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1 RACIAL DISPARITIES IN THE REPORTED CASE OF CAREGIVER BURDEN IN CAREGIVERS OF HEMODIALYSIS PATIENTS: A SCOPING REVIEW:

Natasha Butler-Monteau¹, ¹tulane university

Caregivers of HD patients are often informal caregivers. Informal caregivers may consist of family and friends who provide in-home care to HD patients (Hoang et. al., 2019).

Caregiver burden are caregivers of patients that have sustained physical, psychological, emotional, financial, social, and time-consuming facets. (Hejazi et. al., 2020). Cultural values, race, and ethnicity often influence the role and perception of caregiving.

The purpose of this review is to examine the phenomena of perceived caregiver burden in caregivers of HD patients as it relates to race and ethnicity.

The aim of this scoping review is to identify gaps in research related to racial difference and the perception of caregiver burden among caregivers of HD patients by "systematically searching, selecting and synthesizing existing knowledge" (Colquhoun et al., 2014, p. 1294).

An initial search resulted in 554 articles which were exported into Covidence (2023), of which 104 duplicates that were excluded. The remaining 450 articles were individually screened with 342 being excluded due to lack of relevance to this study.

The results from this review were composed of studies that looked at varying levels of caregiver burden in caregivers of in-center HD patients.

A review of the literature revealed that although there is substantial research on caregiver burden, only two articles focused on the impact of race on caregiver burden among caregivers of in-center HD patients exclusively.

The most prominent limitation of this study is that as the sole author for this review, there is no inter-rater reliability or resolution regarding content to determine relevance, inclusion, or exclusion of studies.

Implications of this study indicate that due to unique cultural and ethnic norms, additional studies need to be conducted to access caregiver as it relates to culture and ethnicity.

Minority caregivers are more likely to perceive their role of caregiver as part of their commitment and responsibility to their family (Skarupski et. al., 2009). Most studies have found that nonminority caregivers of patients of various types of chronic illness are less likely to perceive their caregiver role as being more burdensome than other racial or ethnic groups (Fenton et. al., 2022).

2 PROMOTING ADVANCE CARE PLANNING AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE:

Michelle Rowlett¹, Grace Scarborough¹, ¹Puget Sound Kidney Centers

Nearly 40% of adults haven't had conversations about care preferences if a serious illness were to occur. In addition, over 67% haven't completed both durable power of attorney and advance directives.¹ Patients who share end-of-life wishes with family and healthcare providers experience a 90% success rate in goals being achieved.² To stress the importance of advance care planning (ACP) and encourage action, Puget Sound Kidney Centers' Survive and Thrive with Chronic Kidney Disease six week series includes a class focused on increasing awareness and providing tools to promote conversations about end-of-life care.

To measure awareness, a 2-question pre and post quiz is given. Q1: Who should think about advance care planning? A) People with chronic disease, B) Older adults, C) All adults, D) Both A&B; Q2: According to research 80% of people say they want to talk to their doctor about end-of-life care. What % report doing this? A) 50%, B) 20%, C) 7%, D) 65%.³ To explore this critical topic in a more comfortable environment, the class is taught on week 5 of 6. In addition, patient mentors relay personal stories. To make ACP more approachable and increase likelihood of action, resources such as Death over Dinner and Go Wish Cards are shared.

To date, 383 people have attended the class and participated in the quizzes. Q1 data follows: Pre 64% correct, Post 96% correct, thus marking a 50% score increase between pre and post quizzes. In the same fashion, Q2 data follows: 48% correct and 93% correct, marking a 94% increase between quiz scores. 123 people increased their Q1 knowledge and 172 people increased their Q2 knowledge. Anecdotally, participants commonly report reduced anxiety around ACP after class.

The results reveal a significant increase in knowledge levels between pre/post quizzes, providing empirical evidence of the effectiveness of enhancing participants' understanding and highlighting the potential impact of educational interventions. Utilizing a creative and interactive approach fosters a positive learning environment, even for difficult topics. For larger impact, more programs that encourage critical conversations and documentation need to be implemented on a national level. The relaxed, yet in-depth nature of this class can be used as a framework for future projects.

3 IDENTIFYING SITES FOR A HOSPITAL-BASED INTERVENTION FOR PATIENTS WITH UNEXPECTED END-STAGE KIDNEY DISEASE:

Megan Urbanski¹, Emma Blythe¹, Mengyu Di², Stephen Pastan¹, Kimberly Jacob Arriola¹, Michelle Kegler¹, Laura Plantinga³, Rachel Patzer², ¹Emory University; ²Regenstrief Institute; ³University of California San Francisco

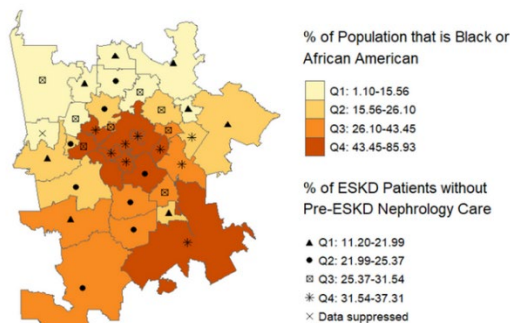
Education for patients approaching end-stage kidney disease (ESKD) is critical for informed decision making, but for the one-third of U.S. patients who had no pre-ESKD nephrology care and start dialysis unexpectedly in the hospital, there is little opportunity for education before dialysis start. This study aimed to identify geographic "hot spots" where patients were less likely to have pre-ESKD nephrology care, which can be targeted in hospital-based interventions for patients with unexpected ESKD.

Data from the United States Renal Data System, American Community Survey, and Dartmouth Atlas were linked to create heat maps of metro-Atlanta to display hospital service area (HSA) level percentages of: people with ESKD without pre-ESKD nephrology care (% no pre-ESKD care), residents who: were Black/African American (% Black assuming a definition of race as a social construct), living under the federal poverty level (% poor), with no high school diploma (% no high school), and aged 18-44 (% 18-44). Pearson's correlation coefficients between % no pre-ESKD care and all other variables were calculated.

HSA-level no pre-ESKD care varied from 11.2-37.3% (median 25.4%; N=34). % No pre-ESKD care was strongly and positively correlated with % Black residents in a neighborhood ($r=0.67, p<0.001$, Figure 1). % No pre-ESKD care was not significantly correlated with % poor ($r=0.08, p=0.64$, Figure 2), % no high school ($r=-0.27, p=0.13$, Figure 3), or % 18-44 ($r=0.25, p=0.16$, Figure 4).

% of pre-ESKD nephrology care varies by HSA in metro-Atlanta and is correlated with the racial distribution of the population. These findings will inform a hospital-based intervention for patients with unexpected ESKD.

Figure 1. Map of Percentage of ESKD Patients without Pre-ESKD Nephrology Care and Percentage of Population of Black or African American Race by Hospital Service Area in Metropolitan Atlanta, GA



4 HIGH BURDEN OF SELF-REPORTED KIDNEY DISEASE AND LACK OF ACCESS TO CARE DUE TO COSTS IN AREAS OF MICHIGAN:

Jennifer Bragg-Gresham¹, Ana Laura Licon¹, Ann Andrews², Mary Wozniak², Yun Han¹, Rajiv Saran¹. ¹University of Michigan; ²National Kidney Foundation of Michigan

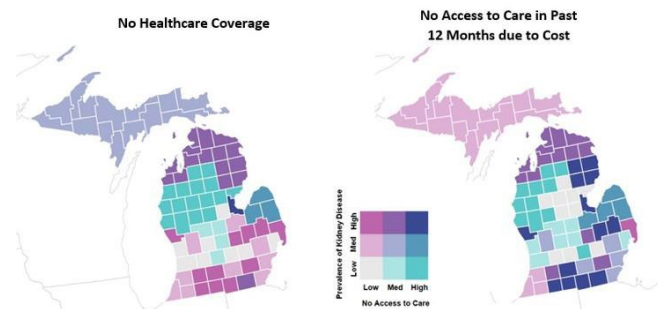
Inadequate or lack of health insurance is one of the largest barriers to health care access in America. Out-of-pocket costs can lead to individuals delaying or forgoing much-needed health care, including doctor visits, dental care, and medication use. We sought to explore self-reported, county-level data on access to care and kidney disease to identify vulnerable regions of Michigan.

Employing data from the Michigan Behavioral Risk Factor Surveillance System Health Indicators and Risk Estimates by Community Health Assessment Regions, 2019 – 2021, we mapped regional estimates of self-reported kidney disease by county-level estimates of two measures of lack of access to care: 1) no health insurance, and 2) no access to care in the past 12 months due to cost. Tertiles were calculated for each measure and bivariate maps were created using R software.

Region-level estimates of self-reported kidney disease ranged from 2.1% in central lower Michigan (Roscommon, Clare, Midland region) to a high of 4.9% in the southernmost counties of central lower Michigan (Branch, Hillsdale, St. Joseph, Calhoun, and Kalamazoo). Counties with the highest prevalence of lack of access to care included most of northern lower Michigan, Jackson, Lenawee, Genesee, Lapeer, Muskegon, and Bay county.

By mapping the intersection of self-reported kidney disease by measures of lack of access to healthcare, we have uncovered regions of the state needing further evaluation and intervention. Work examining the prevalence of risk factors within these regions in conjunction with area-level social determinants of health is underway and may serve to guide interventions to curb rates of new onset of kidney disease. This work also highlights areas in the state needing attention for improved access to healthcare.

Figure: Bivariate County-Level Map of Self-Reported Kidney Disease by Access to Healthcare



5 IMPACT OF A 12-WEEK CARDIOVASCULAR AND STRENGTH TRAINING PROGRAM ON THE HEALTH AND QUALITY OF LIFE SCORES OF KIDNEY TRANSPLANT PATIENTS:

Karen Dyer¹, Heather Marshal¹, Rick Hunter¹, Alyssa Mallia¹, Lande Bridges¹. ¹Ascension Saint Thomas West

While it is standard of care to prescribe physical rehabilitation for heart and lung transplant recipients, no similar program is offered for kidney transplant patients. This, despite the fact that they are faced with many lifestyle-related health risks which can be exacerbated by being sedentary.

We recruited 13 patients (mean age 48 years), 6 women, 7 men, who were within two years post-transplant and had no contraindications to exercise, nor were they currently exercising. They were referred by the transplant team, based on interest, health status and proximity to our hospital-based wellness center. Patients were assessed for general health, cardiovascular fitness, muscle endurance and fall risk prior to the start of the exercise program.

Patients were offered two 60-minute cardiovascular and strength

training sessions per week, supervised by clinical exercise physiologists. Individual exercise prescriptions were written, based on the first visit tests and patient specific goals. Exercise intensity and time were adjusted to suit the patients' needs and condition; however, all followed the same program design. Patients were also encouraged to exercise outside of these sessions and were given access to the wellness center. In addition, patients attended monthly education meetings covering such topics as medications, finances, nutrition and psycho/social issues, led by pharmacists, registered dietitians and licensed social workers who work with the kidney transplant team.

Sit to stand: 36.4% improvement.

One-legged stand: R leg 140% improvement;

L leg 94.4% improvement

50-foot walk: 10.2% improvement

Six-minute walk: 11.9% improvement

Given these findings, it appears that kidney transplant patients benefit from a post-transplant physical rehabilitation program to help improve their quality of life, reduce the risk of cardiovascular disease, hypertension, obesity and diabetes.

6 SOCIAL WORKERS' EXPLANATIONS OF RACIAL DISPARITIES IN PEDIATRIC KIDNEY TRANSPLANTATION:

Kristin Stockard¹. ¹University of Pennsylvania, School of Social Policy & Practice

Prior research has shown that Black children with ESRD have significantly increased mortality risk, decreased transplant rate, and spend more cumulative time on dialysis than other children. To better understand this phenomenon, this study aimed to understand pediatric dialysis and transplant social workers' perceptions of existing disparities for Black children in the transplant process, and to understand social workers' perception of their professional role in addressing these disparities.

Using an integrated conceptual framework of ecological systems and critical race theories, semi-structured interviews were conducted with 16 pediatric dialysis and transplant social workers from across the US. Thematic analysis was used to code the interviews, resulting in 4 primary themes: barriers exist at all system levels, the transplant process is a closed system, transplant expectations are unrealistic, and gatekeeping.

The barriers that Black children face are not limited to the patient-level microsystem as previously described in the literature, but persist across all system layers (micro-, meso-, exo-, macro-, and chronosystem). The transplant referral, evaluation, and selection processes are meso- and exosystem barriers to transplant while institutional racism and the legacy of medical harms are ongoing chronosystem barriers for Black children. The transplant process represents a closed system with rigid boundaries which further amplify ordinary racism and structural barriers for Black families. The expectations of an ideal pediatric transplant patient rely on a social construction of the family that does not include many Black families or their kinship networks. Gatekeeping from the transplant team deliberately utilizes the complexity of the transplant selection process to determine "readiness" for transplant, which magnifies existing disparities for Black children.

The resulting themes raise concern that the transplant selection process may reinforce structural racism in healthcare for Black children. Social workers are conflicted about whether their priority is to the organ, as stewards of a precious resource, or to the pediatric patient in their care. Further research is recommended to quantify barriers for Black children and to develop intervention strategies.