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Understanding and Addressing Disparities in Kidney Transplantation Access: A Focus on Disability and Other Identities

by

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The global prevalence of chronic kidney disease (CKD) is estimated to be between 8.7% and 18.4% (Samuels et. al, 2022), with approximately 843.6 million Americans having been diagnosed with one of the 5 stages of CKD in 2022 (Kovesdy, 2022). As of 2021, 1 in 7 adults were affected, which was about 37 million Americans according to the Centers for Disease Control and Prevention (CDC, 2021). CKD is a long-term condition in which the kidneys gradually lose function, leading to a buildup of waste and fluids in the body. This can result in a variety of symptoms, including high blood pressure, chest pain, shortness of breath, loss of appetite, and fatigue. CKD can be caused by a variety of factors, such as diabetes, high blood pressure, and others (Bentall, 2021). In terms of end-stage renal disease (ESRD), the fifth and final stage of CKD, about 786,000 Americans were diagnosed in 2020, with 71% on dialysis and 29% with a kidney transplant; ESRD is a critical phase in CKD (NIDDK, 2021). This stage is critical because once kidney damage occurs, it cannot be reversed. Patients with ESRD kidneys are diminished to less than 10 percent of their regular capacity, possibly resulting in minimal or no functioning at all. Further complications also include but are not limited to joint, bone, and muscle pain, nerve damage, liver failure, and fluid buildup around the lungs (DiMaria, 2022). Lifestyle choices and genetic factors are among the variables associated with the development of ESRD.

Factors Associated with the Development of ESRD

People with cardiovascular disease (CVD) and CVD risk factors, including family history, age, ethnicity, and sex, are commonly affected by CKD (Levey et al., 2007). CVD can cause damage to the blood vessels that supply the kidneys with blood, leading to impaired kidney function and ultimately the development of CKD and ESRD. Additionally, risk factors for CVD, such as hypertension and diabetes, are also risk factors for CKD and ESRD (Liu et al., 2014).

Diabetes is one of the leading causes of CKD and ESRD. High blood sugar levels can cause damage to the small blood vessels in the kidneys, leading to kidney damage and eventually ESRD (Bentall, 2021). Other causes of ESRD include glomerulonephritis, polycystic kidney disease, and autoimmune diseases such as lupus. These conditions can cause damage to the kidneys and impair their function. One of the biggest problems associated with ESRD is that it is often asymptomatic until late stages (Hashmi et al., 2023). Therefore, regular screening for and management of risk factors for CKD and ESRD, such as CVD, diabetes, and hypertension, are crucial in preventing or delaying the progression of CKD and reducing the risk of developing ESRD.

There is no known cure for ESRD, but it can be managed by ongoing dialysis and eventually kidney transplantation can help restore renal functioning (Sullivan et al., 2012b). Renal replacement therapy (RRT) is the treatment option for ESRD (Fleming, 2011). RRT is a life-saving procedure that removes waste products and excess fluids from the body when the kidneys are no longer able to perform these functions. The two main types of RRT are dialysis and kidney transplantation (Fleming, 2011). Dialysis involves using a machine to filter and remove waste products and excess fluid from the blood, with hemodialysis being the most common type that utilizes a dialysis machine and peritoneal dialysis using the peritoneum as a filter. Kidney transplantation, on the other hand, involves replacing a diseased or damaged kidney with a healthy kidney from a donor, which offers the best long-term outcomes for patients with ESRD (Fleming, 2011). However, not all patients are eligible for kidney transplantation, and there are risks associated with the procedure. Despite the availability of these treatment options, there are disparities associated with accessing treatment for ESRD, which can have significant impacts on patients' health outcomes.

Disparities Associated with Accessing Treatment for ESRD

Patients from marginalized groups often face obstacles to receiving the optimal treatment for ESRD, kidney transplantation. Despite the most suitable approach for individuals with ESRD being a kidney transplant, disparities have been reported associated with gender, race, income, and other factors (Dageforde, 2015; Purnell et al., 2018; Shah et al., 2018; Sullivan et al., 2012a). Race has been found to be a contributing factor in barriers encountered during the steps to transplantation such as referral, evaluation, and wait listing. People of color can face significant complications when trying to access a kidney transplant, especially when they come from low-income backgrounds (Dageforde, 2015; Ku et al., 2020; Purnell et al., 2018). Obstacles to accessing kidney transplantation include, lack of access to appropriate healthcare services, pre-existing medication conditions, limited insurance coverage, lack of knowledge about the transplant process and the benefits of transplantation, and geographic location (Dageforde, 2015; McPherson et al., 2019; Purnell et al., 2018; Sullivan et al., 2012a). Studies have shown that people of color are less likely to be referred for transplantation and may be less likely to receive information about transplantation as a treatment option (Ku et al., 2020). Additionally, there may be implicit biases and discrimination within the healthcare system that affect access to transplantation for people of color (Purnell et al., 2018; Ku et al., 2020). These biases can result in delayed referrals for transplantation, longer wait times, and reduced access to high-quality transplant centers. Black patients, in particular, face lower rates of kidney transplantation compared to White patients, with 25% lower likelihood of being waitlisted (Ng et al., 2020). Physician bias, cultural and racial biases, lack of education and referrals, and ineffective communication between healthcare providers and patients have been identified as underlying causes of this disparity (Almeida et al., 2016; Dageforde, 2015; Navaneethan & Singh, 2006).

This may result in delays in referral, and insufficient pre-transplant work-up, creating barriers for Black patients in accessing appropriate care and treatment (Almeida et al., 2016). However, when African American patients were educated about the benefits and available options, they expressed similar preferences for transplantation as their White counterparts (Manton & Poulton, 2013; King et al., 2020) In addition to racial disparities in access to transplantation, gender has been reported as another disparity.

CKD prevalence is reportedly higher in women than in men, with 15.4% of women developing the disease compared to 12.8% in men from 2011-2012 (Harris & Zhang, 2020). However, men are 50% more likely to develop ESRD than women, with the cause pointing toward sex hormones, renal hemodynamics, and renal mass differences between men and women, as well as differences in health care utilization (Harris & Zhang, 2020). There are significant gender disparities in access to and outcomes of kidney transplantation. A study by Salas et al. (2022) found that men were more likely to receive a kidney transplant than women, even after adjusting for other factors such as age, race, and comorbidities. In addition, women were more likely to experience longer waiting times and to be less likely to receive a living donor transplant. Women are also more likely to donate their organs than men, even being the first to volunteer for organ donation (Bal & Saikia, 2007). While it is true that ESRD is more common in men, this fact does not justify the observed disparity in organ allocation for women who suffer from kidney disease and eventually kidney failure (Palleti et al., 2023) One of the many factors contributing to this disparity is that women tend to have higher panel reactive antibodies as a result of the immune reaction associated with pregnancy, further contributing to the sex disparities found in renal transplantation (Katz-Greenberg & Shah, 2022). When it comes to pregnancy concerns, financial and social support also play a significant role in impacting women's health outcomes, as women without these resources are more likely to experience higher depression rates and lower rates of life satisfaction (Battulga et al., 2021). Prior pregnancy can contribute to sensitization which can make it more difficult to find a matching donor kidney (Senn et al., 2021). Pregnancy after kidney transplantation is an important issue related to gender and transplantation, with risk factors such as, rejection of the transplanted kidney, gestational diabetes, and pre-eclampsia. In the case of transgender individuals (when a person's gender identity is different from the gender that was assigned at birth) with kidney disease, they may face additional barriers in accessing appropriate care. Collister et al. (2021) conducted a narrative review of the literature on providing care for transgender persons with kidney disease and found that there is a lack of research and guidelines on this topic. Transgender individuals may experience discrimination and stigma in healthcare settings, which can lead to delays in diagnosis and treatment (Safer et al., 2016). In addition, they may have unique healthcare needs related to hormone therapy and gender-affirming surgeries that can affect kidney function and require specialized care (Collister et al., 2021). While gender disparities in healthcare have received significant attention, socioeconomic status is another factor that affects healthcare access and outcomes.

Socioeconomic status (SES) is another important factor affecting access to kidney transplantation and outcomes, as this can be a significant impediment to getting a transplant. A registry-based study in Sweden found that patients with low SES were less likely to receive a kidney transplant and had a higher risk of death on the waiting list compared to patients with higher SES (Zhang et al., 2018). This is consistent with previous research indicating that patients with lower income and education levels are less likely to receive a kidney transplant and more likely to experience worse outcomes after transplantation (Gordon et al., 2010). Furthermore, research has shown that households with an annual income of less than $35,000 are at a higher risk of having household members diagnosed with certain diseases, such as kidney disease (Woolf et al., 2015). Reasons that explain these disparities are that patients with low SES may face barriers such as lack of insurance coverage, inability to afford transportation or lodging for medical appointments, and difficulty navigating the healthcare system (Axelrod et al., 2010; Woolf et al., 2015). The disparities in healthcare access and outcomes based on factors such as race, gender and socioeconomic status are particularly concerning for individuals who belong to multiple marginalized groups, such as people of color, women, transgender individuals, and people with disabilities. According to the Centers for Disease Control and Prevention, approximately one in four adults in the United States have a disability, with the prevalence being higher among women, people of color, and those with lower incomes (CDC, 2022). That makes up a staggering 26% of the U.S. population that are living with some form of a disability (CDC, 2022). Individuals with disabilities face significant barriers to accessing healthcare services, including lower rates of health insurance coverage and higher out-of-pocket costs (Kennedy et al., 2017). When combined with other factors such as race and gender, these barriers can create a significant gap in healthcare access and outcomes for individuals who are disabled and belong to other marginalized groups.

Disability Status and Transplantation

Often times, disability is labeled as the result of being diagnosed with CKD and/or ESRD (Plantinga et al., 2011; Kang et al., 2021). However, it is important to recognize that disability can also be a pre-existing condition, and to explore the kidney transplantation process in patients with pre-existing disabilities. People with disabilities encounter substantial obstacles in accessing kidney transplantation due to ableism and systemic biases (Thom et al., 2022). Ableism is discrimination against individuals with disabilities, which can influence medical decisions and diagnostic criteria, leading to biases and limited access to healthcare services (Bogart & Dunn, 2019). Chen et al. (2020) reveals that intellectual disabilities are often deemed a contraindication for transplantation, resulting in fewer referrals for this population. Historical exclusion of individuals with intellectual disabilities from transplantation, justified by ableism, exacerbates this issue, with organs often directed towards those who are perceived to benefit the most, further marginalizing people with disabilities (Chen et al., 2020). McGee et al. (2012) found that disabilities were associated with reduced access to transplantation and increased mortality rates among patients with ESRD. Disability status has also been associated with barriers to accessing transplant such as transportation, lack of social support, and inadequate medical care, which may contribute to these disparities (Plantinga et al., 2012). People with lower SES and disabilities were found to have a higher prevalence of CKD, which may be attributed to a lack of access to quality healthcare and preventative services, leading to difficulties in managing their conditions and avoiding kidney disease progression (Plantinga et al., 2012). Furthermore, individuals with disabilities face challenges within the mental health system, which may impact their eligibility for transplantation. Pinals et al. (2022) highlight the various barriers and disparities encountered by individuals with intellectual and developmental disabilities (e.g., Down syndrome, Becker Muscular Dystrophy, and DiGeorge Syndrome) in the mental health system, including inadequate support and limited access to care. These challenges may affect their ability to manage comorbid conditions, such as depression, bipolar disorder, post-traumatic stress disorder (PTSD), and other mental health disorders, which may impact their eligibility for transplantation. People with disabilities are also more likely to experience discrimination and stigmatization within the healthcare system, making it difficult for them to advocate for their healthcare needs

(Ali et al., 2013). This can be seen with the intersection of other marginalized identities, such as race and gender, which may worsen the disparities faced by this group. Martens et al. (2006) noted significant disparities in organ donation and transplantation among people with disabilities, particularly people with intellectual disabilities who are also people of color. Addressing and eliminating the various forms of discrimination and bias that people with disabilities encounter within the healthcare system is necessary to ensure equitable access to kidney transplantation for all. To identify and eliminate various forms of discrimination, it is crucial to identify different models and theories that explain the experiences of marginalized identities when accessing renal transplantation.

Theories and Models

The social determinants of health theory (SDOH) is a useful framework for understanding the various social factors that contribute to health disparities (Braveman & Gottlieb, 2014). This theory suggests that social and economic factors such as income, education, and social support play a major role in shaping health outcomes for individuals and communities. One of the key components of SDOH is the idea of upstream determinants. This refers to the factors that exist outside of the healthcare system that influence health outcomes. Examples of upstream determinants include poverty, social isolation, and access to quality care (Bharmal et al., 2015). By addressing these upstream factors, it is possible to improve health outcomes for individuals and communities. Another important concept of SDOH is social stratification (Braveman & Gottlieb, 2014). This refers to the unequal distribution of resources, power, and prestige in society. Individuals who occupy different positions in the social hierarchy have different levels of access to resources and opportunities. This can have a major impact on health outcomes, as individuals who occupy lower positions in the social hierarchy experience more stress, fewer resources, and greater exposure to environmental toxins. Gender is an example of an important factor that can shape health outcomes. In many societies, gender roles and expectations can lead to differences in health behaviors and outcomes for men and women (Eagly & Wood, 2012). As was mentioned earlier, studies such as Katz-Greenberg & Shah (2022) and Bal & Saikia, (2007) numerically showed how women are more likely to prioritize the health of others over their own, which can lead to delays in seeking care for themselves.

Disability policy scholars have identified four historical and social models of disability, including the moral, medical, rehabilitation, and disability models (Kaplan, 1999). The moral model views disability as the result of sin, while the medical model regards it as a defect or sickness that needs medical intervention. The rehabilitation model sees the person with a disability in need of services from a rehabilitation professional that can provide training, therapy, or counseling to make up for any limitations caused by the person's disability (Kaplan, 1999). The disability model has gained wider acceptance as the disability rights and independent living movements have grown stronger. According to Kaplan (1999), this model regards disability as a natural aspect of life rather than a deviation and rejects the belief that individuals with disabilities are inherently flawed. Given that most people will experience some form of disability at some point in their lives, the model suggests that designing environments and systems with disability in mind would make it seem less unusual and more accepted as the norm (Kaplan, 1999). The disability model identifies social discrimination as the most pressing issue experienced by people with disabilities, and as the cause of many challenges that are often considered inherent to disability in other models. Furthermore, the disability model acknowledges that social discrimination is a major issue faced by people with disabilities. This discrimination is recognized as a primary factor that leads to many problems that are often mistakenly attributed to the disability itself (Kaplan,1999). Unlike the medical and rehabilitation models, which view individuals with disabilities as deficient and in need of fixing their problems, the disability model views individuals with disabilities as facing barriers caused by societal attitudes and environmental factors. Recognizing the societal and environmental factors that impact individuals with disabilities, the concept of intersectionality further expands on the disability model.

Intersectionality is a concept that was first introduced by Kimberle Crenshaw, a Black feminist scholar, in 1989 (Crenshaw, 1989). It refers to the intersection of various forms of oppression, such as race, gender, class, sexuality, and disability status. Intersectionality recognizes that people have multiple identities and experiences, and these identities interact in complex ways that are often overlooked by traditional approaches to discrimination. A single-axis framework erases the experiences of those with intersecting identities like Black women, trans Black women, Black lesbians, disabled Black women, etc. (Collins, 1990). While intersectionality has become an increasingly popular lens used in the field of public health and science, there is a lack of research examining the intersections of race, gender, and disability status (Saunders et al., 2010). The absence of research surrounding the interactions between these identities highlights the ever-growing issue of understanding the complexities of intersecting identities that are not considered the norm in healthcare. By examining how two or more of these identities intersect, healthcare providers can gain a better understanding of the unique needs of their patients and ensure that access to quality care is attainable. Research conducted by Saunders et al. (2010) has shown that intersectionality can be used to illuminate diverse inequalities and how power structures and processes give rise to them. For instance, their study found that patients living or dialyzing in neighborhoods with a greater proportion of Black

Americans were more likely to wait longer for a kidney transplant or to die on the waitlist. This is because access to transplantation may be shaped not only by clinical factors, but also by the social contexts of specific neighborhoods, such as individuals' social networks and social capital. Previous studies have explored the interactions between race and gender in healthcare (Nguyen et al., 2021; Norris & Nissenson, 2008; Rosenthal et al., 2020). In terms of the social determinants of health (SDOH) framework, a study by Wesselman et al. (2021) they stated that significant racial disparities in wait listing for transplant existed, specifically for Black individuals who were 25% less likely to be waitlisted or receive a transplant even after adjusting for medical factors and social determinants of health (Wesselman et al., 2021). Within the current literature, there are no known studies that have used disability models in their studies on kidney transplantation. This further exacerbates the disparities in access to kidney transplantation as patients with pre-existing disabilities are not being treated with a disability focused lens.

The Current Study

The objective of this study was to review the literature on how individuals with pre-existing disabilities navigate the steps to kidney transplantation. Furthermore, this study sought to explore whether ESRD patients with pre-existing disabilities and intersecting social identities such as race, gender, and income status access transplantation relative to those without intersecting identities. This study had two primary objectives: firstly, to determine if the barriers faced by individuals with pre-existing disabilities have been adequately addressed and, secondly, to examine whether race, gender, disability status, and other marginalized identities contribute to disparities in the various steps to transplantation. This study was the first systematic review to analyze pre-existing disability status, and access to transplantation while exploring the role of other intersecting social identities.

Methods

The review followed the protocol outlined by Traino et al. (2015) and utilized research databases; PubMed/Medline and APA PsycINFO. The systematic review adhered to PRISMA guidelines to ensure a thorough and rigorous analysis of the literature.

Inclusion criteria. Papers that met the following criteria were included: research must have been published after 2005, have been conducted in the United States of America, include participants 18 years old and older, be available in English, have quantitative or qualitative research designs, and the article must mention pre-existing disability status(es) (Traino et al., 2015). The study outlined the theories and models used to guide the analysis process. Disparities and obstacles at various steps to transplantation were all coded in the articles included in this systematic review (Traino et al., 2015).

Data extraction. Articles were identified using the following keywords: kidney transplantation, renal transplantation, intellectual disability(ies), developmental disabilities, disabled persons, learning disabilities, persons with mental disabilities, chronic kidney failure, communication disorders, vision disorders and renal insufficiency. The articles were verified with a librarian to ensure no studies was overlooked.

Results

Search engines, Pubmed and PsychNet were used to retrieve 1,214 articles. 508 of those articles were duplicates and 626 were excluded using the inclusion criteria. 80 articles were screened based on the inclusion criteria to which 38 articles were excluded. 42 studies were identified and were all able to be retrieved online. Of these articles, 18 were excluded since they were not conducted within the United States, 10 were excluded for involving adolescent participants, 8 were excluded for defining disability status as a result of CKD and transplantation, and 2 were excluded for not being written in English. In the final analysis, 4 studies fulfilled the inclusion criteria (see figure 1). These articles were coded for steps to transplantation, namely medical suitability, referral to a transplant center, waiting list, and receiving a transplant, barriers, and whether the articles used models and/or theories on disability and other marginalized identities. Four themes were identified: inequitable and restricted allocation of care due to impairments related to contraindications; problematic use of language; lack of explicit use of disability models; and a lack of reporting on other marginalized identities.

Inequitable and Restricted Allocation of Care

Two out of four of the extracted studies mentioned that levels of contraindications were a reason to deny recommendations and services for receiving an organ transplantation for patients with mild to severe genetic diseases and intellectual disabilities (Thomas et al., 2020; Wall et al., 2020). Thomas et al. (2020) highlighted how various impairments can lead to contraindications based on levels of visual, hearing, walking, and physical impairments. They discovered that visual impairments, in particular, were associated with prolonged hospitalization, prolonged length of stay, and mortality, which may be due to patients with broader classes of visual impairments having difficulty managing medications, leading to poorer adherence with immunosuppressive and non-transplant medication regimens. Wall et al. (2020) stated how a person’s level of severity for their disability was a reason to deny them a kidney transplant. If the disability was deemed too severe then healthcare providers had the authority to decide whether or not a kidney transplant should be given.

Use of Problematic Language

Problematic use of language was identified in three out of the four studies (Kluz et al., 2022; Wall et al., 2020; Uemura et al., 2005). All three studies described intellectual disabilities by referring to it as mental retardation. Given all three studies were conducted and published in a clinical setting, it is understood as an acceptable form of addressing persons with intellectual disabilities since mental retardation is still considered a medical term. In all studies that used this term they referred to the medical definition.

Lack of Explicit use of Disability Models

None of the 4 studies mentioned or reference any disability models or theories when providing treatment for disabled people. Additionally, no other theories, models, or frameworks were used other than statistical models. Regardless of whether the studies were a case study or quantitative research, there was no mention of disability models.

Lack of Reporting on Intersecting Identities

Two out of the four studies briefly reported on race, specifically Hispanic, African American, and Caucasian (Thomas et al., 2020; Uemura et al., 2005). Three out of the four studies reported on gender; however, they only reported on female participants and no other gender (Kluz et al., 2022; Thomas et al., 2020; Uemura et al., 2005). All four studies did not connect gender or race to disability status. All four studies did not look at interactions between different identities and focused primarily on reporting on different disabilities and impairments.

Discussion

The goal of the current study was to investigate how individuals with pre-existing disabilities navigate the process of kidney transplantation, and whether there are disparities in access to transplantation based on intersecting social identities such as race, gender, and income status. The following themes were identified: inequitable and restricted allocation of care due to impairments related to contraindications; problematic use of language; lack of explicit use of disability models; and a lack of reporting on other marginalized identities. Throughout all four studies, pre-existing disability status often impacted the kidney transplant process, further emphasizing the disparities faced by this population.

Of the four studies identified by this systematic literature review, half looked at the levels of contraindications as a determining factor for receiving resources and recommendations for a kidney transplant (Thomas et al., 2020; Wall et al., 2020). Contraindications are symptoms or medical conditions that can be a reason to deny services and/or treatment because it is deemed as potentially harmful for the recipient. Patients with pre-existing disabilities were often times denied a kidney transplant because their disability was seen as harmful if they received a transplant. Therefore, physicians were less likely to comply with a transplantation for adults if they deemed their condition too severe. Essentially this means that the classification of one's disability as a contraindication is reason to deny and/or restrict access to a kidney transplantation. To understand why this is a problem, it is important to mention how allocation of organs is conditional and inconsistent with adults compared to children. In Chen et al. (2017) they conducted a retrospective chart review of all children aged 0-18 years who underwent renal transplantation at their center between January 1, 2002 and June 30, 2012. They found that despite the children having intellectual disabilities, it was still not deemed as a contraindication to receiving a kidney transplantation. Wall et al. (2020) reported data on both adults and adolescents and stated that children with the same disabilities were considered to have less contraindications than adults despite the levels of severity in their intellectual disabilities. These findings indicated a notable discrepancy between adult and pediatric programs regarding the level of contraindication for pre-existing disabilities, specifically when looking at disabilities such as Down syndrome, Becker Muscular Dystrophy, DiGeorge Syndrome, and Wolf-Hirschhorn syndrome. Pediatric programs were less inclined to view these conditions as absolute contraindications to listing, except for Becker Muscular Dystrophy and severe intellectual disabilities which were more likely to be deemed as relevant contraindications to listing (Wall et al., 2020). A large part for why organ allocation is denied for people with disabilities is because it was widely believed that their life expectancy was already short independent from ESRD (Chen et al., 2017). Additionally, patients who are either younger or who do not have a disability are deemed as more ‘worthy’ of receiving a transplantation.

The study conducted by Thomas et al. (2020) sheds light on the difficulties faced by individuals with disabilities in accessing kidney transplantation services. The study reveals that vision, hearing, walking, and physical impairments can lead to contraindications, thereby reducing the chances of receiving a transplant. Interestingly, the study finds that patients with visual impairments may face greater challenges, as they may have difficulty managing medications and complying with immunosuppressive and non-transplant medication regimens. This could directly impact graft survival or indirectly lead to graft loss due to changes in immunosuppression prescribing and compliance. Another important finding of the study is that walking impairment is associated with an increased risk of mortality. This is consistent with previous research on older adults (Newman et al., 2006), highlighting the significance of mobility impairment in overall health outcomes. The challenges faced by individuals with disabilities go beyond their physical impairments. Factors such as socioeconomic status, race, gender, education, insurance problems, and the level of contraindication can also play a significant role in their ability to access transplantation services. Plantinga et al. (2012)

highlights how lack of support from a guardian or caretaker can further exacerbate these barriers. Therefore, it is crucial to address the multifaceted challenges faced by individuals with disabilities in accessing transplantation services. This involves not only addressing the physical impairments but also addressing the social determinants of health that can exacerbate these challenges.

Disability models and models/theories pertaining to marginalized people need to be utilized when treating and navigating their needs and experiences. As evidenced by the findings from this study, there is a significant gap in the research pertaining to the use of disability models being utilized as a framework in medical practice. Often times, the main disability model that has been utilized in medicine is the medical model which views disability as a medical condition that needs to be ‘cured’ in order to make the person ‘normal’ (Hogan, 2019). This means that healthcare providers have been examining and treating individuals with disabilities as a means of getting rid/making their disability less prominent rather than viewing their disability as a facet of their identity. There is a great need for alternative theories in mainstream psychology, medicine and healthcare overall, the social, cultural, political, and historical features of disability as traditional approaches have been inadequate. A great alternative to the medical model would be the incorporation of the social identity approach (SIA). The SIA is a research method that can help us understand how disability is experienced by individuals. According to Dirth and Branscombe (2018), the social category of disability has a significant impact on how individuals experience disability from a psychological perspective. In other words, the way society views and categorizes disability can have a profound impact on how people with disabilities see themselves and their place in the world. Using the SIA can help researchers better understand the complex social and psychological factors that influence the experiences of individuals with disabilities.

Medical and psychological health providers can gain a deeper understanding of the experiences of individuals with disabilities and provide more effective and inclusive care by putting in extra effort to understand their patients, tailoring communication efforts specific to each patient, getting to know them on an emotional level, and improving personal and systemic organizational skills to ensure both provider and patient are not stressed (Ee et al., 2022). Disability models, such as the minority disability model and the social model of disability, help to address the unique challenges and barriers faced by marginalized individuals with disabilities (Disabled World, 2020). These models emphasize the importance of considering the social and environmental factors that contribute to disability and the need to address systemic and structural issues that prevent full participation in society (Snyder et al., 2008). By utilizing disability models in medicine and psychology, healthcare providers can tailor their interventions to address the specific needs of individuals with disabilities and promote greater equity and inclusion. This approach helps to move away from the traditional medical model that focuses solely on the individual's impairments and limitations and towards a more holistic and inclusive approach that considers the broader social and cultural context of disability.

The use of problematic terms to describe patients' conditions in medical research can have a significant impact on their treatment. As highlighted by Kluz et al. (2022), Uemura et al. (2005), and Wall et al. (2020), such language can further alienate people with disabilities and categorize them as "the other." This can lead to stigmatization and discrimination, which can ultimately affect their access to appropriate medical care and treatment. In addition, the use of such language can perpetuate negative attitudes and stereotypes towards people with disabilities, which can create additional barriers to their treatment and care. Therefore, it is important for medical researchers to be mindful of the language they use when describing patients' conditions and to ensure that it does not contribute to further marginalization and discrimination. What was most alarming were the dates of publication for these studies that used these terms, especially with the most recent of the studies being published just last year (2022). Most of the journals that these researchers published from explicitly stated in their guidelines that inclusive language that acknowledges diversity must be used (Kahlan et al., 2022). Yet throughout these studies the terminology was problematic.

The American Medical Association (AMA) acknowledges the harmful consequences of some commonly used words and phrases and offers equity-centered alternatives. They emphasize that language evolves over time, and words come in and out of favor, and that context also matters. The AMA recognizes that pursuing equity requires disavowing words that are rooted in systems of power that reinforce discrimination and exclusion. However, despite their efforts, the AMA still engages in the use of problematic and exclusionary language. For example, the term "mentally retarded" has been replaced with "intellectual disability," yet two studies (Kluz et al., 2022; Wall et al., 2020) included in the research still use the outdated and offensive term despite AMA having updated their guidelines since 2021. In addition, the AMA equity guide states alternative terms and phrases to use when referring to people with disabilities. This demonstrates that while the AMA recognizes the importance of language in promoting equity, there is still work to be done to fully implement their guidelines and to create a more inclusive and equitable healthcare system. According to the American Psychology Association (2021), psychologists are expected to strive for accurate, unbiased communication in their language use. In the APA’s language inclusivity guidelines, they explicitly state the terms to avoid using when describing or referring to people with disabilities and provides suggested terms and phrases to use instead. The studies cited in the text all emphasize the importance of using inclusive and ethical language, yet they still use problematic and exclusionary terms. Using the APA guide (2021) of inclusive language use, it suggests that instead of using historically dehumanizing language, better terms to use include but are not limited to "intellectual disability," “person with a disability, "and “people with intellectual disabilities.”

By using inclusive language, this allows for individuals with mental and/or physical disabilities to be seen as they are and not have their disability be perceived as a problem that needs to be cured or fixed. A study conducted by Stauffer et al. (2022) examined the technical standards from newly established medical schools in the US and evaluated their disability inclusivity practices. The study found that newly created technical standards are more restrictive since they perpetuate historically restrictive technical standards that serve as barriers to applicants with disabilities than those in previous studies, and efforts to create more inclusive standards have not yet been realized. The study highlighted the need for more inclusive technical standards in newly established medical schools to promote disability inclusivity and accommodate students with disabilities. It also emphasized the importance of accrediting bodies to play a more active role in ensuring that technical standards are readily available and appropriately convey the availability of reasonable accommodations for students with disabilities. Despite the well-known barriers that exist for individuals with disabilities, there still seems to be a lack of implementation and awareness to address these barriers and ensure equitable treatment.

The insufficient reporting on marginalized identities in all four studies highlights the need for diversity and inclusion in research to ensure all are being served and equitably seen. The studies revealed a significant lack of attention to intersectional disparities in the kidney transplant process for individuals with pre-existing disabilities and intersectional identities. This may result in a two-way relationship where inadequate use of disability models and lack of reporting on minoritized identities, like being a woman or a person of color, can lead to limited resource allocation for people with disabilities, resulting in a reduced likelihood of kidney transplantation. The limited focus on medical aspects in the retrieved studies neglects the social models that can significantly impact the needs of patients with disabilities. This is significant because social models can help identify and address barriers to healthcare access and treatment for people with disabilities, such as discrimination, stigma, and lack of accommodation. These models would account for other aspects of identities, especially minoritized identities. Neglecting social models can lead to inadequate care and hinder the overall well-being of patients with disabilities. Therefore, it is crucial to acknowledge and address these limitations in future research to ensure that patients with disabilities receive inclusive and comprehensive care that meets their social and medical needs.

There are several limitations to this systematic review. Firstly, by only including studies conducted in the United States and articles written in English, a complete understanding of how disability models are utilized in other cultures across the world could not be obtained. Additionally, limited discussion on the themes and purpose of this study with other lab members may have led to the oversight of potential themes and solutions. Furthermore, only two search engines were utilized, which may have resulted in some relevant articles being overlooked. As a result, the findings of this systematic review may not fully represent the breadth of disability research conducted between 2005 and 2023. However, to mitigate this limitation, a librarian reviewed the study to ensure that relevant research was not overlooked.

To address obstacles in access to transplantation for ESRD patients, it is crucial to conduct research on diverse samples using a minority disability model framework. This approach allows us to gain a better understanding of the unique experiences and challenges faced by individuals from marginalized communities and develop targeted interventions to address these issues. Unfortunately, research has historically disregarded people with marginalized identities and pre-existing disabilities, leading to significant health disparities and inequities in access to transplantation. By excluding these populations, we miss out on critical insights into how to improve the transplant process for all patients. These findings underscore the importance of adopting models and frameworks that consider disability and other marginalized identities in ESRD research. By doing so, we can provide a more holistic approach to care that considers the diverse needs of all patients. This will help us make progress towards reducing health disparities and ensuring equitable access to transplantation for all.

References

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PloS one*, *8*(8), e70855. https://doi.org/10.1371/journal.pone.0070855

Almeida, N., Almeida, R. F., Almeida, K., & Almeida, A. (2016). Attitude of medical professionals regarding controversial issues in kidney donation/transplantation. *Indian Journal of Nephrology*, *26*(6), 393–397. https://doi.org/10.4103/0971-4065.176147

AMA. (2021). Advancing health equity: Guide on language, narrative and concepts. *American Medical Association and Association of American Medical Colleges.* https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf

APA. (2021). Inclusive language guidelines. *American Psychological Association.* https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf

Axelrod, D. A., Dzebisashvili, N., Schnitzler, M. A., Salvalaggio, P. R., Segev, D. L., Gentry, S. E., Tuttle-Newhall, J., & Lentine, K. L. (2010). The interplay of socioeconomic status, distance to center, and inter donor service area travel on kidney transplant access and outcomes. *Clinical Journal of the American Society of Nephrology*, *5*(12), 2276–2288. https://doi.org/10.2215/CJN.04940610

Bal, M. M., & Saikia, B. (2007). Gender bias in renal transplantation: Are women alone donating kidneys in India? *Transplantation Proceedings*, *39*(10), 2961–2963. https://doi.org/10.1016/j.transproceed.2007.08.089

Battulga, B., Benjamin, M. R., Chen, H., & Bat-Enkh, E. (2021). The impact of social support and pregnancy on subjective well-being: A systematic review. *Frontiers in Psychology*, *12*, 710858. https://doi.org/10.3389/fpsyg.2021.710858

Bentall, A. (2021). What is kidney disease? An expert explains. *Mayo Clinic.* https://www.mayoclinic.org/diseases-conditions/chronic-kidney-disease/symptoms-causes/syc-20354521

Bharmal, N., Derose, K. P., Felician, M., & Weden, M. M. (2015). Understanding the upstream social determinants of health. *California: RAND*, 1-18. https://www.rand.org/content/dam/rand/pubs/working_papers/WR1000/WR1096/RAND_WR1096.pdf

Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of Social Issues, 75*(3), 650-664. https://doi.org/10.1111/josi.12354

Braveman, P., & Gottlieb, L. (2014). The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports*, *129*(2), 19-31. https://doi.org/10.1177/00333549141291S206

CDC. (2021). Chronic kidney disease in the United States. *Centers for Disease Control and Prevention*. https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html

CDC. (2022). Disability impacts all of us infographic. *Centers for Disease Control and Prevention.* https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

Chen, A., Ahmad, M., Flescher, A., Freeman, W. L., Little, S., Martins, P. N., ... & Ladin, K. (2020). Access to transplantation for persons with intellectual disability: strategies for nondiscrimination. *American Journal of Transplantation*, *20*(8), 2009-2016. https://doi.org/10.1111/ajt.15755

Chen, A., Farney, A., Russell, G. B., Nicolotti, L., Stratta, R., Rogers, J., & Lin, J. J. (2017). Severe intellectual disability is not a contraindication to kidney transplantation in children. *Pediatric Transplantation*, *21*(3), e12887. https://doi.org/10.1111/petr.12887

Collins, P. H. (1990). *Black feminist thought : Knowledge, consciousness, and the politics of empowerment*. Boston, MA: Unwin Hyman.

Collister, D., Saad, N., Christie, E., & Ahmed, S. (2021). Providing care for transgender persons with kidney disease: A Narrative Review. *Canadian Journal of Kidney Health and Disease*, *8*, 2054358120985379. https://doi.org/10.1177/2054358120985379

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum, 1989*(1), 139-167.

Dageforde, L. A., Box, A., Feurer, I. D., & Cavanaugh, K. L. (2015). Understanding patient barriers to kidney transplant evaluation. *Transplantation*, *99*(7), 1463. https://doi.org/10.1097/TP.0000000000000543

DiMaria, C. (2022). What you need to know about end-stage kidney disease (ESRD). *Healthline.* https://www.healthline.com/health/end-stage-kidney-disease

Dirth, T. P., & Branscombe, N. R. (2018). The social identity approach to disability: Bridging disability studies and psychological science. *Psychological Bulletin*, *144*(12), 1300. https://doi.org/10.1037/bul0000156

Disabled World. (2022). Models of disability: Types and definitions. https://www.disabledworld.com/definitions/disability-models.php

Eagly, A., & Wood, W. (2012). Social role theory. In P. A. M., Van-Lange, A. W., Kruglanski, & T. E., Higgins (Eds), *Handbook of theories of social psychology: Volume 2* (pp. 458-476) Newbury Park, California: SAGE Publications.

Ee, J., Stenfert Kroese, B., & Rose, J. (2022). Experiences of mental health professionals providing services to adults with intellectual disabilities and mental health problems: A systematic review and meta-synthesis of qualitative research studies. *Journal of Intellectual Disabilities, 26*(3), 758–781. https://doi.org/10.1177/17446295211016182

Gordon, E. J., Ladner, D. P., Caicedo, J. C., & Franklin, J. (2010). Disparities in kidney transplant outcomes: A review. *Seminars in Nephrology*, *30*(1), 81–89. https://doi.org/10.1016/j.semnephrol.2009.10.009

Harding, J. L., Perez, A., Snow, K., Retzloff, S., Urbanski, M., White, M. S., & Patzer, R. E. (2021). Non-medical barriers in access to early steps of kidney transplantation in the United States–A scoping review. T*ransplantation Reviews, 35*(4), 100654. https://doi.org/10.1016/j.trre.2021.100654

Harris, R. C., & Zhang, M. Z. (2020). The role of gender disparities in kidney injury. A*nnals of Translational Medicine, 8*(7), 514. https://doi.org/10.21037/atm.2020.01.23

Hashmi M.F., Benjamin O., Lappin S.L. (2022). *End-stage renal disease.* Treasure Island, FL: StatPearls Publishing.

Hogan, A. J. (2019) Social and medical models of disability and mental health: Evolution and renewal. *Canadian Medical Association Journal, 191*(1)*,* E16-E18. https://doi.org/10.1503/cmaj.181008

Kahlan, K.D., Johnson, B., Abbud-Filho, M., Akbulut, S., Argani, H., Schelotto, P. B., Batisti, J.,… Zimmerman, M. A. (2022). Transplantation proceedings. *Elsevier.* 1-18. Retrieved from https://www.elsevier.com/journals/transplantation-proceedings/0041-1345?generatepdf=true

Kang, S. H., Do, J. Y., & Kim, J. C. (2021). The relationship between disability and clinical outcomes in maintenance dialysis patients. *Yeungnam University journal of medicine*, *38*(2), 127–135. https://doi.org/10.12701/yujm.2020.00346

Kaplan, D. (2000). The definition of disability: Perspective of the disability community. *Journal of Health Care Law & Policy, 3*(2), 352–364. http://digitalcommons.law.umaryland.edu/jhclp/vol3/iss2/5

Katz-Greenberg, G., & Shah, S. (2022). Sex and gender differences in kidney transplantation. *Seminars in Nephrology*, *42*(2), 219–229. https://doi.org/10.1016/j.semnephrol.2022.04.011

Kennedy, J., Wood, E. G., & Frieden, L. (2017). Disparities in insurance coverage, health services use, and access following implementation of the affordable care act: A comparison of disabled and nondisabled working-age adults. *Inquiry*, *54*, 46958017734031. https://doi.org/10.1177/0046958017734031

King, A., Lopez, F. Y., Lissanu, L., Robinson, E., Almazan, E., Metoyer, G., Tanumihardjo, J., ... Saunders, M. (2020). Renalreplacement knowledge and preferences for African Americans with chronic kidney disease. *Journal of renal care*, *46*(3), 151–160. https://doi.org/10.1111/jorc.12312

Kluz, A., Gozdowska, J., Domagała, P., & Durlik, M. (2022, May). Kidney transplantation in a patient with tuberous sclerosis complex: A case report. *Transplantation Proceedings* 54(4), 1148-1151. https://doi.org/10.1016/j.transproceed.2022.02.055

Kovesdy C. P. (2022). Epidemiology of chronic kidney disease: an update 2022. Kidney international supplements, 12(1), 7–11. https://doi.org/10.1016/j.kisu.2021.11.003

Ku, E., Lee, B. K., McCulloch, C. E., Roll, G. R., Grimes, B., Adey, D., & Johansen, K. L. (2020). Racial and ethnic disparities in kidney transplant access within a theoretical context of medical eligibility. *Transplantation*, *104*(7), 1437–1444. https://doi.org/10.1097/TP.0000000000002962

Levey, A. S., Atkins, R., Coresh, J., Cohen, E. P., Collins, A. J., Eckardt, K. U., ... & Eknoyan, G. (2007). Chronic kidney disease as a global public health problem: Approaches and initiatives–A position statement from kidney disease improving global outcomes. *Kidney International*, *72*(3), 247-259. https://doi.org/10.1038/sj.ki.5002343

Liu, M., Li, X. C., Lu, L., Cao, Y., Sun, R. R., Chen, S., & Zhang, P. Y. (2014). Cardiovascular disease and its relationship with chronic kidney disease. *European Review for Medical and Pharmacological Sciences*, *18*(19), 2918–2926.

Manton, B., & Poulton, C. J. (2013). African-American attitudes toward kidney transplant: A comparative analysis. *Journal of Nephrology Social Work, 37*, 19-28.

McGee, J., Jackson, N. R., & Slakey, D. P. (2012). Disability and kidney transplantation in the United States. *Clinical Transplantation*, *26*(3), 377-381. https://doi.org/10.1111/j.1399-0012.2012.01612.x

McPherson, L. J., Hamoda, R. E., & Patzer, R. E. (2019). Measuring patient knowledge of kidney transplantation: An initial step to close the knowledge gap. *Transplantation*, *103*(3), 459–460. https://doi.org/10.1097/TP.0000000000002350

Navaneethan, S. D., & Singh, S. (2006). A systematic review of barriers in access to renal transplantation among African Americans in the United States. *Clinical transplantation*, *20*(6), 769–775. https://doi.org/10.1111/j.1399-0012.2006.00568.x

Newman, A. B., Simonsick, E. M., Naydeck, B. L., Boudreau, R. M., Kritchevsky, S. B., Nevitt, M. C., Pahor, M., … Harris, T. B. (2006). Association of long-distance corridor walk performance with mortality, cardiovascular disease, mobility limitation, and disability. *JAMA*, *295*(17), 2018–2026. https://doi.org/10.1001/jama.295.17.2018

NIDDK. (2021). Kidney disease statistics for the United States. *National Institute of Diabetes and Digestive and Kidney Diseases*. https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease

Ng, Y. H., Pankratz, V. S., Leyva, Y., Ford, C. G., Pleis, J. R., Kendall, K., Croswell, E., … Myaskovsky, L. (2020). Does racial disparity in kidney transplant wait listing persist after accounting for social determinants of health? *Transplantation*, *104*(7), 1445–1455. https://doi.org/10.1097/TP.0000000000003002

Nguyen, T., Sise, M. E., Delgado, C., Williams, W., Reese, P., & Goldberg, D. (2021). Race, education, and gender disparities in transplantation of kidneys from hepatitis C viremic donors. *Transplantation*, *105*(8), 1850-1857. https://doi.org/10.1097/TP.0000000000003511

Norris, K., & Nissenson, A. R. (2008). Race, gender, and socioeconomic disparities in CKD in the United States. *Journal of the American Society of Nephrology*, *19*(7), 1261–1270. https://doi.org/10.1681/ASN.2008030276

Palleti, S. K., Avula, S., & Dewan, S. Kidney. (2023) A review on end stage renal disease, dialysis and transplant. *International Clinical and Medical Case Reports Journal, 2*(10), 1-8. https://doi.org/10.5281/zenodo.7791286

Pinals, D. A., Hovermale, L., Mauch, D., & Anacker, L. (2022). Persons with intellectual and developmental disabilities in the mental health system: Part 2. Policy and systems considerations. *Psychiatric Services*, *73*(3), 321-328. https://doi.org/10.1176/appi.ps.201900505

Plantinga, L. C., Johansen, K., Crews, D. C., Shahinian, V. B., Robinson, B. M., Saran, R., Burrows, N. R., … CDC CKD Surveillance Team (2011). Association of CKD with disability in the United States. *American Journal of Kidney Diseases*, *57*(2), 212–227. https://doi.org/10.1053/j.ajkd.2010.08.016

Plantinga, L. C., Johansen, K. L., Schillinger, D., & Powe, N. R. (2012). Lower socioeconomic status and disability among US adults with chronic kidney disease, 1999-2008. *Preventing Chronic Disease, 9,* E12. http://dx.doi.org/10.5888/pcd9.110052

Purnell, T. S., Hall, Y. N., & Boulware, L. E. (2012). Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. *Advances in Chronic Kidney Disease*, *19*(4), 244–251. https://doi.org/10.1053/j.ackd.2012.01.008

Purnell, T. S., Luo, X., Cooper, L. A., Massie, A. B., Kucirka, L. M., Henderson, M. L., Gordon, E. J., … Segev, D. L. (2018). Association of race and ethnicity with live donor kidney transplantation in the United States from 1995 to 2014. *JAMA*, *319*(1), 49–61. https://doi.org/10.1001/jama.2017.19152

Rosenthal, L., & Lobel, M. (2020). Gendered racism and the sexual and reproductive health of Black and Latina women. *Ethnicity & Health*, *25*(3), 367-392. https://doi.org/10.1080/13557858.2018.1439896

Safer, J. D., Coleman, E., Feldman, J., Garofalo, R., Hembree, W., Radix, A., & Sevelius, J. (2016). Barriers to healthcare for transgender individuals. *Current Opinion in Endocrinology, Diabetes, and Obesity*, *23*(2), 168–171. https://doi.org/10.1097/MED.0000000000000227

Salas, M. A. P., Chua, E., Rossi, A., Shah, S., Katz-Greenberg, G., Coscia, L., ... & Adey, D. (2022). Sex and gender disparity in kidney transplantation: Historical and future perspectives. *Clinical Transplantation*, *36*(12), e14814. https://doi.org/10.1111/ctr.14814

Samuels, J., Connelly, K., & Tangri, N. (2022). Risk prediction in chronic kidney disease. *Evidence-Based Nephrology*, *1,* 60-71. https://doi.org/10.1002/9781119105954.ch5

Saunders, M. R., Cagney, K. A., Ross, L. F., & Alexander, G. C. (2010). Neighborhood poverty, racial composition and renal transplant waitlist. *American Journal of Transplantation*, *10*(8), 1912-1917. https://doi.org/10.1111/j.1600-6143.2010.03206.x

Senn, L., Wehmeier, C., Hönger, G., Geiger, I., Amico, P., Hirt-Minkowski, P., ... & Schaub, S. (2021). Outcome of husband-to-wife kidney transplantation with mutual children: Single center experience using T cell-depleting induction and review of the literature. *Frontiers in Medicine, 8*, 724851. https://doi.org/10.3389/fmed.2021.724851

Shah, S., Leonard, A. C., Meganathan, K., Christianson, A. L., & Thakar, C. V. (2018). Gender and racial disparities in initial hemodialysis access and outcomes in incident end-stage renal disease patients. *American Journal of Nephrology*, *48*, 4-14. https://doi.org/10.1159/000490624

Snyder, A. R., Parsons, J. T., Valovich McLeod, T. C., Curtis Bay, R., Michener, L. A., & Sauers, E. L. (2008). Using disablement models and clinical outcomes assessment to enable evidence-based athletic training practice, part I: Disablement models. *Journal of Athletic Training*, *43*(4), 428–436. https://doi.org/10.4085/1062-6050-43.4.428

Stauffer, C., Case, B., Moreland, C. J., & Meeks, L. M. (2022). Technical standards from newly established medical schools: A review of disability inclusive practices. *Journal of Medical Education and Curricular Development*, *9*, 23821205211072763. https://doi.org/10.1177/23821205211072763

Sullivan, C., Leon, J. B., Sayre, S. S., Marbury, M., Ivers, M., Pencak, J. A., ... & Navaneethan, S. D. (2012a). Impact of navigators on completion of steps in the kidney transplant process: a randomized, controlled trial. *Clinical Journal of the American Society of Nephrology*, *7*(10), 1639-1645. https://doi.org/10.2215/CJN.11731111

Sullivan, D. C., Mirmalek-Sani, S. H., Deegan, D. B., Baptista, P. M., Aboushwareb, T., Atala, A., & Yoo, J. J. (2012b). Decellularization methods of porcine kidneys for whole organ engineering using a high-throughput system. *Biomaterials, 3*3(31)*,* 7756-7764. https://doi.org/10.1016/j.biomaterials.2012.07.023

Thom, R. L., Dalle-Ave, A., Bunnik, E. M., Krones, T., Van-Assche, K., Ruck Keene, A., & Cronin, A. J. (2022). Inequitable access to transplants: Adults with impaired decision-making capacity. *Nephrology Dialysis Transplantation*, *35*, 10084. https://doi.org/10.3389/ti.2022.10084

Thomas, A. G., Ruck, J. M., Chu, N. M., Agoons, D., Shaffer, A. A., Haugen, C. E., ... & McAdams-DeMarco, M. (2020). Kidney transplant outcomes in recipients with visual, hearing, physical and walking impairments: A prospective cohort study. *Nephrology Dialysis Transplantation*, *35*(7), 1262-1270. https://doi.org/10.1093/ndt/gfz164

Uemura, T., Sanchez, E. Q., Ikegami, T., Watkins, D., Narasimhan, G., McKenna, G. J., & Klintmalm, G. B. (2005). Successful combined liver and kidney transplant for COACH syndrome and 5-yr follow-up. *Clinical Transplantation*, *19*(6), 717-720. https://doi.org/10.1111/j.1399-0012.2005.00409.x

Wall, A., Lee, G. H., Maldonado, J., & Magnus, D. (2020). Genetic disease and intellectual disability as contraindications to transplant listing in the United States: A survey of heart, kidney, liver, and lung transplant programs. *Pediatric Transplantation*, *24*(7), e13837. https://doi.org/10.1111/petr.13837

Wesselman, H., Ford, C. G., Leyva, Y., Li, X., Chang, C. C. H., Dew, M. A., ... & Myaskovsky, L. (2021). Social determinants of health and race disparities in kidney transplant. *Clinical Journal of the American Society of Nephrology, 16*(2), 262-274. https://doi.org/10.2215/CJN.04860420

Woolf, S. H., Aron, L. Y., Dubay, L., Simon, S. M., Zimmerman, E., & Luk, K., Virginia Commonwealth University, & Urban Institute. (2015). How are income and wealth linked to health and longevity? *Virginia Commonwealth University, Center on Society and Health*. http://societyhealth.vcu.edu/media/society-health/pdf/IHIBrief1.pdf.

Zhang, Y., Gerdtham, U. G., Rydell, H., & Jarl, J. (2018). Socioeconomic inequalities in the kidney transplantation process: A registry-based study in Sweden. *Transplantation Direct*, *4*(2), e346. https://doi.org/10.1097/TXD.0000000000000764

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only

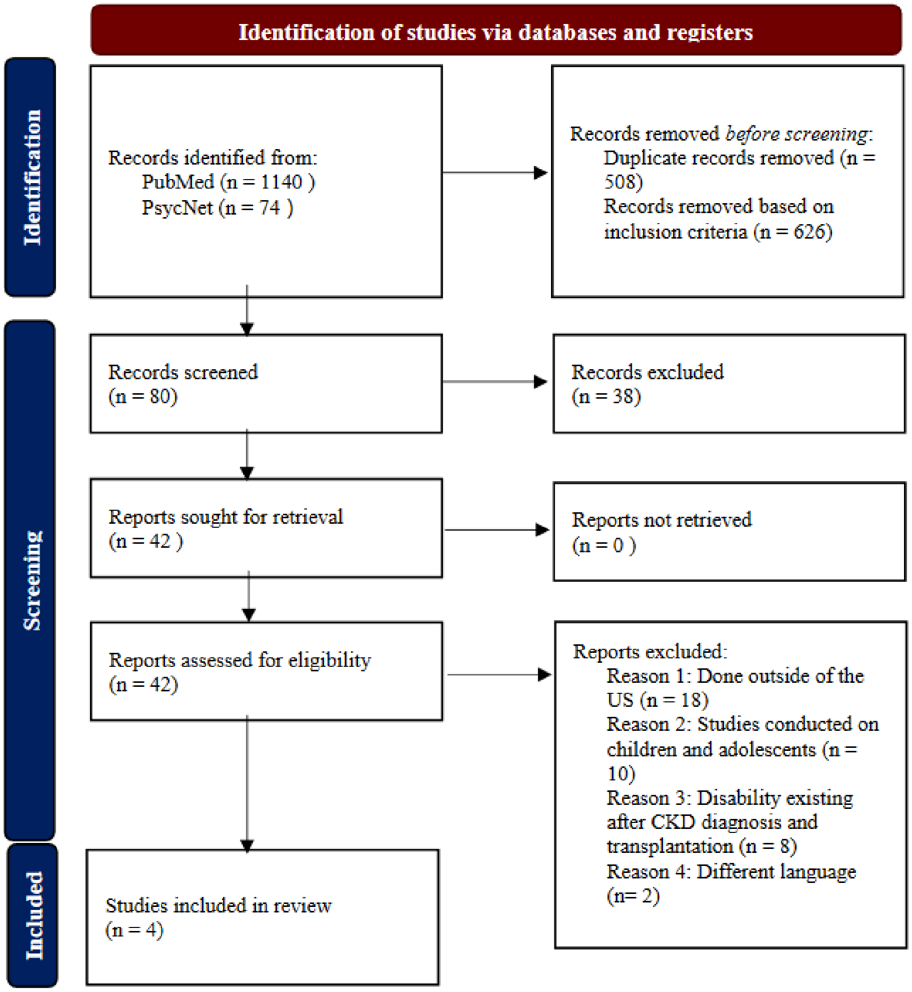

Figure 1: PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only.