

ETHICAL ASSESSMENT OF SOCIAL SUPPORT AS A CRITERION IN
KIDNEY TRANSPLANT CANDIDACY IN AN URBAN, NORTH
PHILADELPHIA SETTING

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

by
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Diploma Date: May 2023

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ABSTRACT

When it comes to inclusion of social support as a criterion for kidney transplantation, there is lack of standardization and understanding of what it truly means to staff, clinicians, even patients and their families. Despite the variability in what “social support” means to many kidney transplant teams and centers, studies (mostly through survey studies) have shown that inadequate social support serves as an exclusion for patients awaiting kidney transplantation. With inadequate social support serving as an exclusion criterion and without it being properly addressed, inequities currently present in the kidney transplant considerations may be perpetuated. This thesis aims to tangibly define this social support criterion within an urban setting – North Philadelphia. Through REDCap survey administration to practitioners and support staff that handle candidacy for kidney transplantation, we will get a sense of how social support defined by wealth, marriage relationship and parental relationship affect views on the ethics of kidney transplant considerations. Discussions will also be applied to pediatric settings. This thesis will be a commentary on whether the current transplant system fulfills the standards of urban bioethics principles. This will present a framework for social support referrals to be implemented as a necessary resource if a patient on the transplant list presents with inadequate social support. I will argue support of the urban bioethical principles of social justice and solidarity for the purpose of helping healthcare systems, government and insurance understand that such resources should be funded by them to support candidates who truly need it.

DEDICATION

I have had the opportunity to work with many patients
who have dealt with issues of their kidneys
and many who have needed transplants.

I dedicate this to them as a reminder that full stories should
be heard, and that holistic care should be priority.

I also dedicate this to my late Grandmother Esther Jenrade Adeyemo
who always believed in me and gave me courage to
accept and overcome challenges.

ACKNOWLEDGMENTS

I would like to thank my thesis advisor, Professor Nicolle Strand for their mentorship and guidance throughout this thesis as well as throughout my time at Temple. In addition, the center for urban bioethics has been a wonderful resource to utilize and am eternally grateful for every person there I have had the chance to interact and work with.

I would also like to thank the nephrology department at Temple University Hospital, most especially Dr. Avrum Gillespie and Dr. Jean Lee who guided me in the literature review as well as with crafting and distributing the survey instrument I created.

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CHAPTER 1 – INTRODUCTION

During the second semester of our Urban Bioethics core curriculum, we discussed transplant ethics, allocation, and embodiment. We also had discussions surrounding the racial disparities present in organ transplantation. I was most drawn to this section because opportunities have allowed me to work with pediatric patients in the field of nephrology – many of which needed kidney transplants. Minority groups face barriers at every stage of the transplant process even prior to consideration. When I had the opportunity to work with a diverse population for example, I had to utilize a medical legal partnership to help advocate for a patient experiencing barriers, such as lack of transportation for transplantation meetings/appointments.

In a nation founded on systemic racism, it is important to acknowledge that its foundation is still affecting marginalized populations today in the realm of healthcare. If we look for example, at the history of race and the glomerular filtration ratio (GFR), we see that this assumption assigned Black patients as having higher kidney functions than they actually do. This assumption leads to incorrect diagnoses that further delay necessary referral to nephrology specialty care, as well as kidney transplantation evaluation (Inserro 2020). Assumptions like this further perpetuate the cycle of limiting access to transplant for marginalized populations. When you look at GFR without racial assumptions, the Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Disease found that the prevalence of chronic kidney disease (CKD) is 2% higher in Black patients and 1.5% lower in non-Black patients (Gutierrez et al. 2022). According to the United Network for Organ Sharing (UNOS), 10,522 of 25,498 kidney transplant

recipients nationwide were White non-Hispanic in the year 2022. That is approximately 41% – two-fifths of kidney transplants that are allocated to a group of people who are not the most affected by end stage kidney disease in the U.S. In accordance with the CDC, CKD, “is more common in non-Hispanic Black adults (16%) than in non-Hispanic White adults (13%) or non-Hispanic Asian adults (13%).” This further demonstrates the inequities present in those receiving kidney transplants in the U.S.

In our Urban Bioethics course section, which was centered on transplant ethics, we also discussed the black market. It is clear that this market emerged because there is a vast imbalance between supply and demand – there are way more people on the list than organs donated (Shafer & Cunningham 2010). This raises the question of the ethics surrounding the creation of a market for organ transplantation. During our discussions of cases globally, many within my cohort were against creating this market because persons who were more vulnerable would end up being exploited by the system. Those who would not be able to afford a transplant would face yet another socioeconomic barrier. Not to mention that those who sell their kidneys/organs could be coerced into selling if they are in drastic need of money. With such inequities in place, it is no wonder that the black market for organs illegally exists today and just perpetuates the cycle of inequity.

The major reason for writing this thesis lies within finding ways to make transplant consideration a more standardized and equitable process, most especially taking into consideration the complexities of urban settings and the stories of the marginalized. The next section will discuss how far transplant guidelines have come but also the much-needed work that still needs to be done for guidelines to be more in line with urban bioethics principles.

CHAPTER 2 – EVOLUTION OF KIDNEY TRANSPLANT EVALUATION, ALLOCATION, AND TRANSPLANT ETHICS

Bioethical Principles and Organ Donation

Distributive Justice or redistributive justice as a Bioethics tenet is a particularly powerful one in relation specifically to organ donation. A moral society is meant to encourage more well-off persons to contribute their excess goods in order to improve the quality of life of those less well-off (without substantially lessening their own quality of life) (Rosoff 2018). However, in present day society where organ donations are scarce, most donor recipients that pass the psychosocial and socioeconomic eligibility criteria are usually more well, from more stable families and usually not from the marginalized populations (Rosoff 2018). Therefore, even though guidelines for transplant allocation are multifaceted, there is still a major exclusion of ethnic minority groups due to social circumstances. This is one of the major reasons why Rosoff argues that compulsory organ retrieval is morally but not socially justified – we do not live in a perfect society free from prejudice, free from inequities.

The principle of distributive justice also supports why we need organ transplantation for society and its members. Justice requires that in the system of donation, there must be rules or policies set in place that take the best interests of the donors and recipients into consideration; this process must therefore be fair (Caplan 2008). Unfortunately, since transplant centers are at the forefronts of decision making on transplant candidacy, their policies all vary (Caplan 2008). Organ donation also touches

upon the facet of altruism. This is when an individual's actions focus on the benefit of others without dealing with the consequences to themselves (Dalal 2015). Organ donation is a selfless process and works towards helping others in society. In fact, signing up to be an organ donor so that one's organs are donated upon one's passing demonstrates that harm does not have to be done to the donor. If they already passed and had first signed up to be a donor, it is almost a circle of life: I have passed but now my organs can help keep another alive.

Autonomy is also a tenet that plays a role in organ donation. Every human being in society has a right to their respective bodies. Nobody should feel forced or coerced into giving up an organ if they do not want to. This is why donation is the most moral method in present day society, it creates a balance between distributive justice and autonomy. Beneficence and non-maleficence are included in this discussion as well. Since beneficence is the moral obligation to do good to others (and connects to altruism) – signing up to become a donor is an expression of doing a good deed (Blondeau et al. 2004). Non-maleficence which is to do no harm can be connected to utilizing organ donation to prevent the deaths of persons waiting on the transplant list (Blondeau et al. 2004). A study that looked at how ethical principles explain the moral norm looked at autonomy, beneficence and justice and found that they interrelated significantly with one another but the only one that significantly affected the moral norm was beneficence (Blondeau et al. 2004). The basic bioethical principles stand as motive for organ donation and help keep the process moral. It is important to use these principles to help shape a more comprehensive approach to organ donation and candidacy.

Shifting to Urban Bioethics Principles and Holistic Organ Donation

It is important to note however that although the fundamental bioethical principles of autonomy, justice, and beneficence/non-maleficence are important to consider in the concepts of organ donation, they don't fully capture the complexities that are encompassed in urban settings. Blustein and Fleischman elicit that urban bioethics challenges us to look past just the traditional bioethics tenets to gather larger multicultural context in relation to equity and disparities, public health concerns as well as other ethical dilemmas. Our Urban Bioethics coursework has taught us to transform the basic bioethical principles to an "Urban Bioethics Toolbox." Instead of autonomy we look at agency that takes into consideration capacity of decision making and the factors that affect it. Rather than justice, which also contains distributive justice, we should turn to social justice and solidarity. The strength in utilizing social justice rather than distributive justice makes allowances for that we already know equality should be transformed into equity, but even within equity we must account for each individuals' different contexts and stories – we must advocate to provide for people given that society may have perpetuated their current circumstances. Solidarity is already acknowledging biases that we have and being a vessel for advocacy. Given this "Urban Bioethics Toolbox," these tenets should serve as the foundation for creating more complete criteria for organ transplantation considerations.

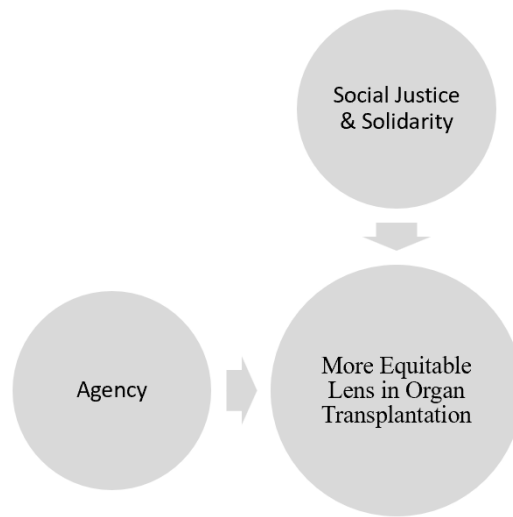


Figure 1: Urban Bioethics Toolbox in Organ Transplantation – This figure demonstrates the relationship between organ transplantation and the urban bioethics toolbox. We need to utilize principles such as agency social justice and solidarity for more equitable care in organ transplantation especially given urban contexts.

To ensure that transplant candidacy is holistic, criteria include a set of non-medical factors in addition to the medical. They are also incorporated to promote equity and justice in a system that favors the white majority. According to OPTN, non-medical factors include life expectancy (not age as an exclusion factor), potential injurious behaviors, adherence to medical regimens and appointments, repeat transplantation, incarceration status (as it should not exclude them from consideration), immigration status, social support (the main criterion I wish to define) and considerations of vulnerable populations like children (OPTN 2015). For social support specifically, there have been connections to improved quality of life post-transplant but not necessarily graft/overall survival (OPTN 2015). Social support is so important because it is sort of used as a place holder for other measures of success such as motivation, self-care transportation, future adherence. However, when inadequate support is listed as something that can negatively affect transplant candidacy this highlights the need for

social justice to take over. It brings to light that social support might be difficult to assess if a patient has limited proficiency in English or if they must have inflexible employment schedules in order to survive (OPTN 2015).

In an effort to make organ transplantation candidacy not only more holistic but more equitable, psychosocial pre-transplant evaluation has become more multidisciplinary. Goals of this multifaceted evaluation include promoting fairness and equal access to care; maximization of optimal outcomes; identifying a patient's social network; identifying and addressing psych issues; reducing harm, mitigating risk, optimizing graft survival to ultimately improving patient's quality of life (Maldonado 2019). And since studies have shown that pre-transplant issues surrounding the psychosocial can persist— even post-transplant, affecting outcomes and medication adherence for example—it is important to address them prior to transplant (Maldonado 2019). Multiple studies have specifically looked at the correlation between social support criterion for transplant candidacy and post-transplant outcomes. In a 2016 national survey utilizing the American Society of Transplant Surgeons and the Society of Transplant Social Work, providers were more likely to choose a transplant candidate who had social support (OR 1.68, 95% CI) in addition to medication adherence and 15-year life expectancy with transplant (Ladin et al. 2018).

It is also important to consider that although Centers for Medicare and Medicaid (CMS) as well as the Organ Procurement and Transplantation Network (OPTN) encourage utilizing social support as criterion for transplant candidacy, they do not definitively define what social support is or how to objectively measure it. In a national survey of 551 providers, only 17.3% believed that CMS guidelines evaluating for and

using social support for transplant evaluation were clear (Landin et al. 2019b). Up to 70% of providers were in agreement for a more uniform approach to using social support to evaluate (Landin et al. 2019b). Moreover, inadequate social support in organ transplant candidacy was believed by providers to exclude about 20% of patients in need of an organ (Landin et al. 2019b). We do not only face unclear guidelines but if it is found to be inadequate, social support can become a barrier to patients hoping to receive a transplant.

Although they are meant to make the process more equitable, barriers to patients receiving transplants can also lie within the updated guidelines itself. OPTN notes that even though non-medical factors were added to make candidacy more equitable and holistic, they still present with ethical concerns and limitations. Limitations and ethical concerns include that standards are unclear; these criteria are not always universally applied; stereotyping and judgment can occur; they are not always clear/transparent to patients (and providers); and evidence does not always support their use (OPTN 2015). The lack of clarity about what non-medical factors are, the differences from location to location and not enough evidence supporting their use, pose a threat to patients waiting for organ donation and for those waiting to be placed on the list. In an article about capacity building in community health workers, Ghanekar describes a community health model that needs to vary depending on the setting of the community: the model that works for the rural setting does not work for the urban (2022). Not only do non-medical factors need to be properly clarified but there should also be a push to adapt them to their specific contexts (i.e., urban vs rural vs suburban). There are a multitude of non-medical

factors kidney transplant considerations need to properly define, however, this thesis will focus primarily on social support.

There have been efforts to try to objectively define social support. According to Yang, “objective support refers to visible or actual support, including material assistance and the participation of social groups. Subjective support refers to the emotional experience and satisfaction of an individual being respected, supported, and understood in society, which is closely related to the one's subjective feelings” (Yang et al. 2021). Social support can be defined as “informal care and emotional ties to others, which for many is comforting and helpful especially during health challenges and transitions, such as transplant evaluation and recovery” (OPTN 2015). Another survey study defined key domains of social support as “informational, emotional, instrumental, motivational, paid support, and the patient’s importance to others” (Ladin et al. 2019a). Despite efforts to define social support there is a need for clearer guidelines and definitions in addition to support from transplant teams or insurance. For example, according to the NYS department of health, when a health system is a patient centered health home, the plans of care should include community-based/social support services in addition to healthcare services to address patients’ needs and goals (HH Standards 2022). This model implies that the government would be able to subsidize such a need for patients with valid reasoning; this is what transplant teams should try to model.

What is difficult to grasp is that even with the expansion of guidelines, we still see that the racial majority – White Non-Hispanics are benefiting the most from organ donation and transplantation. When compared to racial majority, African American patients experience worse health, earlier morbidity, decreased access to health care,

inferior treatments when they can access health care and decreased recovery from diseases/illnesses (Russell 2016). Race/ethnicity cannot also be reduced to just socioeconomic status as well – studies have shown that it is racism itself that negatively impacts health (Russell 2016). When researchers control for socioeconomic status, racial minorities still end up with worse effects/outcomes when compared to their white counterparts, specifically in the U.S. (Russell 2016). Russell goes on to argue that philosophers and bioethicists of color should make it necessary for discussions of race to be at the center rather than on the margins. Many of the studies that focused on provider responses in relation to organ candidacy guidelines do not take note of the demographics of the providers. When providers look like and share similar lived experiences as their patients, conversations on the margins can be brought to the center.

CHAPTER 3 – DEFINING SOCIAL SUPPORT

It is important to create a solid definition for social support because I will be using the term to help measure the impact of this criterion in kidney transplant candidacy. It is also important to acknowledge how providers are defining the terms to see which aspects of social support hold the most weight in organ transplant candidacy. Moving forward, I will be focusing primarily on kidney transplant and dialysis. Given that most people are born with 2 kidneys and can live normal lives with just one, it is one of the few organs where live donation is altruistic and has the true essence of the bioethical principle of distributive justice and even social justice/solidarity. Looking into organ donations like the heart, those ethical arguments become a bit foggier. Returning to the discussion of defining social support, there are environmental forms of support that can be further divided into structural and functional measures (Helgeson 2003). Structural support refers to those within one's social network for example marital status, friendships, membership with organizations (Helgeson 2003). Functional support can include "the resources that people within an individual's social network provide" (Helgeson 2003). Within the functional there 3 main categories emotional – people available to listen and care, instrumental – tangibles/concrete assistance and informational support – guidance (Helgeson 2003). Figure 1 demonstrates a diagram of social support divided into its different categories. From this we see that there is not just one way for someone to receive social support. Despite so many ways to measure social support, it still presents as a barrier in transplant candidacy.

Helgeson argues that the kind of support that patient needs must match or depend on the nature of the stressors they are facing. She tested in a study of cardiac patients and hypothesized that informational support would be best for them: information regarding lifestyle changes and how to prevent future coronary events. A regression analysis was used to predict the type of functional support, informational, instrumental, and emotional, that would help in a patient's (and their spouse's) adjustments in the future. She found that the only type of support that was related to reducing distress was instrumental support (Helgeson 2003). Instrumental support again are the tangibles – concrete assistance. Given this context on how social support can be defined into multiple categories, I am interested in investigating how it is mainly defined specifically at my home institution – Temple University. If some institutions consider functional support more highly than structural and vice versa at other facilities, this solidifies that there is a lack of standardization of the social support criterion. From the Helgeson paper we also observe that instrumental support is quite impactful in making a difference in patients and their families' lives. If this is a form of impactful support, I argue that transplant teams should be able to put in referrals of this tangible support for patients that lack or have inadequate social support. Therefore, with this set-in place, we should no longer see patients excluded and urban bioethics principles are at the forefronts of kidney transplant considerations.

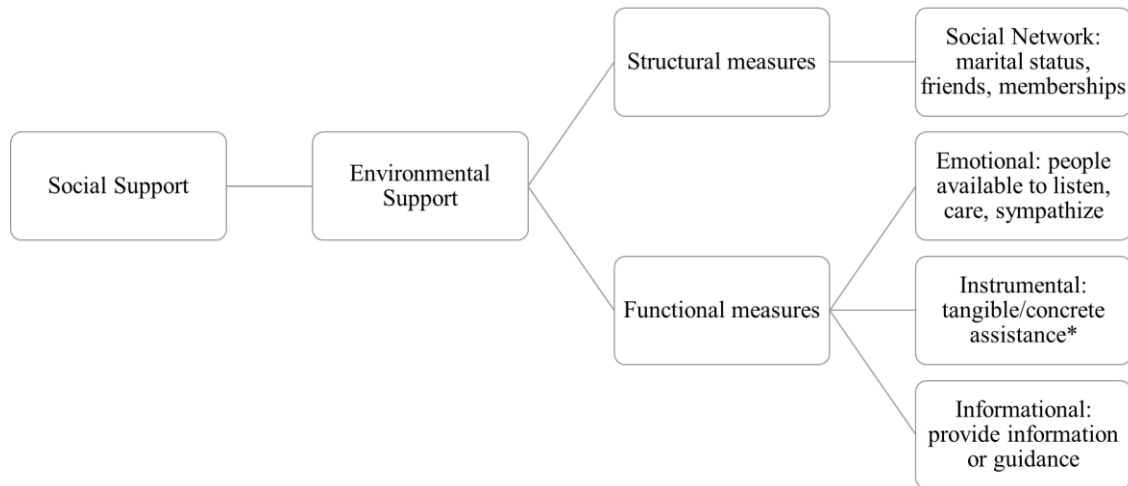


Figure 2: Social Support Broken Down – This figure represents the different ways to characterize social support created based on the Helgeson 2003 paper “Social Support and Quality of Life.” Instrumental support has an “*” as it will be further argued as a means provisional support that should be funded for patients who do not have adequate support.

Previous studies have looked at a combination of structural and functional measures of social support in efforts to reduce barriers to kidney transplantation. D’Cunha et al., created a behavioral intervention targeting social networks and utilizing emotional and informational support. The counseling and educational session for the "Journey to Transplant" intervention group aims to shift the focus of discussions from the periphery to the forefront. The JtT intervention received feedback and was reviewed by patient and family advisory panels that mirrored the patient population. The steps the intervention included were normalization, education, risk perception and action (D’Cunha et al. 2022). The session had a standardized education and perception of risk section followed by a more personalized section. The intervention had a presentation of patients' calculated outcomes on “the kidney transplant waiting list to help with the issue of risk perception and expectations” (D’Cunha et al. 2022). After all the information was provided, there was a focus on setting goals for the patients and their social support

network “to address barriers and needs specific to that of the patient and their friends and family members” (D’Cunha et al. 2022). This intervention has demonstrated that social support can be strengthened in already existing networks but that it also can be provided as a resource for patients (i.e. informational functional support).

If such interventions can exist, then it is reasonable to argue that inadequate social support should not serve as an exclusion criterion for patients seeking transplant candidacy since resources exist to supplement. In fact, Maldonado discusses how social networks may not actually demonstrate proof of support. Some patients could be in a marriage only in name so that they can be considered for candidacy – they are in a supportless marriage. While others may need to divorce from their significant others for social support/disabilities insurance – their separated partners still serve as a major form of social support for them (Maldonado 2019). Social support becomes too complex a criterion and therefore is another reason why it should not serve as an exclusion if a patient cannot demonstrate forms of social support. Centers, hospitals, and the government should be actively working to increase access to tangible support, informational support for patients in need. Not enough studies look at data post providing a patient with social support. This would help with the rationale of keeping social support as a criterion for transplant candidacy – we need more studies demonstrating its impact on long term transplant goals.

Others can make the argument that inadequate social support should be an exclusion criterion because it can negatively affect transplant outcomes. Some studies have demonstrated that unstable social networks predicted loss of graft post-transplant (Maldonado 2019). However, most of this data is limited and inconclusive (Berry 2019).

Besides measure of quality of life, in terms of long-term maintenance of graft and immunosuppression adherence, analyses have failed to find a relationship with social support (Berry 2019). We are now presented with conflicting data which makes arguments for and against inclusion of social support as a criterion difficult. Berry also notes that since most centers require social support for listing and candidacy that there might even be a selection bias issue – “we have limited data and ability to evaluate outcomes among patients at the extremes of poor social support” (Berry 2019). It is the responsibility of the government and hospital systems to determine how the social support criterion should be adapted to their settings, taking into consideration the community contexts and the stories of the marginalized. With this in mind, if a patient lacks social support, avenues to get connected to support should be provided such as the journey to transplant intervention.

Since I have the privilege of attending an institution that serves the North Philadelphia community, one of the major goals of my thesis is to look at the kidney transplant candidacy and dialysis team to get a sense of how they believe social support is being defined at Temple University Hospital. With the African American population being largely served as they make up a large portion of the north Philadelphia population, I am interested in seeing marginalized discussions moved to the center. In other words, I had mentioned earlier in this thesis that previous studies fail to capture the demographic data of the teams and providers – I wish to capture that data. I hope to see if those in control of patient care, those that have the decision-making capabilities, look like, and have shared lived experiences with the population they serve. I also am an aspiring

pediatrician, so I am interested in seeing how definitions of social support and provider demographics at Temple can be applied to pediatric patient settings.

I created a REDCap questionnaire that captures demographic information such as age, ethnicity, gender, and race, of the transplant candidacy and dialysis team including from support staff. The second part of the questionnaire focuses on social support. I will have staff define freely what social support means to them (this question is optional). The second question in this section asks staff to determine which form of social support is most important for transplant candidacy at Temple (social networks vs emotional vs instrumental vs informational). The last section of the questionnaire patient scenarios adapted from the Megan Urbanski et al. paper: "Transplant Professionals' Perceptions of Long-Term Care Residents' Candidacy for Kidney Transplantation." I created 6 patient scenarios tying in and comparing themes of wealth, unstable marital status, and parental relationship (specifically in relation to autonomy). Given each scenario using an 11-point Likert scale I will gather if they believe whether it is ethically sound to provide each patient with transplant/treatment. I also created reaction questions for each scenario to get more insight into why they selected their answer on the Likert scale.

CHAPTER 4 – RESULTS & DISCUSSION

Predictions/Hypotheses

Based on what I have observed from being able to rotate at Temple University Hospital Center and at St. Christopher Children’s Center I predict that the staff members and providers will not reflect the population that they serve. I anticipate that most doctors and psychologists will be White Non-Hispanic. So far, I have only met one African American nephrology provider between these two institutions. This however does not consider nephrology fellows and new nurses – they may be expanding to include more underrepresented persons due to diversity, equity, and inclusion efforts. I do believe that support staff (social work transplant team support staff, technicians) will better reflect the population and their involvement again is necessary for marginalized discussions to reach the center. Through the transplant consideration meetings, I have had the privilege of attending, it is evident that social work and transplant support staff advocate for patients that are considered complex cases.

I predict that beliefs surrounding what is considered ethical or not will depend on race, ethnicity and even age. For example, older providers may feel that having inadequate social support warrants exclusion while younger providers may realize the complexities of social support and would not feel comfortable excluding a patient who does not have it. For definitions surrounding social support I predict that staff and providers will select social networks as the most important measure of social support at their institutions. It is one of the easier social support measures to demonstrate: does this

patient have friends and family that will help take care of them post-transplant in relation to medication and adherence and follow-up appointments?

Results

After distribution of my survey to providers, seven members out of a staff of fifteen to twenty completed the survey. Ages of the participants range from 18 – 74. These staff members consist of a social worker, transplant surgeon, transplant nephrologist, transplant support staff, transplant coordinator, physician assistant, internal medicine physician and an internal medicine resident. Out of the staff members who participated in the survey, 6 out of 7 were White Non-Hispanic males. The social worker who completed the survey is a Hispanic female who identifies with more than one race: American Indian/Alaska Native and White. Figure 1 illustrates the demographics of the personnel who work in transplant and dialysis. Previous literature has demonstrated that providers are not very confident in social support as a criterion in transplant evaluation: “Nearly half of respondents (42.4%) were only somewhat or not at all confident in using social support to determine transplant suitability, with 57.6% being confident” (Ladin et. al 2018). From my survey it is evident however that these providers understand what social support means. The social worker defines it as “having the consistent & reliable persons for physical and emotional support to go to medical appts, receive teaching with meds, understand need for compliance, have flexibility of schedule and lifestyle to assist in a medical emergency to get the transplant pt to the hospital.” While another participant emphasizes the importance of social networks and emotional support: “Adequate and available family/social network to facilitate and support pre- and post-transplant needs

around emotional and medical support. Includes but not limited to assuring follow up visits and medication compliance.” Ultimately, there are many similarities in how each provider defines social support.

One of the primary objectives of this survey is to determine the most significant type of social assistance, such as emotional, practical, informative, and social connections, for individuals who are potential candidates for a kidney transplant at Temple. Contrary to my prediction, most providers believe that the most important form of social support at Temple is instrumental support (tangible/concrete assistance) rather than social networks: 75% of participants selected instrumental support while 14% selected social networks. One participant chose emotional support as the most crucial form of social support, while none of the participants chose informational support as the most important form of social support.

The final part of the survey centered on six patient scenarios that dealt with various issues such as poverty versus wealth, marital problems like infidelity, and child autonomy. The responses from the staff members to the six patient scenarios were diverse. For the marital infidelity scenario, whether it was a spouse that was unfaithful or the patient themselves that were unfaithful, most providers believed that it was still ethically sound for the patient to remain a transplant candidate – even given that the closest familial support was 2000 miles away (Likert scales ranged from 7-8 for this marital category). One of the respondents noted, “many times the ex-spouse still will help because they are the parent of a mutual child.” Three out of seven staff members were either neutral or disagreed that it was ethical for the patient to remain a kidney transplant

candidate. One participant noted, “the patient would not have the supports needed if they leave their spouse.”

Measure	Item	Count (n=7)
Gender	Male	6
	Female	1
Age	18-24	
	25-34	2
	35-44	1
	45-54	1
	55-64	2
	65-74	1
Ethnicity	75 and older	
	Hispanic or Latino	1
	NOT Hispanic or Latino	6
Race (can select multiple check boxes)	Unknown / Not Reported	
	American Indian/Alaska Native	1
	Asian	
	Native Hawaiian or Other Pacific Islander	
	Black or African American	
	White	7
	More Than One Race	1
	Unknown / Not Reported	
Occupation	Other	
	Social Work	1
	Transplant Surgeon	1
	Transplant Nephrologist	1
	General Nephrologist	
	Psychologist	
	Transplant Team Support Staff	1
	Dialysis Technician	
	Transplant Nurse	
	Coordinator	
	Dialysis Nurse	
	Transplant Dietitian	
	Dialysis Dietitian	
	Other	4

Table 1: Demographics – delineates gender, race/ethnicity, occupation and age on kidney transplant staff at Temple University Hospital who completed the survey.

When looking at the wealth vs poverty data, both patients with end stage kidney disease (ESKD) whether rich or poor did not readily have available support systems to help them get to appointments. These scenarios also demonstrated that the staff members had differing responses. Six out of the seven providers did not believe that the poor patient should receive a kidney transplant. One respondent noted: “His life is of value, but he does not have the support and will need to go into a facility possibly to ensure his

needs are met.” However, for the rich patient, five out of the seven staff members did believe that it was ethically sound to give them a kidney transplant. One staff member noted, “they do not have people to support their emotional needs but can afford caretakers to help with the physical requirements.” Many of the staff acknowledge the intricacies of lacking a social support system while also being unable to provide support for themselves: “unfortunately no support or means of getting support.” For child autonomy the scenarios are detailed by a 16-year-old teenaged patient not wanting to pursue kidney transplant while their parent wants them to as well as the reversal. In the case where the child wants the transplant, but the parent does not believe they should, most of the staff believed it was ethical for them to remain a kidney transplant candidate. However, when the patient does not want the transplant and the parent want them to get transplanted, most staff disagreed with having the patient remain a kidney transplant candidate. One respondent wrote: “Most likely not, unless the 16-year-old is willing to get transplanted. A non-compliant teenager is the perfect predictor for rapid kidney graft loss.”

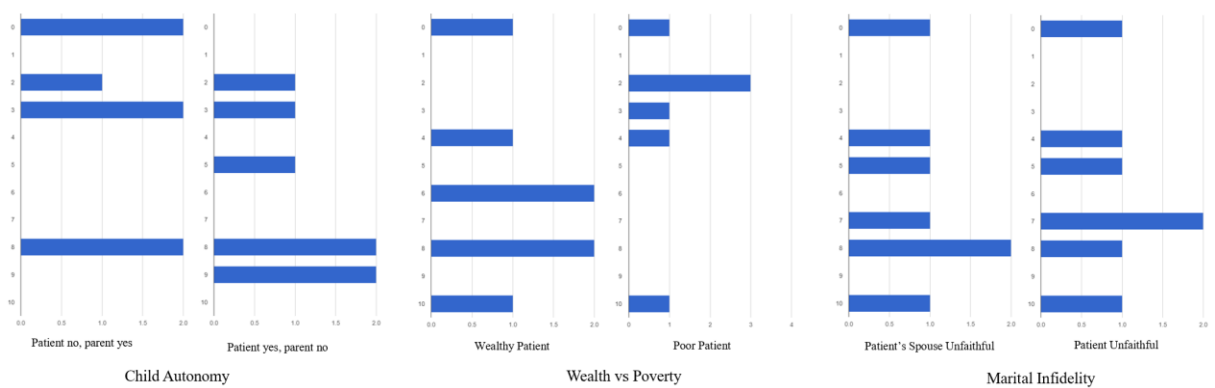


Figure 2: 6 Patient Scenarios, Is it Ethically sound for this Patient to remain a Transplant Candidate/Receive Treatment (Wealth vs Poverty, Child Autonomy, Marital Infidelity)

Discussion

Previous studies have demonstrated inconsistencies on how providers define social support and how it is used as a criterion at their respective institutions. In the 2016 National Survey Study, “while 86.3% of respondents agreed that patients with inadequate support were less likely to be listed, only 67.6% believed that this should be the case” (Ladin et al., 2018). Data from this survey, however, demonstrates that there are similarities in how providers and staff define social support. In addition, prior studies have not demonstrated which form of social support hold most weight in kidney transplant considerations. This survey study points to instrumental support as the most important. The prior 2016 National Provider Survey Study notes that, “while 71.4% perceived social support was important for preventing organ waste (utility), respondents were less sure about the evidence for this. Only 61.4% believed that lack of social support was strongly predictive of medication nonadherence posttransplant” (Ladin et al., 2018). The revelation that instrumental support is the most crucial type of support can facilitate the development of further studies aimed at exploring the connection between providing instrumental support, organ utility, and medical adherence.

Based on the answers to the patient scenarios, it is apparent that social networks in the context of marital status do not carry as much significance for providers at Temple. If a patient is unable to demonstrate proof of social networks, this should therefore not exclude them from kidney transplantation considerations. Discussions regarding wealth and the independence of pediatric patients can be somewhat challenging to address. If a patient lacks the financial means to support themselves, healthcare providers should consider options for the hospital and insurance to cover those expenses. This should not

serve as exclusion criteria to kidney transplant. As a future pediatrician, it is also important to acknowledge the complexities of the pediatric population and autonomy. The patients in the scenarios are 16 years and are on verge of adulthood. It is crucial for them to take responsibility for the clinical care they receive. Although the survey data supports the decision made by the teenage patient (based on the staff that completed the survey), I am curious to see if the results would vary in a pediatric hospital setting. This would be an avenue for future survey studies.

Although this survey study has produced new data, it still has some limitations. It is well known that previous survey studies regarding provider views on social support as criterion kidney and organ transplant candidacy utilize large numbers of providers. These are nationwide studies that have 500 responses. Since I focused primarily on north Philadelphia, that number significantly reduced and even further reduced since response were limited to Temple University Hospital. In addition, the entire staff did not complete the survey. Another limitation of the survey was not expanding this questionnaire to members of the community. Their input was not taken into consideration when constructing this survey. Concordantly, this work is mostly from the view of staff and providers. This can be an avenue for future studies to compare perceptions of social support from the community members and patients themselves. If patients and communities lack comprehension regarding social support and the additional factors that can contribute to it, then it becomes another ethical quandary that requires investigation.

CHAPTER 5 – IMPLICATIONS FOR CRITERIA STANDARDIZATION AND PROVIDING SOCIAL SUPPORT

Based on current guidelines, previous studies, and on data from my questionnaire study, social support, as it stands now, as a criterion in kidney transplant candidacy considerations only serves as a partial ethical criterion. It is a legitimate effort to bring more holistic and equitable considerations to organ donation and transplantation since focusing on just the medical also perpetuates a cycle of barriers for marginalized patients. Nevertheless, as there is no standardization and each institution interprets the policies differently, it creates a gray area that could lead to further disparities for marginalized groups. Persaud et al. describes an option for a just allocation system as “the complete lives system” (2009). This system would have 5 principles: “youngest-first, prognosis, save the most lives, lottery, and instrumental value” (Persaud 2009). This is meant to take into consideration multiple aspects of allocation and create the most combinations possible in support of distributive justice. In this particular model, this still tends to discriminate against the older population for example (as advanced age is no longer an exclusion criteria). There is no perfect way to make the social support criterion perfectly ethical as we do not live in a perfect world.

The use of subjective and comprehensive criteria in kidney transplantation appears to continue to promote inequalities. For example, in this survey study, the poor patient was believed to not have enough social support and finances and therefore deemed to not be ethical to give them a kidney transplant. Economist John Creamer has analyzed census data and found that although the poverty rates across the country are

decreasing, certain marginalized groups such as Blacks and Hispanics are still facing inequalities. In 2019, the poverty rate for African Americans was 18.8%, the lowest rate ever seen for this group, but it was still higher than most other groups (Creamer 2019). These inequities can also affect other marginalized groups, like individuals with disabilities who may face discrimination. Due to the history of systemic racism, wealth disparities among marginalized groups, and societal complexities like medical mistrust, there is a need to reform the kidney transplant eligibility criteria from its core. While some reforms are underway to improve the process, there are still disparities with White patients experiencing better transplant and survival outcomes than their minority counterparts.

Rather than striving for perfection in this criterion, institutions, the government, and people in positions of authority should focus on providing patients with social support whenever necessary. In terms of what is most cost effective in the treatment of end stage renal disease, kidney transplantation trumps dialysis/renal replacement therapy (RRT) (Wong et al. 2012; Jarl et al. 2018). Dialysis has an “annual expenditure of over \$20 billion in the United States” (Wong et al. 2012). In a study that used a before and after design, they found that kidney transplantation rapidly decreased health care costs per patient (Jarl et al. 2018). In the international study, this corresponded to a total savings of €380 000 (€324 000 discounted) over 10 years for each transplanted patient all while the cost of dialysis/RRT showed an upward costs trend over time in treatment (Jarl et al. 2018). To call for structural sustainable changes in healthcare, it is always important to demonstrate financial incentives for making that change. If kidney transplantation is this cost effective, the money that we save from patients getting transplanted can be put

towards not only tangible social support for patients but also towards gathering more minority populations to donate to the organ pool.

Work is already being done by those in power to help marginalized patients. Berry et al. discusses using social support evals to help find the patients that need assistance and not using it as exclusion. We must recognize our biases and realize that even though the transplant/allocation system is not the cause of “unjust social conditions that destabilize social networks or prevent family and friends from engaging in their loved one’s care, it should at least avoid exacerbating these inequities and further marginalizing underserved and diverse groups in society” (Berry et al. 2019). Berry goes on to provide suggestions on how institutions can accommodate patients with inadequate social support: patient support groups, treatment navigators home health aides to name a few. There are even advancements in technology that can help patients from transportation to medication adherence such as rideshare apps, robotic pill sorting and apps for monitoring post-op recovery (Berry 2019). I argue that funds should be allocated to these social support accommodations to utilize distributive justice ethically and correctly in organ transplantation considerations. As Berry emphasizes, such initiatives “require support from state governments and CMS, for example, to reimburse for non-emergent medical transport and home and community-based services, and to balance the regulatory incentives that prompt transplant centers to avoid potentially risky patients or innovations in patient care” (2019). This needs to be funded by persons in power for sustainability and other funded programs are needed to get minority populations interested in organ donations – we need to be having conversations about the inequities of our transplant system with the community.

The guidelines for organ and specifically kidney transplantation is constantly updated as more studies advocate for more holistic approaches to candidacy. The added aspect of the cost effectiveness of creating more tangibles of social support for patients gathers fuel for stakeholders to invest in such initiatives. More research and studies are needed specifically looking at the marginalized patients and those most affected by end stage renal disease to make this process more equitable. I have faith that someday we will adopt a more comprehensive and ethical approach to determining kidney transplant eligibility. This will involve not only establishing more explicit guidelines but also implementing a proactive plan for cases where a potential candidate does not have sufficient social support.

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