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Social Support: From Exclusion Criteria to Medical Service

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Abstract

One of the criteria used by many transplant centers in assessing psychosocial eligibility for solid organ transplantation is social support. Yet, social support is a highly controversial requirement that has generated ongoing debate between ethicists and clinicians who favor its consideration (i.e., utility maximizers) and those who object to its use on equity grounds (i.e., equity maximizers). The assumption underlying both of these approaches is that social support is not a commodity that can be purchased in the marketplace. This essay argues for the reconceptualization of social support as a product that can—and should—be purchased for transplant candidates to render them eligible for transplant.

Keywords: transplant; social support; equity; solid organ transplant; psychosocial evaluation

Introduction

Since its emergence as a novel therapy in the 1950s, the transplantation of solid organs has become an “established” and “definitive treatment option” that “has transformed the survival and quality of life of patients with end-organ dysfunction.”¹ Unfortunately, in the United States, the number of individuals in need of organs significantly exceeds supply.² An estimated “17 people die waiting for an organ transplant each day,” whereas “one person is added to the transplant waiting list every 9 minutes.”³ According to the Organ Procurement and Transplantation Network (OPTN), 5,758 individuals “were removed from the waiting list in 2021 because they died and another 5,371 because they became ‘too sick to transplant.’”⁴ At present, the number of Americans on waiting lists for solid organs exceeds 105,000.⁵ To address this imbalance, healthcare policymakers and institutions have designed both a national system for allocating cadaveric solid organs and, in some cases, issued consensus guidelines to ensure meaningful stewardship of a scarce and precious lifesaving resource.^{6,7} The federal regulations operationalizing the National Organ Transplant Act of 1984 and creating OPTN do not seek to “micro-manage the development of purely medical criteria or routine decisionmaking of attending medical professionals,” leaving American transplant centers significant latitude in deciding which patients to list as transplant candidates.⁸ These centers have universally adopted some form of assessment for “psychosocial suitability” as a prerequisite for transplantation, although centers vary considerable in the application of this eligibility criterion.⁹

The stated goal of psychosocial assessment is to measure a patient’s ability to steward an organ successfully, rather than any broader appraisal of individual well-being, contribution to society, or perceived social worth.¹⁰ As such, the decision by social workers and mental health professionals is binary (i.e., either a patient is suitable for transplant or is not), and once a candidate is deemed suitable for transplant, psychosocial condition should not affect that patient’s ranking on waiting lists. Of course, transplant centers can—and, arguably, should—strive to enhance patients’ psychological and social well-being, although they await transplantation in order to increase their odds of survival. Evidence suggests strong support for such an approach among those involved in evaluations.¹¹

One controversial aspect of psychosocial suitability used to assess eligibility is an evaluation of the candidate's perceived social support.¹² Definitions of "social support" vary considerably, but as Berry et al. note, the term "generally refers to the perception and actuality of care, services, and encouragement provided by members of a patients' social network, typically spouses or partners, friends, or family."¹³ Many transplant programs specifically require that patients identify a "primary support person" who can assist in recovery, accompany patients to appointments, and even be available to patients 24 hours a day during the months following transplant; some programs require an "alternative" or backup support person as well.¹⁴ Various assessment tools have also been developed to measure "psychosocial suitability" for transplant.^{15,16} Ladin et al. report that approximately 10% of transplant candidates are excluded from transplant eligibility due to the evaluators' perception of inadequate support, but with considerable variability between centers—with some programs excluding up to one in five patients on this basis.¹⁷ Advocates for the use of social support criteria—of whom psychiatrist Jose R. Maldonado of Stanford University is the leading voice—justify the use of social support criteria on the basis of a demonstrated "strong association between pretransplant psychosocial vulnerability factors and a number of negative outcomes."¹⁸ Critics question the strength of this evidence and also note that the use of "social support" criteria exacerbates existing inequities and biases reflected in underlying social determinants of health.¹⁹ Debates surrounding resource allocation during the coronavirus disease (COVID-19) pandemic have made this compounding (or "double whammy") effect all the more apparent.^{20,21} At its most fundamental level, the conflict appears to be one between utility (i.e., allocating organs to save the most lives) and equity (i.e., ensuring that patients are not denied organs as a result of underlying and unjust social structures). Fortunately, such a trade-off may not prove necessary. After briefly reviewing the current state of the debate below, this paper argues for the reconceptualization of "social support" as a medical service that can and should be synthesized, distributed, and paid for like any other lifesaving healthcare resource.

The Current Debate

The debates surrounding the use of "social support" in transplant eligibility assessment are complex and nuanced.²² On one side are ethicists and clinicians who prioritize the stewardship of organs in order to ensure the survival of the largest number of patients.²³ These individuals might be thought of as "utility maximizers" seeking to use a scarce resource in the most efficient manner. On the other side is a variegated group of ethicists and clinicians who emphasize the importance of considering the underlying structural forces that lead certain patients to present with more social support than others at baseline. They wish to consider the implications of these determinants for individuals of different economic, racial, and cultural backgrounds.²⁴ These individuals might be thought of as "equity maximizers" seeking to use a scarce resource in a manner that acknowledges and considers broader aspects of social justice. (It is worth noting that increasing equity might enhance public perceptions of organ donation and hence lead to more available organs, so in theory, at least, equity and utility may not stand in conflict over the long haul; this possibility is speculative, however, and best left for discussion elsewhere.)

A parallel debate exists between whether "social support" is actually an effective tool in assessing likelihood of stewardship success, but a detailed assessment of the evidence on the subject lies beyond the scope of this paper. It is enough to note that significant evidence suggests *some* utility for social support in predicting the success of solid organ transplants including livers and hearts.^{25,26} In that context, the central question that follows is whether this impact is grounds enough to justify tolerating the problematic equity implications of using "social support" as a criterion.

What is important to emphasize is that both sides of this debate share a common belief in the value of working to improve the social support and psychosocial conditions of transplant candidates. Neither believes that such factors are inherently immutable. Rather, a general consensus exists that societal resources should be spent to optimize candidates for eligibility and to strive to support them during and beyond the transplantation process. The ethical disagreement arises in cases where such optimization cannot be achieved prior to listing.

The case for equity maximization received renewed attention in the context of ventilator triage during the early days of the COVID-19 pandemic. Several of the most widely debated proposals for ventilator allocation—both those that favored survival to hospital discharge and those that favored long-term survival “unjustly disadvantage[d] people with disabilities and patients with comorbidities that are at least in part attributable to inequities in the social determinants of health (e.g., poverty, unequal access to healthcare, and racism).”^{27-28,29,30} In other words, patients who had lower prospects for surviving to discharge, or for long-term survival, were more likely to be victims of long-term structural biases such as racism, economic challenges, and lack of access to adequate healthcare. Social support in the context of transplant may also prove an unintended proxy, at least in some instances, for various underlying structural barriers (e.g., racism, poverty, and isolation) to obtain the sort of social support looked for by transplant evaluation teams. Having family and friends healthy enough, sufficiently empowered financially, and able to reconfigure their own lives to the degree necessary to serve as primary supports for transplant patients is often a direct measure of underlying social capital. Under such circumstances, utility maximization and equity maximization stand in conflict.

Social Support as Medical Resource

Both the approaches discussed above rely on similar conceptions of “social support,” although they differ radically in their understanding of the ethical and practical implications of using such a standard as a clinical tool. What the utility maximizers and equity maximizers appear to agree on is that “social support” is an attribute *of the patient* as that patient enters the medical system in need of transplantation: Some patients will be married, others single; some will have close networks of friends, others will live in isolation. The psychosocial evaluator, under either model, is charged with determining whether to incorporate these factors into an assessment of capability to steward an organ successfully. One of the leading advocates of equity maximization emphasizes that social support “should be distinguished from financial support (e.g., patients’ ability to finance their transplant care and medications via health insurance and savings), which is a distinct criterion for transplantation that poses a different threat to access and set of normative considerations than a social support criterion.”³¹ Financial support is treated as a commodity, generally fungible, subject to large-scale modification.³² The legislature, for instance, could choose to use tax revenues to cover all costs related to transplant. In contrast, “social support” is generally viewed as *not* commodifiable. Purchasing spouses or friends for transplant patients, which likely strikes many readers as an absurdity, would indeed raise a wide range of ethical and legal challenges in contemporary society, not to mention the opposition of public sentiment. Although the nature of what is commodifiable does evolve—paid mourning, for example, is described in the Bible, survived in the novels of Balzac and Forster, and reemerged recently with the advent of companies such as Rent A Mourner—the prospect of transplant candidates buying a social support network is not remotely plausible.³³

What *can* be purchased are the specific attributes of a social network that increase the likelihood of stewarding an organ: namely, the services of a primary support person, and possibly a backup, trained to fill the same role in the transplant process as friends and family. Unlike purchasing a spouse or friend, hiring a primary support person already occurs in other settings, sometimes at taxpayers’ expense. In many jurisdictions, for instance, Medicaid covers at least partial home care for adults with disabilities. Long-term care overall costs federal and state Medicaid programs \$129 billion in 2019.³⁴ Personal attendants often prove very loyal to the patients they care for and serve as long-term companions who are as devoted as they are skilled. Extending similar services to transplant recipients might fulfill many of the requirements of social support. In particular, the transplant recipient is likely to require homemaking services, such as care with shopping and cleaning, and health services, which might range from assisting with medical adherence to helping with transitioning, toileting, and bathing. The insurance conglomerate, Genworth, estimates that full-time homemaking services cost \$4,957 a month and a full-time health aide costs \$5,148 a month. In other words, for \$10,105 a month—or \$121,260 a year—the taxpayers could fund most of the services that primary social support individuals are expected to play in

the lives of transplant recipients.³⁵ At first, this price tag may appear prohibitive. However, these figures would still represent only a small fraction of overall transplant costs: The average heart transplant bill in 2020 reached \$1,664,800, after all, whereas the average liver transplant ran to \$878,400.³⁶ One might think of paying for social support as a 10%–20% equity surcharge imposed on the taxpayers to overcome underlying structural biases in society. Moreover, most patients will not require such services: If only 10% of patients are currently being denied listing on account of insufficient social support, then such services might be targeted solely at these potential candidates. Psychosocial evaluators might assess social support just as they do now, but rather than declining to list candidates who fail the assessment, they would arrange to purchase social support services for patients through either public or private insurance.

The commodification of social support is not a panacea. Certainly, family and friends may offer intangibles that a paid primary supporter cannot: shared historical experiences or physical affection or specific forms of emotional connection. Yet, there is no evidence to indicate that these factors, rather than assistance with activities of daily living and monitoring and companionship, are the elements of social support that further organ stewardship. With appropriate training and experience, paid primary supporters may prove even more adept than family or friends at meeting certain needs, possibly increasing the odds for organ stewardship for patients with professional—as opposed to personal—supporters.

Another challenge of commodification will be the potential transplant patient who is unwilling, or psychologically unable, to accept the assistance of paid social support staff. Even in patients with existing social supports, some evidence suggests that “patients’ use of social support rather than the availability of support... may affect whether they are listed for transplant.”³⁷ This finding likely has implications for the use of paid support. In fact, some of the character attributes that may render a patient less likely to have social support at baseline, such as independence and suspicion, might also render connection with a paid primary supporter more challenging. However, the acknowledgment that the commodification of social support is not a cure-all does not justify forgoing such an option for those candidates who would value and benefit from such assistance. By thinking of social support as a medical resource, the justification for denying it to some patients, simply because they do not have access to it on their own, seems increasingly hard to excuse.

Conclusions

The concept of what can be ethically commodified has varied considerably throughout history and in various cultural contexts. Contemporary American society generally disdains the commodification of emotional engagement—whether paid escorts for love or paid mourners for death or the purchasing of “friendship.”³⁸ Unfortunately, this resistance to the commodification of the emotional, which may have social utility in other areas, creates a blind spot for policymakers and transplant clinicians. Although enhancing existing social support is considered desirable, the notion of buying social support for transplant candidates—whether funded publicly or privately—is largely, if not entirely, absent from the literature. That oversight creates an unnecessary conflict between utility and equity in transplant services. By commodifying social support to the degree possible, ideally with tax dollars, policymakers could ensure that all transplant candidates have an equitable opportunity to receive lifesaving solid organs. Nobody deserves to die because they do not have friends or family to rely on.

Notes

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