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# Can Focusing on Self-Care Reduce Disparities in Kidney Transplant Outcomes?

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## INTRODUCTION

Considerable scholarly attention has been paid to examining racial and ethnic disparities in organ transplantation, notably access to transplantation and organ allocation. Less discussion has been directed toward the disparities in transplant outcomes: of both patient and graft survival. Patient and graft survival can be attributed to a diverse array and interplay of biological and sociocultural factors. This report focuses on one factor, self-care, as a new approach for examining transplant outcomes. More importantly, this article highlights how self-care may identify and reduce social disparities in long-term transplant outcomes.

## KIDNEY TRANSPLANT OUTCOMES

Kidney loss in the first 10 years following transplantation remains a significant problem despite tremendous scientific advances in treating acute and chronic rejection. This problem is pressing because kidney transplantation is the treatment of choice for most patients with end-stage renal disease (ESRD) and because the shortage of transplantable kidneys provides a moral and societal imperative to optimize their use. Physicians have proposed that attention be directed toward the prevention of chronic allograft nephropathy (CAN) (1), the leading cause of late graft failure (2). CAN refers to a progressive decline in renal function associated with both alloantigen-dependent and alloantigen-independent factors (3). Prevalence rates of CAN vary from 81% to 86% (4). Patients can play a vital role in limiting the progression of CAN by engaging in self-care activities.

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## WHAT IS SELF-CARE?

Self-care refers to “the range of behavior[s] undertaken by individuals to promote or restore their health” (5). Self-care encompasses more than just adherence to medications, and includes how patients follow dietary recommendations, monitor symptoms, maintain physical function, execute medical regimens, and make decisions about seeking care (6). Self-care behaviors associated with proper management of the kidney transplant include include: taking immunosuppressive medications; staying well-hydrated; following a low salt, low fat, and low cholesterol diet; vigilant monitoring of vital signs and symptoms of infection or rejection; exercising; wearing sun protection; and avoiding contact with people who are ill (7). Those who are less able to care for themselves will likely have lower graft survival. For example, noncompliance is the third leading cause of graft loss (8). In addition, evidence suggests that physical exercise training after kidney transplantation diminishes risk factors for cardiovascular disease (9). These self-care practices must begin immediately following transplantation. Yet the typical 4-day hospital length of stay following transplantation (10) may be insufficient time for providers to adequately instruct patients on appropriate self-care.

### Self-Care Programs: Methods and Limitations

Efforts undertaken by transplant programs to routinely foster post-transplant self-care are limited, suggesting relatively little attention to this need. Most programs focus on improving compliance through participation in social support groups (11–14), and distributing educational pamphlets (10). Other transplant programs help identify social network resources (15), and provide assistance in finding employment (16) to improve patient quality of life and foster patient empowerment. Both methods have been shown to be cost-effective (17).

Other efforts include the use of a clinical pharmacist to provide counseling to patients and recommendations to nephrologists about medication therapy to enhance compliance (18); providing education about disease prevention and dietary counseling, and cholesterol and cancer screenings (19); and behavioral interventions promoting medication and mind-body therapies to enhance well-being (20).

These programs have several limitations, including using single intervention strategies, focusing on one aspect of self-care rather than comprehensively addressing patient needs, and sponsoring programs at the transplant center instead of being home-based. Further, minimal work has been directed toward the self-care needs of minorities. There is also a lack of systematic program evaluation (e.g., 10,14,15). Addressing these specific limitations would help to improve current and future programs.

## DISPARITIES IN SURVIVAL

A disconcerting feature of kidney loss is the racial/ethnic and socioeconomic differences in kidney survival rates that result in disparities in graft outcomes. Some patient groups have higher rates of CAN depending on the immunosuppression regimen. With tacrolimus, the mean time to CAN was shorter in African American than white recipients (18 vs. 37 months), although the incidence of CAN was comparable (21). With cyclosporine, lower graft survival occurs among the elderly (22), males (23), and African Americans (24–26). In the long-term (> 3 years), African American recipients experience a 5% to 15% lower graft survival rate than whites (27). The half-lives for deceased donor kidneys in adult African American and white recipients are 8 years and 14 years, respectively (28). The 3- and 5-year unadjusted graft survival rates by race/ethnicity are: 81% and 69% for whites, 73% and 57% for African Americans, and 84% and 69% for Hispanics/Latinos (29).

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The basis of these demographic correlates of lower survival rates is unclear. Reports attribute increased incidence of graft loss in African American and older male recipients to immunologic and nonimmunologic factors, e.g., HLA mismatching and ischemic time (27). Even after controlling for these factors, African Americans were 1.7 times as likely as whites to suffer graft failure over 9 years, which suggests that socioeconomic or behavioral factors contribute to racial/ethnic disparities in outcomes (25). Reports also attribute lower survival rates to social factors including, noncompliance with immunosuppressants, insurance status, and low socioeconomic status (26,27).

### Reframing the Problem

The orientation of the post-transplant literature has been narrow in its effort to examine this problem. It has focused on reactive, clinical efforts by transplant professionals to prevent graft rejection (e.g., 30), rather than on proactive, behavioral measures taken by recipients to promote their kidney function. The focus on the medical determinants of kidney rejection has diverted attention away from factors promoting kidney survival. Re-framing the problem to examine patients' post-transplant behavior as proactive efforts to sustain health can enable investigators to better understand what makes some kidneys last longer than others. Thus, focused attention to self-care by transplant recipients is warranted to help explain disparities in long-term survival.

## DISPARITIES IN SELF-CARE

Since self-care is essential to the survival of the kidney, it may help explain sociodemographic disparities in survival rates. Evidence suggests that there are disparities in self-care practices and in the factors influencing self-care. Studies show that kidney transplant self-care practices are affected by financial resources, social support factors, and culturally-shaped health beliefs and attitudes (31–33), and these resources for self-care are not equitably distributed in the population. Consequently, engagement in and capacity for self-care varies by race/ethnicity and insurance coverage (34).

Financial constraints can adversely affect patients' capacity to maintain a kidney transplant. Medicaid patients had lower graft survival than patients with private insurance (35); and low-income patients were more likely to experience allograft failure after one and five years of graft function than patients with an adequate income (36). Most studies have found that the high costs of immunosuppressive medications and limited insurance coverage results in noncompliance (37). Immunosuppressive medications are expensive even for patients with adequate health insurance (38), with co-payments of approximately $167-$233 per month (38).

Insurance coverage among kidney recipients varies by ethnicity and type of coverage, resulting in a differential ability to have access to medications, which in turn affects engagement in self-care practices. For example, 31% of whites compared to 16% of blacks had private insurance in one study (35). A review of United Network for Organ Sharing data on 9,398 cadaveric renal transplants revealed the insurance coverage for medical care varied by insurance type as follows: 68% Medicare, 25% private insurance, and 5% Medicaid (35). Over 12% of the ESRD population are not eligible for Medicare and rely on Medicaid instead (39). Eligibility remains an issue for the Medicaid-only population (39). To compensate for limited financial support, some kidney recipients share medications with other patients, or work 'under the table' to increase income (31,40). Financial resources may also impact other aspects of self-care, such as having time for exercise or being able to purchase high nutritional value foods.

Another contributing factor to self-care behaviors is social support and the informal care network. Social support refers to "the resources provided by other persons" (41) that "lead the

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subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations" (42). Among hemodialysis patients and other organ transplant recipients, there is evidence that social support affects patient survival (43,44), adaptation to dialysis (45), number of comorbid conditions (46), adherence to dialysis (47), and even access to kidney transplantation (48). Little is known about the effects of social supports, e.g., family and friends, on kidney recipients' medical outcomes. However, evidence that less social support among kidney recipients contributes to noncompliance includes: being single (31), and a lower ability to participate in social activities (49). Also, living-donors who often provide social support may ensure that recipients take their medications (50). While there is not yet empirical support, members of a patient's social support network may affect transplant outcomes by providing patients with information on how to follow medical regimens; financial assistance to purchase medications and other daily needs; and physical assistance including transporting patients to visit doctors. Research is needed to both determine whether the availability, size, and functions of social support are associated with self-care, and whether social disparities exist in these social support factors which may help explain differential transplant outcomes.

Finally, the patients' preferences and beliefs contribute to their self-care practices. Patient self-care practices, particularly for chronic illness management, are fundamentally shaped by cultural beliefs, values, and attitudes, and are usually expressed in a framework of explanatory models (51). Explanatory models refer to ideas about etiology, symptom onset, pathophysiology, course, and treatment for episodes of illness (52). Although no studies have directly examined perceptions and attitudes related to self-care for this population, Becker and colleagues (53) have found that many Latino patients with chronic illnesses often do not subscribe to mainstream cultural values embedded in the US medical system regarding individual responsibility for taking care of chronic illness, and believe that medication alone, rather than self-care practices like diet and exercise, control illness.

Accordingly, diverse ethnic and cultural groups will have different self-care practices that may result in disparate transplant outcomes. Retrospective surveys and interviews have examined kidney recipients' beliefs contributing to noncompliance by race/ethnicity and found that African American and Hispanic American patients were more likely than Anglo American patients to believe that: a) the transplant was functioning so well that immunosuppressants were not needed, b) immunosuppressants remain active in the body for several days thus requiring less intake, and c) immunosuppressants were no longer needed when the dosage was reduced (33). No research has specifically examined kidney transplant recipients' more comprehensive explanatory models about managing their symptoms, promoting their health, or preventing CAN. However, it is highly likely that different ethnic and cultural beliefs will emerge about: a) kidney physiology, b) the risks and causes of CAN, c) the process of CAN, and d) appropriate treatments for symptoms of infection and side effects from immunosuppression. Such varying beliefs and values may have a differential impact on patients' self-care activities and actual graft outcomes. The research on noncompliance generally supports the conclusion that African Americans and Hispanic Americans are significantly more likely to be noncompliant than Anglo Americans (26,33), although findings are not consistent (54).

## LIMITATIONS

Critics may argue that a focus on self-care blames the victim for poor health outcomes (55). While self-care is not entirely causal of outcomes, it is critical to the success of kidney transplantation. The relative impact of self-care on graft survival is as yet unknown. It is certainly the case that individuals who practice self-care may still experience adverse outcomes. We argue that attributing CAN to patients' volitional behaviors can be minimized by devising interventions that address underlying social structural factors contributing to self-

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care behavior. The literature on post-transplant quality of life (QOL) shows that kidney recipients' expectations about QOL are not met (56). Patients' unrealized expectations and QOL may have a profound effect on the level of self-care expected of them; this relationship remains to be determined.

## RECOMMENDATIONS

There is great need for systematic research on patients' beliefs about self-care, including how self-care practices contribute to kidney transplant survival as well as to disparities in survival rates. Much remains to be determined on the self-care strategies patients draw upon to keep themselves and their kidneys healthy, the social processes involved in survival, the cultural reasons why they engage in certain self-care strategies, and how they manage the expenses of self-care management. This psychosocial behavioral approach is necessary given the pressure from policy makers and clinicians to identify behavioral and ethnic correlates of chronic kidney failure, prevention, and management (57).

Investigating the strategies and resources kidney recipients mobilize to keep their kidneys healthy and to survive can help to identify disparities in kidney transplant survival. This investigation can also help to identify ways to reduce kidney rejection rates, which helps to diminish the increasing demand for scarce kidneys. This endeavor may point to new avenues for self-care intervention to extend long-term survival, such as outpatient health education, targeted to those facing greatest disparities (58). This research effort may help identify effective ways to improve compliance with immunosuppressant drugs that take into consideration social, economic, and cultural beliefs, help prepare transplant candidates for life with a kidney transplant, and provide insight into the role of Medicare policy in patients' capacity to obtain immunosuppressive medications. It is shortsighted for our health care system and policies to support most of the costs of attaining a kidney transplant, but to devote almost no resources to promote self-care activities that can help optimize transplant outcomes.

## CONCLUSION

Examining the economic, social, and cultural factors that are associated with transplant recipients' ability to maintain their kidney grafts' survival will illuminate ways to reduce health disparities and promote greater equity in transplant outcomes. Moreover, an equitable transplantation system requires justice not only in access to transplantation but also in facilitating the self-care behaviors associated with good transplant outcomes. Justice refers to the fair distribution of risks and benefits among all groups. An egalitarian theory of distributive justice promotes equity in access to health care regardless of wealth or social identity and position (59,60). Promoting better transplant outcomes by all means will maintain public trust in the endeavor and justify costs. It is imperative that we identify whether some patient subgroups are at a disadvantage in maintaining their kidney grafts. Determining which self-care activities promote health and longevity among transplant recipients will enable policy makers to devise more effective social, medical, and financial interventions that accommodate those specific needs. It may also justify a policy that provides resources that promote appropriate self-care in at-risk populations.

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