

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

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*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.*

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## 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).

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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
<b>Number of patients</b>	22	40
<b>Age range</b>	28–77	26–93
<b>Mean age</b>	58	68
<b>Male</b>	55%	57%
<b>Female</b>	45%	43%
<b>English as primary language</b>	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
<b>Hypertension</b>	100%	97.5%
<b>Diabetes</b>	50%	52.5%
<b>Cardiac-related issues</b>	50%	82.5%
<b>Gout</b>	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.

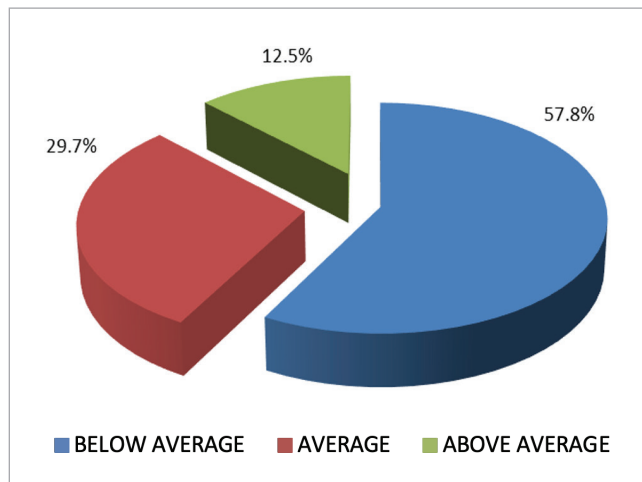
### Data Analysis

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

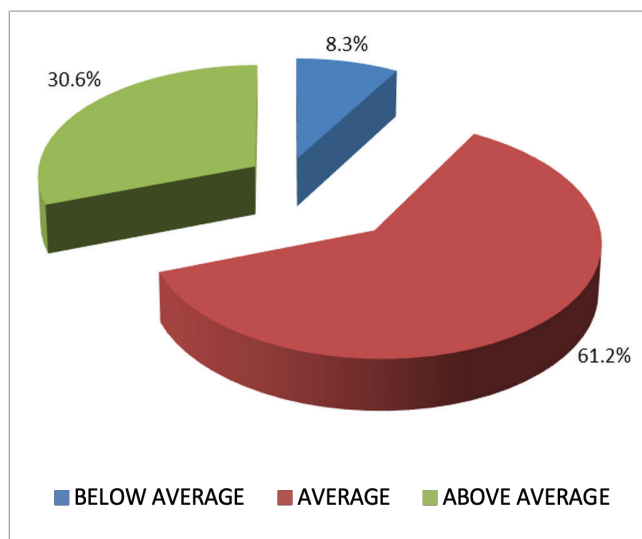
### **Burden of Kidney Disease Subscale: Surveys**

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

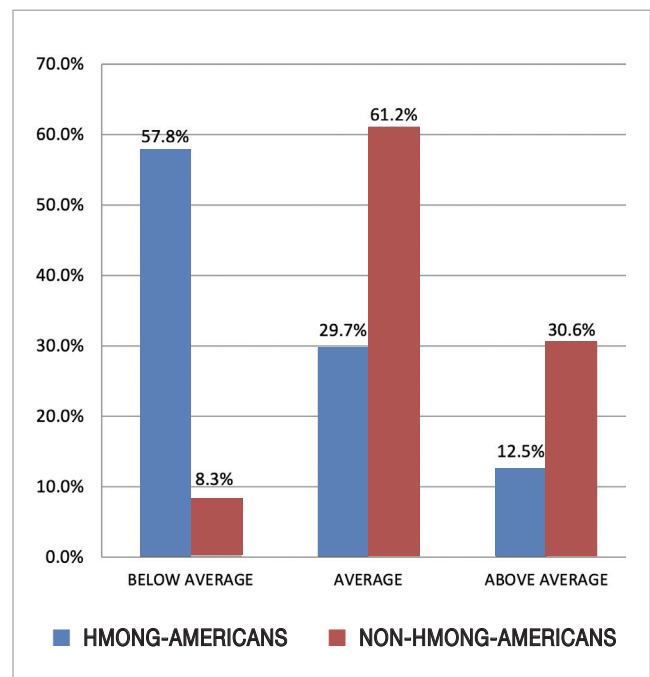
The Non-Hmong-American patients completed the survey 121 times. The Burden of Kidney Disease subscale was scored “below average” collectively only 10 times (8.3%; see **Figure 2**).



**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**).



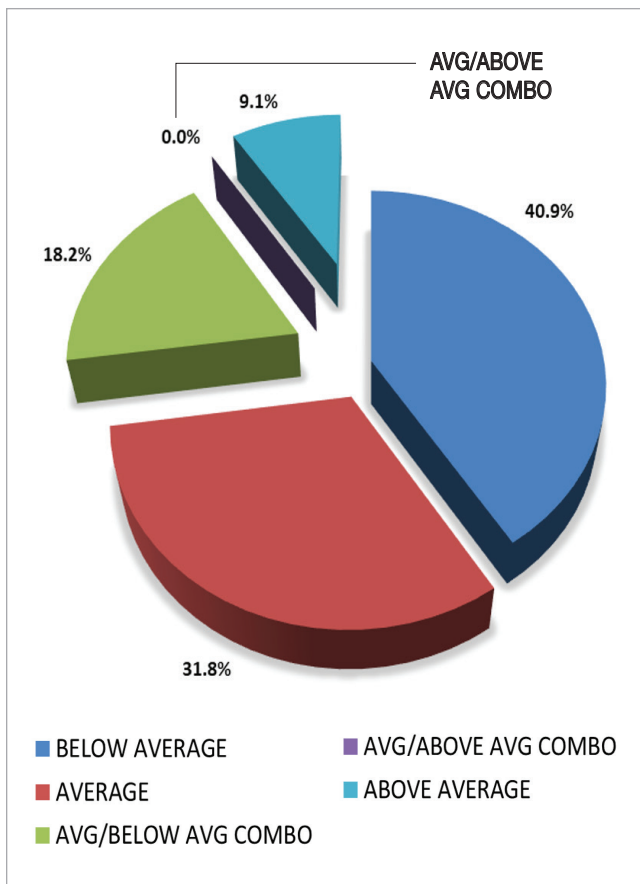
**Figure 3.** Burden of Kidney Disease Subscale Comparison Between Hmong-American and Non-Hmong-American Survey Responses

### **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).

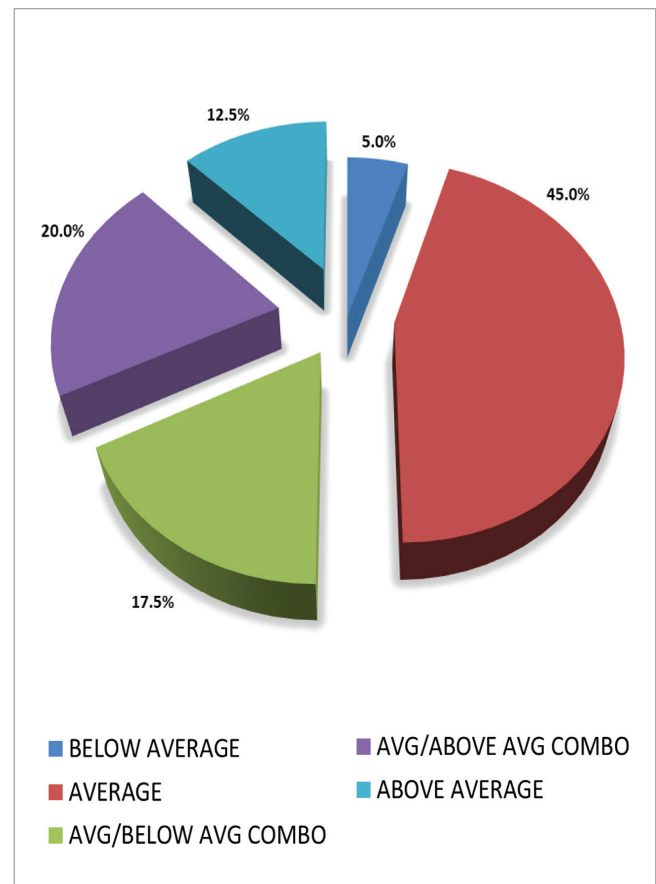


**Figure 4.** Burden of Kidney Disease Subscale of Hmong-American Patients

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**).



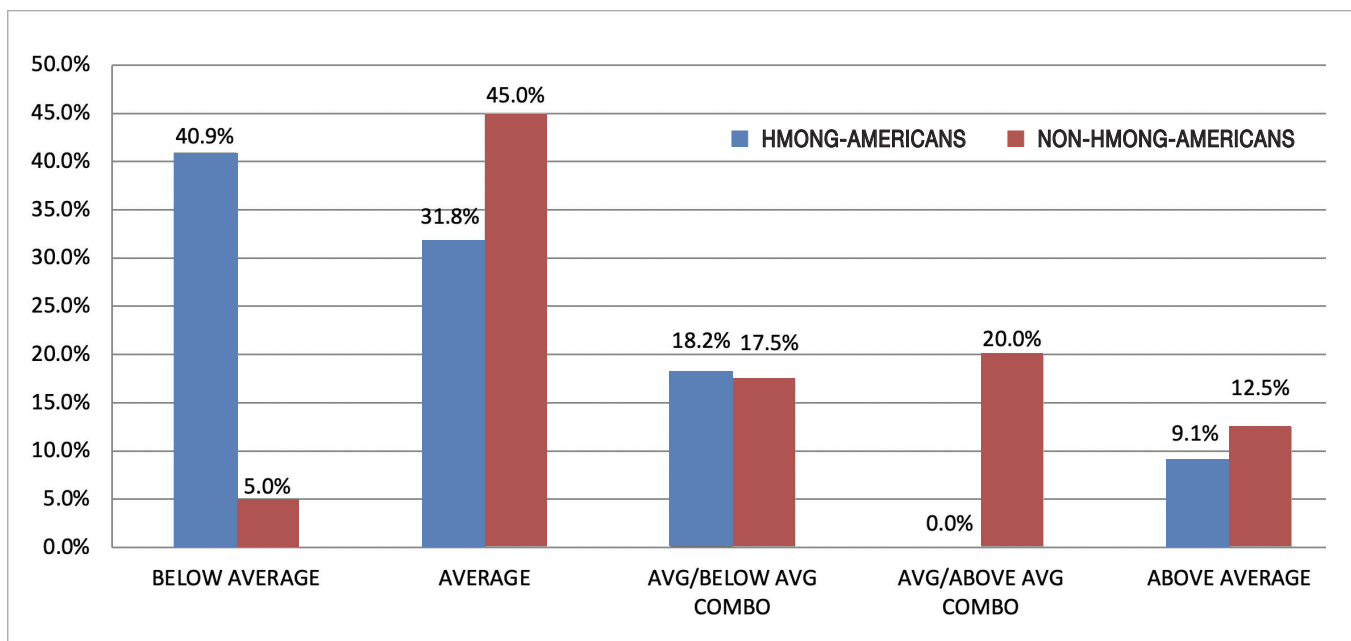
**Figure 5.** Burden of Kidney Disease Subscale of Non-Hmong-American Patients

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.

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