively participate in and lead PCOR projects. The social work code of ethics recommends that social workers participate in research and has an entire "Evaluation and Research" section (Section 5.02) (NASW, 2017). There are numerous psychosocial barriers to CKD care, and social workers have expertise in these areas (Browne et al., 2019). They can contribute their research expertise by connecting with others in their organizations who are conducting research or by seeking out partnerships with faculty at local schools of social work or public health. Social workers employed by academic medical centers can also connect with researchers in those institutions to see how they can contribute to CKD PCOR. Those who work in large dialysis companies can seek out collaborative opportunities with their organization's research departments. Additionally, PCORI has funding for smaller PCOR projects and research-related events and activities that may be a good "first step" for social workers looking for support for CKD PCOR projects. PCORI also has a free research fundamentals training (<https://www.pcori.org/engagement/research-fundamentals>) that social workers can complete.

Many patients and care partners in our study stated that having a centralized information and communication hub about CKD research and ways to get involved would be beneficial. Currently, NKF is working on a PCORI-funded project to improve the knowledge of PCOR among researchers, patients, and other stakeholders; building an infrastructure that will provide education about PCOR, connect patients, family members, and researchers for collaboration; and creating a centralized location for patient-friendly research summary results (PCORI, 2020). Nephrology social workers should be aware of the development of these resources and use them to help connect interested CKD patients and care partners to researchers when the communication hub is launched.

Encouragingly, most of the respondents from both the patient and care partner survey and the researcher surveys believed patients and care partners should be involved throughout the research process, from question generation to disseminating results. Both groups also commonly stated that they thought PCOR requires a more diverse pool of CKD patients to be involved.

Study Limitations

There are some limitations to this study. Although our sample sizes for both patients and care partners ($n = 847$) and kidney disease researchers ($n = 647$) were large, our lack of demographic data and convenience sampling methodology limited our ability to say whether these samples were representative. These results were likely biased toward patients, care partners, and researchers who subscribe to, read, and respond to NKF listservs and communications and are, naturally, more interested in research and the research process. However, these patients and care partners who were engaged with stakeholder organizations like NKF may also be an excellent representation of patients and care partners more likely to be engaged in research.

CONCLUSIONS

Overall, these results suggest that patients with CKD, care partners, and CKD researchers have valuable ideas about patient-centeredness in CKD research and that both groups share many of the same beliefs about PCOR. Both groups indicated that patient-centeredness is essential for the field of CKD research. Patients with CKD and care partners in the sample group expressed significant interest in research and a willingness to engage in the research process. Likewise, CKD researchers expressed a willingness to engage in patient-centered research methodology. These findings should be encouraging to the field of CKD PCOR. Future patient-centered research on CKD may highlight programs that successfully navigate the challenges of PCOR within the CKD community, inform other researchers about the value of PCOR, and include best practices for actively engaging patients and care partners in the research process. Specifically, we believe

that nephrology social workers can utilize their patient engagement and patient empowerment skills to help achieve these goals for CKD PCOR. Future research may also seek to better understand the barriers that kidney care providers experience when incorporating PCOR into kidney healthcare services delivery.

As one of the patient respondents commented, “[I]nvolvement of people living with CKD is key to any relevant research. Too many projects are designed and managed by people who are not directly impacted by kidney disease.” More CKD PCOR is needed to address the disconnect between the patient, care partner, and researchers. Nephrology social workers can play a critical role in facilitating these connections through their professional skills in addressing problems of human relationships. They can help bring about the next era of CKD research that is more patient-centered, outcomes-oriented, and empowering to CKD patients, care partners, and researchers.

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REFERENCES

- Boulware, L. E., Ephraim, P. L., Browne, T., Strigo, T., Hill-Briggs, F., Green, J., & Hauer, C. (2020). Achieving patient-centered health care innovation through stakeholder engagement. In: Emily B. Zimmerman (Ed.), *Researching health together: Engaging patients and stakeholders from topic identification to policy change* (pp. 302–322). Thousand Oaks, CA: SAGE Publishing.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Browne, T., Merighi, J. R., Washington, T., Savage, T., Shaver, C., & Holland, K. (2019). Nephrology social work. In S. Gehlert and T. Browne (Eds.), *Handbook of health social work* (pp. 411–440). <https://doi.org/10.1002/9781119420743.ch18>
- Browne, T., Swoboda, A., Ephraim, P. L., Lang-Lindsey, K., Green, J. A., Hill-Briggs, F., Jackson, G. L., Ruff, S., Schmidt, L., Woods, P., Danielson, P., Bolden, S., Bankes, B., Hauer, C., Strigo, T., & Boulware, L. E. (2020, November 1). Engaging patients and family members to design and implement patient-centered kidney disease research. *Research Involvement and Engagement*, 6, Article number: 66. <https://doi.org/10.1186/s40900-020-00237-y>
- Chukwudozie, I. B., Fitzgibbon, M. L., Schiffer, L., Berbaum, M., Gilmartin, C., David, P., Ekpo, E., Fischer, M. J., Porter, A. C., Aziz-Bradley, A., & Hynes, D. M. (2018). Facilitating primary care provider use in a patient-centered medical home intervention study for chronic hemodialysis patients. *Translational Behavioral Medicine*, 8(3), 341–350. <https://doi.org/10.1093/tbm/iby021>
- Cukor, D., Cohen, L. M., Cope, E. L., Ghahramani, N., Hedayati, S. S., Hynes, D. M., Shah, V. O., Tentori, F., Unruh, M., Bobelu, J., Cohen, S., Dember, L. M., Faber, T., Fischer, M. J., Gallardo, R., Germain, M. J., Ghahate, D., Grote, N., Hartwell, L., ... Mehrotra, R. (2016). Patient and other stakeholder engagement in Patient-Centered Outcomes Research Institute-funded studies of patients with kidney diseases. *Clinical Journal of the American Society of Nephrology*, 11(9), 1703–1712. <https://doi.org/10.2215/CJN.09780915>
- Demian, M. N., Lam, N. N., Mac-Way, F., Sapir-Pichhadze, R., & Fernandez, N. (2017). Opportunities for engaging patients in kidney research. *Canadian Journal of Kidney Health and Disease*, 4, 1–10. <https://doi.org/10.1177/2054358117703070>
- Epstein, R. M., & Street, R. L., Jr. (2011). The values and value of patient-centered care. *Annals of Family Medicine*, 9(2), 100–103. <https://doi.org/10.1370/afm.1239>
- Forsythe, L. P., Carman, K. L., Szydlowski, V., Fayish, L., Davidson, L., Hickam, D. H., ... Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the Patient-Centered Outcomes Research Institute. *Health Affairs*, 38(3), 359–367.
- Green, J. A., Ephraim, P. L., Hill-Briggs, F. F., Browne, T., Strigo, T. S., Hauer, C. L., Stametz, R. A., Darer, J. D., Patel, U. D., Lang-Lindsey, K., Bankes, B. L., Bolden, S. A., Danielson, P., Ruff, S., Schmidt, L., Swoboda, A., Woods, P., Vinson, B., Littlewood, D., Jackson, G., ... Boulware, L. E. (2018). Putting patients at the center of kidney care transitions: PREPARE NOW, a cluster randomized controlled trial. *Contemporary Clinical Trials*, 73, 98–110. <https://doi.org/10.1016/j.cct.2018.09.004>
- Grubbs, V., Moss, A. H., Cohen, L. M., Fischer, M. J., Germain, M. J., Jassal, S. V., Perl, J., Weiner, D. E., & Mehrotra, R. (2014). A palliative approach to dialysis care: A patient-centered transition to the end of life. *Clinical Journal of the American Society of Nephrology*, 9(12), 2203–2209. <https://doi.org/10.2215/CJN.00650114>

- Hanson, C. S., Gutman, T., Craig, J. C., Bernays, S., Raman, G., Zhang, Y., James, L. J., Ralph, A. F., Ju, A., Manera, K. E., Teixeira-Pinto, A., Viecegli, A. K., Alexander, S. I., Blydt-Hansen, T. D., Dionne, J., McTaggart, S., Michael, M., Walker, A., Carter, S., Wenderfer, S. E., ... Tong, A. (2019). Identifying important outcomes for young people with CKD and their caregivers: A nominal group technique study. *American Journal of Kidney Diseases*, 74(1), 82–94. <https://doi.org/10.1053/j.ajkd.2018.12.040>
- Huang, J., Lipman, P. D., & Mullins, C. D. (2017). Bridging the divide: Building infrastructure to support community-academic partnerships and improve capacity to conduct patient-centered outcomes research. *Translational Behavioral Medicine*, 7(4), 773–782. <https://doi.org/10.1007/s13142-017-0487-z>
- Hynes, D., Arruda, J., Berbaum, M., Chukwudozie, I., Fischer, M., Fitzgibbon, M., Porter, A., & Schiffer, L. (2019). *Evaluating a patient-centered medical home for patients receiving dialysis for kidney disease*. Washington, D.C.: Patient-Centered Outcomes Research Institute® (PCORI®). <https://doi.org/10.25302/5.2019.IH.12115420>
- IBM. (2019). *IBM SPSS Statistics for Windows*. Version 26.0. Armonk, NY: IBM Corp. <https://www.ibm.com/products/spss-statistics>
- Institute of Medicine (IOM) Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: National Academies Press (NAP).
- Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., & Community-Campus Partnerships for Health. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health (Abingdon, England)*, 14(2), 182–197. <https://doi.org/10.1080/13576280110051055>
- Jacobson, J., Ju, A., Baumgart, A., Unruh, M., O'Donoghue, D., Obrador, G., Craig, J. C., Daputo, J. M., Dew, M. A., Germain, M., Fluck, R., Davison, S. N., Jassal, S. V., Manera, K., Smith, A. C., & Tong, A. (2019). Patient perspectives on the meaning and impact of fatigue in hemodialysis: A systematic review and thematic analysis of qualitative studies. *American Journal of Kidney Diseases*, 74(2), 179–192. <https://doi.org/10.1053/j.ajkd.2019.01.034>
- Lee, Y. L., Cui, Y. Y., Tu, M. H., Chen, Y. C., & Chang, P. (2018). Mobile health to maintain continuity of patient-centered care for chronic kidney disease: Content analysis of apps. *JMIR Mhealth and Uhealth*, 6(4), e10173. <https://doi.org/10.2196/10173>
- National Association of Social Workers (NASW). (2017). *Read the code of ethics*. NASW website. <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
- National Kidney Foundation (NKF). (2016). *Patients to lead national research priorities for kidney disease* [Press release]. NKF website. <https://www.kidney.org/news/patients-lead-national-research-priorities-kidney-disease>
- National Kidney Foundation (NKF). (2018). *Maryland nephrologist receives NKF patient-centered outcomes research grant* [Press release]. NKF website. <https://www.kidney.org/news/maryland-nephrologist-receives-patient-centered-outcomes-research-grant-national-kidney>
- O'Lone, E., Howell, M., Viecegli, A. K., Craig, J. C., Tong, A., Sautenet, B., Herrington, W. G., Herzog, C. A., Jafar, T. H., Jardine, M., Krane, V., Levin, A., Malyszko, J., Rocco, M. V., Strippoli, G., Tonelli, M., Wang, A. Y.-M., Wanner, C., Zannad, F., Winkelmayer W. C., Wheeler, D. C., on behalf of the SONG-HD Investigators. (2020, October 1). Identifying critically important cardiovascular outcomes for trials in hemodialysis: An international survey with patients, caregivers and health professionals. *Nephrology Dialysis Transplantation*, 35(10), 1761–1769. <https://doi.org/10.1093/ndt/gfaa008>
- Patient-Centered Outcomes Research Institute (PCORI). (n.d.). The PCORI approach to patient-centered outcomes research: Research fundamentals learning package interactive PDF. Patient-Centered Outcomes Research Institute website. <https://www.pcori.org/engagement/research-fundamentals/pcori-approach-pcor>
- Patient-Centered Outcomes Research Institute (PCORI). (2017, March 27). *Our story*. PCORI website. <https://www.pcori.org/about-us/our-story>
- Patient-Centered Outcomes Research Institute (PCORI). (2020, June 11). Kidney research connect: A patient-centered outcomes community engagement program. PCORI website. <https://www.pcori.org/research-results/2019/kidney-research-connect-patient-centered-outcomes-community-engagement-program>
- Roumelioti, M. E., Steel, J. L., Yabes, J., Vowles, K. E., Vodovotz, Y., Beach, S., Rollman, B., Weisbord, S. D., Unruh, M. L., & Jhamb, M. (2018). Rationale and design of technology assisted stepped collaborative care intervention to improve patient-centered outcomes in hemodialysis patients (TACCcare trial). *Contemporary Clinical Trials*, 73, 81–91. <https://doi.org/10.1016/j.cct.2018.09.002>
- SurveyMonkey. (n.d.). *Survey Monkey*. San Mateo, CA: SurveyMonkey, Inc. www.surveymonkey.com
- VERBI Software. (2019). *MAXQDA 2018*. Berlin, Germany: VERBI Software. <https://www.maxqda.com>

Table 1. Patient and Care Partner Survey Multiple-Choice Answers (n = 847)

Question	Response Options	Answers % (n)
Q1: Are you a:	Patient living with kidney disease	79.46% (673)
	Care partner for a patient living with kidney disease	20.54% (174)
Q2: Are you interested in research being carried out on the prevention and treatment of kidney disease? (Please check all that apply.) (n = 849)	Yes, I read about it when I happen to see it.	54.18% (460)
	Yes, I seek it out to read.	49.35% (419)
	I am not sure. I do not know enough about it.	9.54% (81)
	Yes, I have been involved in the research process.	7.18% (61)
	No, it does not interest me.	2.36% (20)
Q3: If you read about research on kidney disease, where do you find it? (Please check all that apply) (n = 832)	I read studies that are referenced in kidney patient forums or patient newsletters.	60.22% (501)
	I read studies that are published in national or regional newspapers (print or online).	48.20% (401)
	I read studies that are published in medical journals (print or online).	36.90% (307)
	I read studies that a healthcare provider recommends to me.	31.25% (260)
	Other (Please explain.)	15.02% (125)
Q4: Have you ever been directly involved with a research study related to kidney disease? (n = 851)	Yes	12.69% (108)
	No	87.31% (743)
Q5: How would you describe your involvement with kidney disease research? (Please check all that apply.) (Answered by n = 103 (95%) of those who responded "yes" on Q4.)	My clinical data was collected and used as part of a study.	71.84% (74)
	I was interviewed or participated in a focus group.	38.83% (40)
	I commented on documents for use in the study. (For example: proposals, questionnaires, participant handouts.)	20.39% (21)
	I helped to inform the research topics or questions being developed.	14.56% (15)
	I helped share the results of the research study.	10.68% (11)
	I helped select or develop the methods used.	8.74% (9)
	I helped recruit or select participants.	6.8% (7)
	I formally reviewed and commented on the findings or interim findings.	4.85% (5)
	Other (Please explain.)	13.59% (14)
Q6: Did you feel your input had a meaningful impact on the research being carried out? (Answered by n = 101 (94%) of those who responded "yes" on Q4.)	Yes, definitely	49.50% (50)
	Somewhat	21.78% (22)
	No	4.95% (5)
	I am not sure.	23.76% (24)
Q7: How do you think patients and care partners can best ensure that research about kidney disease is relevant to their needs? (Please check all that apply.) (86% of respondents who answered "yes" to Q4; n = 728.)	Helping share information about the research results with other patients, family members, and the medical and research community	63.05% (459)
	Giving input into topic and question selection	53.98% (393)
	Actively participating in the research project design and implementation	50.69% (369)
	Reviewing research results	41.48% (302)
	I am not sure.	14.01% (102)
	Other (Please explain.)	5.08% (37)

Table 2. Patient and Care Partner Survey Results on Importance of Kidney Disease Research Topics

In your opinion, which topics are most important in kidney disease research? Please rank the following topics in order of most important to least important, with 1 being “most important” and 9 being “least important.” (n = 717)	Mean (SD)
Preventing kidney disease	3.14 (2.55)
Keeping kidney disease from getting worse	3.25 (1.96)
Quality of life (For example: controlling symptoms, personalizing treatment to lifestyle preferences.)	3.58 (1.85)
Helping patients get the treatment options they prefer (For example: home hemodialysis, transplant.)	4.78 (2.07)
Understanding the biology of kidney disease	4.76 (2.95)
Patient costs	5.57 (2.38)
Mental health	5.79 (2.09)
Healthcare delivery (For example: clinician training, dialysis center management.)	6.08 (2.50)
Support for care partners	6.54 (2.08)

Table 3. Researcher Survey Multiple-Choice Answers (n = 647)

Question	Response Options	Answers % (n)
Q1: Please select your field or primary interests: (n = 641)	Nursing	24.18% (155)
	Social work	22.46% (144)
	Dietetics	20.75% (133)
	Clinical medicine	14.82% (95)
	Healthcare delivery or policy	5.3% (34)
	Basic science	1.40% (9)
	Psychology	0.78% (5)
	Other (Please explain.)	10.30% (66)
Q2: Have you worked on a research project involving CKD patients or care partners in the past 5 years? (n = 645)	Yes	26.82% (173)
	No	73.18% (472)
Q3: How were patients or care partners involved with the project? (Check all that apply.) (Answered by n = 143 (83%) of those who responded “yes” on Q2.)	Their clinical data was collected and used as part of a study.	85.31% (122)
	They participated in interviews or focus groups.	46.15% (66)
	They helped to inform the research topics or questions being developed.	18.88% (27)
	They commented on documents for use in the study. (For example: proposals, questionnaires, participant handouts.)	18.88% (27)
	They helped to recruit or select other participants.	13.29% (19)
	They formally reviewed and commented on the findings or interim findings.	6.99% (10)
	They helped select or develop the methods used.	4.90% (7)
	They helped disseminate/translate the research findings.	4.90% (7)
Q4: What was the process for patients/care partners to provide input into your project(s)? (Answered by n = 139 (80%) of those who responded “yes” on Q2.)	Patients or care partners provided individual input.	66.19% (92)
	Patients or care partners provided input through a panel or group.	19.42% (27)
	Other (Please explain.)	14.39% (20)

continues

Question	Response Options	Answers % (n)
Q5: How were the patient or care partner participants recruited? (Answered by n = 141 (82%) of those who responded "yes" on Q2.)	Patients were known to the researchers or clinicians involved with the study.	39.72% (56)
	Patients were purposefully selected based on particular characteristics.	23.40% (33)
	Patients were chosen as part of an existing dataset.	19.15% (27)
	Patients responded to an advertisement or invitation.	9.22% (13)
	Other (Please explain.)	8.51% (12)
Q6: Did you feel that patient or care partner input had a meaningful impact on the research being carried out? (Answered by n = 140 (81%) of those who responded "yes" on Q2.)	Yes	68.57% (96)
	No	11.43% (16)
	I am not sure.	20.00% (28)
Q7: Do you (or does your institution) promote your research to patients or lay audiences? (Check more than one, if applicable.) (n = 425)	Yes, through healthcare provider or clinic materials.	31.53% (134)
	Yes, through non-profit or patient advocacy organization publications (print or online).	4.24% (18)
	Yes, through national or regional newspapers (print or online).	3.53% (15)
	Yes, through CKD patient online forums or message boards.	3.06% (13)
	No	46.82% (199)
	Yes, other (Please explain.)	10.82% (46)
Q8: How do you think patients and care partners can most effectively engage with CKD research? (Please choose the one you feel would matter most.) (n = 429)	Giving input into topic and question selection	37.30% (160)
	By helping disseminate/translate research findings	12.12% (52)
	Participating in the research design	8.16% (35)
	Reading and responding to published research	6.76% (29)
	Reviewing interim and final results	1.86% (8)
	I am not sure.	21.68% (93)
	Other (Please explain.)	12.12% (52)

In your opinion, which topics are most important in kidney disease research? Please rank the following topics in order of most important to least important, with 1 being "most important" and 8 being "least important."	Mean (SD)
Quality of life (For example: controlling symptoms, personalizing treatment to lifestyle preferences.)	2.53 (1.57)
Preventing the onset of CKD and disease progression	2.82 (2.26)
Helping patients get the treatment options they prefer (For example: home hemodialysis, transplant.)	4.06 (1.73)
Patient costs	4.25 (2.55)
Mental health	5.12 (1.81)
Basic science/understanding the biology of CKD	5.54 (2.45)
Healthcare delivery (For example, clinician training, dialysis center management.)	5.53 (2.15)
Support for care partners	5.49 (1.70)

Practice Note: The Importance of Kidney Disease Peer Mentor Programs During the COVID-19 Pandemic

*Kristy Washinger, MSN, FNP-BC, Nephrology Associates of Central PA, Camp Hill, PA;
Robin Asick, MSW, LSW, NSW-C, University of New England, Maine;
Lynne Wright, MSW, LSW, Kidney Foundation of Central Pennsylvania, Harrisburg, PA*

When someone is told they have kidney disease, they can go into shock and denial. Although this diagnosis can be overwhelming, talking with someone “who has been there,” through a peer mentor program, can be helpful in coping successfully.

Peer mentor programs have a documented, positive impact on the lives of people affected by kidney disease (Ghahramani, 2015). The Kidney Foundation of Central PA (KFCP) developed its peer mentoring program in 2004. The Patient and Family Partner Program (PFPP) was created to provide patients with a mentor who can offer emotional support. Mentors are referred by nephrology professionals and can be patients with chronic kidney disease (CKD) or a family member or caregiver of someone with CKD. The mentors attend a six-week training course that includes a weekly class, required readings, interactive exercises, and lectures from kidney professionals. After completing the course work, the mentor can then be paired with a mentee by the program coordinator. The program currently has about 26 peer mentors.

The COVID-19 pandemic has increased emotional distress and amplified psychiatric illnesses (Pfefferbaum & North, 2020). Nephrology professionals recognize that the COVID-19 pandemic is also having a deleterious effect on people with kidney disease. Peer mentor programs are currently changing because of COVID-19. Some of the questions that are being asked by these programs include: Will these programs and partnerships be utilized more, less, or have no impact at all? Will the quality of the relationships deepen, subside, or remain unchanged? The need for a concerted effort to help patients cope with negative emotions from the pandemic is clear. COVID-19 has had a significant impact on the PFPP and its mentors. This article discusses the modifications that were made to our peer mentoring program during COVID-19 and what our experiences have been with these changes.

A major modification to our peer mentoring program was to convert the training course into a virtual classroom on an online platform. All of the coursework materials were converted to electronic versions that were visually appealing and engaging. Prior to 2020, this training was limited by distance,

and to candidates willing to drive for in-person trainings. Moving the training online expanded the reach of each new mentor class, adapted the skills of the program coordinator, and increased the availability of guest speakers. In 2020, PFPP was able to offer two online mentor classes.

Although some previous barriers like transportation were overcome, new issues related to technology arose. For example, a thunderstorm temporarily disabled one mentor’s internet. Another mentor felt overwhelmed by the process of downloading the training platform to her phone. She resorted to going to her telephone carrier’s local store and asking them to load the app to her phone. Other routine difficulties, such as ensuring the screen share feature worked, or that mentors are muted while not speaking, were additional distractions that were not a part of the previous in-person mentor training, pre-COVID-19.

The pandemic necessitated many changes to our “normal” operations, particularly in the way that our mentors communicate with their mentees. Prior to COVID-19, many of the interactions had been in person. To ensure the safety of our mentors and mentees, the communications were changed to letters, emails, phone calls, or texts. However, this has increased the number of times mentors are making contact with their mentees.

The pandemic imposed many changes to the daily lives of people with kidney disease. Many people may feel more isolated due to limitations on visitors and social activities. More than one mentor mentioned the sorrow of not being able to visit grandchildren and hug them. Other issues mentors and mentees mentioned were the changes in the procedures at dialysis clinics (e.g., the need to wear masks, no visitors in the lobby area, no food or drink in the clinic area). Self-care also looks different now because of COVID-19. For example, patients may now be limiting trips to the gym and doing more outdoor activities.

One recently transplanted mentor reported that she is vigilant about keeping well-meaning family at a safe distance and encourages her mentees to do the same. When she visits facilities for necessary lab work, she wears a mask, gloves,

Corresponding author: *Lynne Wright, MSW, LSW; The Kidney Foundation of Central PA, 900 S. Arlington Ave., Suite 134A, Harrisburg, PA 17109; 717.713.1713*

and wipes down every surface to minimize any exposure that could jeopardize her new kidney. When this patient saw a fellow mentor's car parked at the post office, she instructed her husband to park nearby so that she could wave and say hello to her friend from a safe distance. Because of her rich history of volunteering with that fellow mentor, she made this connection despite COVID-19 social distancing restrictions. She shared her concerns about feeling sick due to the anti-rejection medicines and her worries about the pandemic. Her fellow mentor encouraged her to keep taking her medications and to have faith that better days are ahead.

Despite the impact of COVID-19 on our peer mentoring program, we have found that our mentors continue to use their time and talents to help others cope with kidney disease. While implementing new technologies proved challenging initially, it also has been rewarding to the mentors, mentees, and staff at PFPP. We encourage others to start and continue peer mentoring programs, even during the COVID-19 pandemic, as our patients will continue to need emotional support that is best provided by someone who has "been there."

Note from the editors:

The Patient and Family Partner Program can be accessed through the Kidney Foundation of Central PA at 800.762.6202; <https://www.kfcp.org>

If you would like to implement peer assistance at your location, NKF also has a national PEERs help line: 855.NKF.PEER (855.653.7337); NKFpeers@kidney.org

REFERENCES

- Ghahramani, N. (2015). Potential impact of peer mentoring on treatment choice in patients with chronic kidney disease: A review. *Archives of Iranian Medicine*, 18(4), 239–243.
- Pfefferbaum, B., & North, C. (2020). Mental health and the Covid-19 pandemic. *New England Journal of Medicine*, 383, 510–512.

National Kidney Foundation
NKF 2021 Spring Clinical Meetings Abstracts
April 6–10, 2021

CKD/ESRD—Other

- 1 **Patient Impact of a Kidney Disease Patient-Centered Outcomes Research Study**
Teri Browne¹, Jamie Green², Christina Yule², Sara Kwiecien², Patti Ephraim³, Ashley Cabacungan⁴, Sherri Wydra², Tara Strigo⁴, Katina Lang-Lindsey⁵, Patty Danielson⁶, Lana Schmidt⁶, Amy Swoboda⁷, Brian Bankes⁶, Suzanne Ruff⁷, Shakur Bolden⁶, Peter Woods⁶, George Jackson⁴, Felicia Hill-Briggs³, L. Ebony Boulware⁴. ¹University of South Carolina, Columbia, SC, United States; ²Geisinger Health System, Danville, PA, United States; ³Johns Hopkins University, Baltimore, MD, United States; ⁴Duke University School of Medicine, Durham, NC, United States; ⁵Alabama A&M University, Huntsville, AL, United States; ⁶Patient Co-Investigator, Durham, NC, United States; ⁷Family Member Co-Investigator, Durham, NC, United States
- 2 **Organizational Predictors of High-Quality Performance in Medicare’s Comprehensive End-Stage Renal Disease Care Initiative**
Kelsey Drewry, Adam Wilk. Emory University, Atlanta, GA, United States
- 3 **Engagement and Experiences in a Kidney Disease Patient-Centered Outcomes Research Study During COVID-19**
Shamika Jones², Teri Browne¹, Ashley Cabacungan³, Tara Strigo³, Patti Ephraim⁴, Jamie Green⁵, Katina Lang-Lindsey⁶, Shakur Bolden¹⁴, Amy Swoboda¹⁵, Suzanne Ruff¹⁵, Patty Danielson¹⁴, Lana Schmidt¹⁴, Brian Bankes¹⁴, Peter Woods¹⁴, Kelli Collins⁷, Diana Clynes⁸, Diane Littlewood⁹, Dori Schatell¹⁰, Dale Singer¹¹, Stephanie Stewart¹², Brandy Vinson¹³, Felicia Hill-Briggs⁴, L. Ebony Boulware³. ¹University of South Carolina, Columbia, SC, United States; ²University of South Carolina, Columbia, SC, United States; ³Duke University School of Medicine, Durham, NC, United States; ⁴Johns Hopkins, Baltimore, MD, United States; ⁵Geisinger Health System, Danville, PA, United States; ⁶Alabama A&M University, Huntsville, AL, United States; ⁷National Kidney Foundation, New York, United States; ⁸American Association of Kidney Patients, Tampa, FL, United States; ⁹Pennsylvania Medical Society, Harrisburg, PA, United States; ¹⁰Medical Education Institute, Madison, WI, United States; ¹¹Renal Physicians Association, Rockville, MD, United States; ¹²Mayo Clinic, Mankato, MN, United States; ¹³Quality Insights Renal Network 5, Richmond, VA, United States; ¹⁴Patient Co-Investigator, Durham, NC, United States; ¹⁵Family Member Co-Investigator, Durham, NC, United States
- 4 **Everyday Racial Discrimination and Medication Adherence: A Qualitative Study**
Tamara Estes Savage. University of North Carolina - Pembroke, Pembroke, NC, United States

Other

- 5 **Patient and Decision Partner Shared Decision-Making in Dialysis**
Renata Sledge^{1,2}, Dixie Meyer², Max Zubatsky², Kaite Heiden-Rootes², Marie Philipneri², Teri Browne³. ¹Medical Education Institute, Madison, IL, United States; ²Saint Louis University School of Medicine, Saint Louis, MO, United States; ³University of South Carolina, Columbia, SC, United States
- 6 **Female Sexual Function in an Inner-City Population of Chronic Kidney Disease (CKD), Dialysis and Kidney Transplant (KTx) Patients**
Tatyana Yatsenko, Stefan Hamaway, Michael Goldberg, Gabrielle Estevez-Inoa, Basim Ahmad, Mariana Markell. SUNY Downstate Health Sciences University, Brooklyn, NY, United States
- 7 **Treatments and Trauma**
Sonya-Lee Zezza. Fresenius, Palatka, FL, United States

1. PATIENT IMPACT OF A KIDNEY DISEASE PATIENT-CENTERED OUTCOMES RESEARCH STUDY:

Teri Browne¹, Jamie Green², Christina Yule³, Sara Kwecien², Patti Ephraim³, Ashley Cabacungan⁴, Sherri Wydra², Tara Strigo⁴, Katina Lang-Lindsey⁵, Patty Danielson⁶, Lana Schmidt⁶, Amy Swoboda⁷, Brian Bankes⁶, Suzanne Ruff⁷, Shakur Bolden⁸, Peter Woods⁹, George Jackson⁴, Felicia Hill-Briggs³, L. Ebony Boulware⁴. ¹University of South Carolina, Columbia, SC, United States; ²Geisinger Health System, Danville, PA, United States; ³Johns Hopkins University, Baltimore, MD, United States; ⁴Duke University School of Medicine, Durham, NC, United States; ⁵Alabama A & M University, Huntsville, AL, United States; ⁶Patient Co-Investigator, Durham, United States; ⁷Family Member Co-Investigator, Durham, United States

Introduction

PREPARE NOW is a 5-year patient-centered outcomes research study testing a health system intervention to change kidney disease care. Patients received kidney care transitions services including nurse case management, classes, & referrals to peer mentors, behavioral health and dietitians. We conducted a study to examine the patient impact of the interventions.

40 patients were randomly selected for phone interviews. Patient & family Co-Investigators collaborated to design the interview guide. Transcripts were analyzed using MaxQDA software. First-cycle coding was performed using provisional codes derived from interview prompts. Second-cycle axial coding was then performed to differentiate and organize codes used to identify the most salient themes.

The PREPARE NOW interventions helped patients make shared decisions about their ESKD treatment choice, empowered patients, helped patients accept their kidney disease and provided emotional support to patients. Patients appreciated both in-person and virtual classes. Patients who chose not to do intervention components (peer mentor, dietitian, behavioral health) did so because they did not feel they needed that help or were too busy with other medical appointments.

Overall, most patients were highly satisfied with the PREPARE NOW project and thought that both the nurse case management and classes on ESKD treatment choices and living with kidney disease were very valuable. Although infrequently used by patients, referrals for peer mentors, dietitians and behavioral health were valued by those who used these services.

2. ORGANIZATIONAL PREDICTORS OF HIGH-QUALITY PERFORMANCE IN MEDICARE'S COMPREHENSIVE END-STAGE RENAL DISEASE CARE INITIATIVE:

Kelsey Drewry¹, Adam Wilk¹. ¹Emory University, Atlanta, GA, United States

Introduction

Medicare is increasing the prevalence of alternative payment models in nephrology to improve the quality and value of care for beneficiaries with CKD and ESRD. Previously, Medicare implemented the analogous ESRD Seamless Care Organization (ESCO) program, through which provider groups (ESCOs) that provided high-quality care and reduced spending for ESRD patients could share in Medicare's savings. This study analyzed the relationship between ESCO organizational and staffing characteristics and quality performance.

We captured key information for all 37 ESCOs during 2015-2018 using data from CMS reports and the National Provider Identification registry. We performed bivariate and generalized logistic regression analyses of ESCOs with above vs. below median quality scores, focusing on measures potentially related to ESCO organization and staffing and controlling for community characteristics at the county level. Statistical significance was evaluated at the 5% level with Bonferroni corrections to account for multiple comparisons.

ESCO composition and quality performance varied widely (e.g., eye exam 0-95%; depression screening 60-99%; dialysis care rating 53-72%). Logistic regression models suggested that high performance on clinical process quality measures (eye and foot exams, depression screenings) was negatively associated with increasing ESCO size (+10 affiliated practices associated with 5-7 percentage point (pp) *decreases* in likelihood of achieving high performance on eye/foot exams and depression screenings [p=0.002, p<0.001, & p=0.028, respectively]). Patient information and dialysis care ratings were positively associated with ESCO size (+10 affiliated practices associated with 5 pp *increase* in likelihood of high performance [p=0.001 for both outcomes]), but were significantly negatively associated with increasing non-physician clinician staffing.

During 3 years of Medicare's ESCO program, the measures of care quality delivered by ESCOs varied greatly. We found that ESCO size was the most consistent predictor of performance on a variety of quality measures: larger ESCOs were less likely to achieve high performance on clinical process quality measures but more likely to achieve high performance on patient information and dialysis care ratings. This study provides crucial evidence to inform the decisions of provider groups participating in Medicare's new nephrology-focused payment models.

3. ENGAGEMENT AND EXPERIENCES IN A KIDNEY DISEASE PATIENT-CENTERED OUTCOMES RESEARCH STUDY DURING COVID-19:

Shamika Jones², Teri Browne¹, Ashley Cabacungan³, Tara Strigo³, Patti Ephraim⁴, Jamie Green⁵, Katina Lang-Lindsey⁶, Shakur Bolden¹⁴, Amy Swoboda¹⁵, Suzanne Ruff¹⁵, Patty Danielson¹⁴, Lana Schmidt¹⁴, Brian Bankes¹⁴, Peter Woods¹⁴, Kelli Collins⁷, Diana Clynes⁸, Diane Littlewood⁹, Dori Schatell¹⁰, Dale Singer¹¹, Stephanie Stewart¹², Brandy Vinson¹³, Felicia Hill-Briggs⁴, L. Ebony Boulware³. ¹University of South Carolina, Columbia, SC, United States; ²University of South Carolina, Columbia, SC, United States; ³Duke University School of Medicine, Durham, NC, United States; ⁴Johns Hopkins, Baltimore, MD, United States; ⁵Geisinger Health System, Danville, PA, United States; ⁶Alabama A & M University, Huntsville, AL, United States; ⁷National Kidney Foundation, New York, United States; ⁸American Association of Kidney Patients, Tampa, FL, United States; ⁹Pennsylvania Medical Society, Harrisburg, PA, United States; ¹⁰Medical Education Institute, Madison, WI, United States; ¹¹Renal Physicians Association, Rockville, MD, United States; ¹²Mayo Clinic, Mankato, MN, United States; ¹³Quality Insights Renal Network 5, Richmond, VA, United States; ¹⁴Patient Co-Investigator, Durham, United States; ¹⁵Family Member Co-Investigator, Durham, United States

Introduction

PREPARE NOW is a patient-centered outcomes research study testing a health system intervention to change kidney disease care. We conducted a qualitative study to examine the impact of COVID-19 on patient-centered engagement in research.

7 patient and family Co-Investigators & 8 kidney disease stakeholders were interviewed. Transcripts were analyzed to differentiate and organize codes used to identify the most salient themes.

COVID-19 has impacted patients by restricting travel, requiring isolation, increasing mortality concerns & the use of telehealth. COVID-19 has increased anxiety & fear among patient and family members, but it has not affected their ability to participate in virtual PCOR research activities.

PREPARE NOW team members were highly engaged in research. Problems that may occur when participating on research teams during COVID-19 include technology knowledge, limitations of virtual meetings, and internet bandwidth. Suggestions for PCOR research in general & during COVID-19 include frequent communication and technical assistance. The virtual engagement approaches of the PREPARE NOW project can serve as a model for the PCOR community.

4. EVERYDAY RACIAL DISCRIMINATION AND MEDICATION ADHERENCE: A QUALITATIVE STUDY:

Tamara Estes Savage¹. ¹University of North Carolina Pembroke, Pembroke, NC, United States

Introduction

Poor medication adherence leads to increased risk for morbidity and mortality in dialysis patients. African American dialysis patients have poorer rates of medication adherence when compared to Whites. Studies have not investigated the impact of broader social issues such as everyday racial discrimination on this disparity. It is critically important to understand how everyday racial discriminatory acts within the healthcare system contribute to this disparity in medication adherence. Thus, a qualitative study was conducted.

Primary data were gathered from five in-depth interviews with African American ESRD patients (N = 5). Each interview was 1 to 1.5 hours in duration. Participants were recruited from attendees at a National Kidney Foundation Patient Empowerment Meeting. The interviews were transcribed verbatim. Grounded theory was used to identify themes that emerged from a line-by-line review of the interview transcripts.

Participants stated that health providers assumed that participants could not pay for prescriptions, free medication samples given to White patients but not African American patients, participants treated unkindly or ignored by medical staff, participants treated as a "typical" African American, and information about medication and lab results were withheld or given to participants without further consultation. In contrast, White patients received in-depth consultations.

These findings provide the basis for development of future research concerning the impact of everyday racial discrimination on medication adherence in the African American dialysis population. Such research could lead to antiracist strategies, and targeted interventions that can address the medication adherence health disparity.

5. PATIENT AND DECISION PARTNER SHARED DECISION-MAKING IN DIALYSIS:

Renata Sledge^{1,2}, Dixie Meyer³, Max Zubatsky², Kaitie Heiden-Rootes², Marie Philipperi², Teri Browne³. ¹Medical Education Institute, Madison, IL, United States; ²Saint Louis University School of Medicine, Saint Louis, MO, United States; ³University of South Carolina, Columbia, SC, United States

Introduction

Caregiver and family involvement by medical professionals in decisions vary over the dialysis treatment trajectory, yet family preferences are important considerations for patients starting dialysis. Existing literature has not explored the experience of patient and decision partner shared decision-making. Consequently, dialysis providers focus on education about expected benefits of dialysis, rather than personalizing the dialysis decision discussions.

This interpretive phenomenology study explores how dialysis patients and their partners experience dialysis decisions. A purposive sample of 13 patient-decision partner dyads were recruited from dialysis clinics and on-line dialysis patient groups and participated in semi-structured interviews. Eligible participants were over 18 years old, English speaking, involved with their treatment teams for at least 6 months, and the patient was currently on dialysis. Decision-partners included those who have participated in decision-making with the patient. Crist and Tanner's (2003) five-step iterative process of data analysis occurred concurrently with data collection.

Thirteen dyads (26 participants) were interviewed with patients on ICHD (n=6), PD (n=3) and HDD (n=4). Decision partner relationships included romantic partner (n=9), parent (n=2), sibling (n=1), and friend (n=1). Fifty-seven percent of participants were White; 46% of patients were women; and 76% of decision partners were women. Emerging patterns include a shifting focus of the dyad across treatment trajectory; balancing bodily integrity with relational autonomy; and activities honoring the ultimate responsibility of decision by the patient with their shared responsibility to the family.

Dyads making modality decisions are attuned to patient autonomy while managing the collateral effects of dialysis. Shifting the paradigm of dialysis treatment decisions from promoting patient autonomy to dialogues exploring relational autonomy will help providers to balance the competing demands of incentivized standards to promote home dialysis with the realities of patients and their decision partners.

6. FEMALE SEXUAL FUNCTION IN AN INNER-CITY POPULATION OF CHRONIC KIDNEY DISEASE (CKD), DIALYSIS AND KIDNEY TRANSPLANT (KTX) PATIENTS:

Tatyana Yatsenko¹, Stefan Hamaway¹, Michael Goldberg¹, Gabrielle Estevez-Inoa¹, Basim Ahmad¹, Mariana Markell¹. ¹SUNY Downstate Health Sciences University, Brooklyn, NY, United States

Introduction

Sexual dysfunction (SD) can greatly affect quality of life, but most studies of SD in kidney disease are limited to men. We studied trends in psychosocial factors, beliefs, and lifestyle habits in relation to Female Sexual Function Index scores (FSFI) in an inner-city population with kidney disease.

A random sample of female CKD (7), dialysis (4), and transplant (8) pts were surveyed by telephone using the PSS (Perceived Stress Scale), PHQ9, SSS (Stress and Social Support), SEAR (Self Esteem and Relationships), Lubben Social Network and BIAAQ (Body Image Acceptance and Action) questionnaires. 24 hour diet intake was recorded and analyzed using ASA-24. There were no differences between the three groups, so data were pooled. Associations were calculated using Pearson's r.

Mean age was 57± 10. 63% of patients were Black, 11% Hispanic, 5% white, 5% other, and 16% unreported. 74% of patients had FSFI scores consistent with sexual dysfunction (mean 14±12, out of 36). FSFI was not correlated with PHQ9, SSS, PSS, SEAR, Lubben Social Network, or BIAAQ-5 scores. FSFI was also not correlated with age, exercise habits, or diagnosis of HTN or diabetes. FSFI was correlated with intake of sugar (r=0.6, p<0.05), fiber (r=0.7, p<0.01), and 4-week herbal supplement history (r=0.6, p=0.01), and inversely associated with total fat intake (r=-0.7, p=0.01) and sodium (r=-0.6, p=0.04). 26% and 16% of patients discussed sexual dysfunction with a physician after any chronic disease diagnosis and within the last year, respectively. Pts who had discussed sexual dysfunction reported more sexual activity within the past 4-weeks (r=0.5, p<0.05). 11% had discussed treatment for sexual dysfunction. Two patients commented on physician inattention and discomfort when discussing sexual health and one patient also noted insufficient education related to kidney disease and sexual dysfunction.

In our population: 1. Female sexual dysfunction was reported by almost three quarters of patients surveyed. 2. Sexual dysfunction did not correlate with age, comorbidities, or psychosocial factors. 3. Sexual dysfunction was associated with diet that featured less sugar and fiber and more sodium and fat. 4. Patients with better sexual function were more likely to have taken herbal supplements. 5. Sexual function is likely multifactorial and is an important component of overall health. Three quarters of pts had never discussed it with their healthcare provider and several noted that their physician was uncomfortable discussing the topic. 6. More attention should be paid to this important issue in order to improve quality of life for our female patients with kidney disease.

7. TREATMENTS AND TRAUMA:

Sonya-Lee Zezza¹. ¹Fresenius, Palatka, FL, United States

Introduction

There is very little research on medical self-management in adulthood dialysis treatments and the links to childhood abuse. However, by utilizing the Adverse Childhood Experiences (ACE) study and what is known about affect dysregulation in traumatized people we can start to see a relationship between childhood trauma and self-management treatment among adult dialysis patients and attending their treatments.

Methods: We conducted a literature review into the relationship between childhood trauma and the self-management of treatment on adults on dialysis. The ACE study along with affect dysregulation patterns were used to gather information. Affect dysregulation behaviors include being self-destructive due to traumatizing experiences such as different types of abuse. The ACE study had over 17,000 participants which had questions on several types of abuse and family stressors. Two other studies used parts of the ACE questions to formulate their research. One was on general health and childhood trauma where they studied 272 adults with 5 measurements of childhood trauma and lastly, a study on trauma and low-income country where there were 468 participants.

Results: The ACE's study revealed that childhood trauma significantly impacted more than 60% of adults physically and mentally. Studies within HIV in General Health Care and in the Trauma History and Depression Predict Incomplete Adherence to Antiretroviral Therapies in a Low-Income Country in adults reveal that the higher the ACE score and the more frequent medical treatments the less they are to participate in self-managed treatments, therefore engaging in affect dysregulation.

Conclusion: It is known that the most common ways for traumatized people to cope are through self-destructive/affect dysregulation behaviors leading the adult dialysis patient to poorly manage their treatment. Self-destructive behaviors can be seen as a way to control their environment and medical treatments. With early detection of childhood trauma and expanding mental health services to the dialysis patient, dialysis centers would see an increase in positive self-management.



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