COMMUNITY AND STAKEHOLDERS PREFERENCES FOR ORGAN ALLOCATION AN OVERVIEW

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ABSTRACT

Although organs are a public resource, community preferences are not explicitly incorporated into organ allocation policies. Hence, this review aims to integrate various populations' studies to explore whether and how community members, alongside other stakeholders, believe that priority should be assigned to waitlist candidates.

The review, which includes an abundance of studies conducted in the US, the UK, and Australia, discovered that the vast majority of the public shares similar opinions. It is prepared to accept an overall diminution in the transplantation system's efficacy in exchange for a fairer and more equitable allocation. Namely, the public is willing to waive some gain in utility for growth in fairness in the distribution of organs. Therefore, we propose that key stakeholders are most likely to perceive an allocation system as efficient and equitable if the scheme considers those stakeholders' ideas regarding which criteria yield efficiency and equity.

Keywords: Community Preferences, Organ Allocation, Efficiency, Equity, Stakeholders' Preferences, Prioritization.

INTRODUCTION

Deceased donor organs for transplantation are a community resource; thus, it seems that allocation policies should, to some extent, consider community preferences regarding which factors should be prioritized in allocation decisions (Tong et al., 2010). Yet current allocation schemes do not explicitly incorporate such preferences, nor do they characterize them clearly, if at all. Nonetheless, a growing recognition that a better comprehension of community standpoints and inclinations is vital to design acceptable and balanced allocation systems (Schwappach, 2002 & Tong et al., 2012). Achievement of such an understanding is necessary to measure public values and perceptions systematically (Browning & Thomas, 2001). Therefore, this review's focal point is to integrate various populations' studies to explore whether and how community members, alongside other stakeholders, believe that priority should be assigned to waitlist candidates. In this paper, we discuss the preferences of various stakeholders regarding organ allocation, focusing on the general community and patients in need of transplantation. Moreover, we demonstrate the differences in preferences among medical professionals and other stakeholder groups.

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Search Strategy and Selection Criteria

Two electronic databases, PubMed and Google Scholar, were searched to identify references for this literature review. The following terms were used: "*organ transplantation*" and "*organ allocation policies*"; combined with "*efficiency and equity*," *"community preferences*," "*patients' perspectives," or "clinicians' priorities*." Search terms were also logically integrated with notions such as: "*systematic review,"* "*survey,*" and "*qualitative study."* Additional references were identified by carrying out a manual search of the sources cited in the retrieved articles. Further data were obtained by accessing websites and reports of national transplant registries (Ghofur & Asiyah, 2019).

The time frame selected for the publications was 1995–2019. A broad time frame was chosen to identify changes in community and stakeholders' preferences and perspectives throughout the years. Most of the included publications relate to community or stakeholders' preferences and values to allocate deceased donor organs for transplantation. Since public preferences are likely to be similar across allocation policies corresponding to different organs, the review was not limited to specific organ-related studies; hence, papers that studied kidney, liver, heart, or lung transplantation were reviewed. Articles for which full text was not available, were not in English or Hebrew, or did not delve into organ allocation preferences were excluded.

Community Preferences Regarding Specific Factors in Organ Allocation

In the following paragraphs, we will draw from surveys conducted by different researchers among diverse communities (Dolan & Shaw, 2004) to identify general community preferences regarding specific factors that might influence organ allocation decisions. We assume that community values, preferences, and standards about organ allocation are the same across different organs (e.g., kidneys, liver and heart).

Maximum Benefit

According to the surveys we reviewed, the public widely agrees that organs should be preferentially allocated to candidates who are likely to benefit from them the most regarding life expectancy and quality of life. This criterion caused the least moral discomfort among survey respondents and was rated as the most crucial parameter in selecting transplant recipients (Dolan & Shaw, 2004). Nonetheless, the public extended its perception into advantages other than absolute time gained. It took into consideration relative time and quality of life during time gained. Notably, however, in surveys in which respondents were requested to make hypothetical allocation decisions in situations in which a limited number of organs were available, the majority determined not to abandon patients with lower expected survival perhaps because they considered those extended criteria of benefit. Moreover, in a survey by (Howard et al., 2015). Respondents assigned more weight to pre-transplant life expectancy and Quality Adjusted Life Years (QALYs) than post-transplant life expectancy and QALYs, favoring those patients who were currently suffering more. This finding suggests that, despite the current tendency to shift toward allocation algorithms favoring high life expectancy after transplant (efficiency), emphasis

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also should be given to necessity as measured by pre-transplant life expectancy and quality-adjusted life expectancy.

Time Spent on the Waiting List

Overall, survey respondents expressed the opinion that priority should be given to candidates who have been waiting a long time for a transplant. This criterion is more objective and unequivocal compared with other measures; hence people feel less ambivalent when incorporating it into their decisionss. The majority of respondents perceived this criterion as culturally acceptable and treated it as an automatic parameter invoking a systematic and mechanical procedure, thereby enabling them and preventing them from making difficult decisions (Wilmot & Ratcliffe, 2002). Notably, however, a minority assumed that time spent on the waiting list interrelated with loss in life expectancy and sided with giving preference to candidates who had been on the waiting list for the least amount of time (Tong et al., 2010). These observations suggest that the public considers first come, first served (FCFS) an acceptable principle, with lengthy waiting times given a higher priority.

Fair-Innings

The principle of fair innings effectively refers to the idea that organs should be preferentially provided to younger recipients to give them an opportunity for a ‘normal’ life span. Likewise, it implies that patients waiting for a first transplant should be prioritized over those awaiting a re-transplant.

Regarding age, members of the general public have specified that, when organ availability is limited, they are willing to prioritize the young over the elderly. They believe that younger people should have an opportunity to live and expect them to have a better prognosis than older individuals. Nonetheless, respondents encountered difficulty defining the age threshold that should distinguish the young from the elderly and considered vast life stages rather than absolute age (Tong et al., 2010).

Concerning the distinction between primary versus re-transplant candidates, on the one hand, one might claim that re-transplant candidates should not be given the same precedence as primary transplant candidates due to poor prognosis and the fact that they have already been afforded a chance. On the other hand, it can be argued that re-transplant patients should be given equal priority based on distress since their first transplant was unsuccessful due to medical reasons (Ratcliffe, 2000). Indeed, public preferences regarding this criterion are equivocal. A survey by found that the general public preferred to allocate a higher number of organs to re-transplant patients discovered the opposite, namely, that people chose to give organs to first-time recipients rather than to individuals who had previously received transplants (Wilmot et al., 2004). found that people were reluctant to discuss this criterion at length.

Personal Responsibility

The majority of transplant clinicians think that patients ought to receive treatment regardless of the cause of their organ failure and following their potential to survive and benefit.

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However, there are concerns among health professionals and the general public that patients who have self-inflicted their disease may return to abusing their bodies, become non-compliant, and have poor medical outcomes. Some professionals have even argued that these patients are personally accountable for their medical situation. Thus should not be given the same precedence as patients who are not liable for their medical condition and have acquired the disease through no fault of their own (Pinho & Borges, 2019). Some indications and conformation imply that the general public shares this view (Neuberger et al., 1998).

Moral Deservingness

This criterion is an extension of the personal responsibility parameter. Moral deservingness is a consideration of '*worthiness*' based on social standing and lifestyle decisions. In the surveys we reviewed, the most compelling finding regarding this criterion is that most of the public gives less preference to candidates who engage in socially undesirable behaviors such as smoking, drug use, excessive alcohol drinking, and crime. Especially if such behavior is believed to have caused the illness (Sears et al., 2000). Contrarily, the minority feels that everyone deserves an opportunity or should receive equal priority. It claims that substance abuse may not be the patients' fault It is noteworthy that, though respondents agreed that moral deservingness should factor into the extent to which an individual candidate is prioritized, they did not believe that engagement in undesirable behavior should utterly deprive being allocated an organ (Howard et al., 2015). The notion of preferred status for registered donors also falls under the category of moral deservingness. Some respondents felt that, indeed, patients who are registered donors should be prioritized.

Social Valuation

The principle of social valuation refers to prioritizing prospective transplantation candidates based on social gain or utility considerations, such as employment status, occupation, citizenship, ability to pay, or the need to support dependents. The majority of respondents did not voice any preference based on patients' occupation, socioeconomic or employment status, citizenship, or ability to pay Nevertheless, respondents did believe that priority should be given to patients with family responsibilities in caring for dependents, particularly those with young children It is important to note that, in practice, reliance on social worth criteria such as these might be challenging and complex. In some jurisdictions, it might be illegal under equal opportunity legislation (Browning & Thomas, 2001).

Prejudice

This principle refers to making judgments based on personal ideological viewpoints. Many people were unwilling to deny candidates an organ transplant based on country of origin, religion, race, gender, sexual orientation, or political affiliation (Tong et al., 2010).

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Medical Urgency

This criterion refers to illness severity and the necessity of transplantation as a means of saving a candidate’s life. Survey respondents indicated that medical urgency in terms of risk of death should be a factor in prioritizing organ allocation (Stahl et al., 2008). However, they were reluctant to state any predilection for the candidate’s physical and social characteristics in this regard, such as age, gender, post-transplant prognosis, lifestyle, social factors, social utility, citizenship or ethnicity, time on the waiting list, or previous transplant (Tong et al., 2010).

Incorporation of Community Preferences into Organ Allocation Policy

The discussion above suggests that community members hold opinions regarding transplant candidates’ prioritization, and these preferences depend on a multifaceted balance of efficiency, social valuation, morality, fairness, and equity principles (Tong et al., 2010). The general public is capable and willing to differentiate and distinguish among groups of individuals based on their features (Ratcliffe, 2000) and prepared to answer difficult ethical trade-off questions (Stahl et al., 2008). In other words, people can differentiate among potential recipients according to a range of characteristics beyond their estimated benefit from treatment.

Taken together, the various surveys we reviewed reveal that the public considers transplant recipient age and prognosis to be the most critical factors in determining the priority ranking for organ allocation. More specifically, a longer waiting time, better prognosis, younger age, and being a parent were the most frequently chosen criteria for organ allocation decisions. Notably, although some community members felt that organ allocation should yield maximum benefit, they were unsure and hesitant about what constituted such benefit and how it could be adequately quantified or qualified. Additionally, in contrast to current guidelines of organ allocation, the public considers the patient’s social worth, lifestyle choices, and behavior to be relevant criteria in determining the extent to which they should be prioritized to receive an organ (Tong et al., 2010).

More generally, the surveys indicate that community members can deliberate and decide about organ allocation and have a fluid concept of what they deem fair and valid. Accordingly, we propose the public should be allowed to seek clarification, engage in discussions, express their standpoints, and listen to other opinions. In turn, decision-making entities (e.g., the United Network for Organ Sharing, Eurotransplant, etc.) should consider community preferences when formulating their guidelines (Frerichs et al., 2017). However, a challenge remains to incorporate and resolve diverse and mutually incompatible views (Tong et al., 2010).

It is noteworthy that, in the US and the UK, the public does have a formal role in health-related policymaking. Specifically, in the US, the public can provide feedback on policy proposals put forward by the US Health and Resources and Services Administration, and its comments constitute an essential part of the policy development process. The Department of Health and Human Services hosts forums, public hearings, and summits as a means of learning about public concerns, allowing community members to share ideas, and identifying areas for improvement. There is a declared government policy of establishing citizen panels and local advisory forums in the UK, and primary care trusts seek to connect with public opinion systems (Geddes et al., 2005). However, the extent of public involvement or its effect on the process is unknown, and we are unaware of the contributors' identity or motives (Degeling et al., 2015). Therefore, the all-encompassing process ought to be formal and standardized.

In practice, many factors considered in current allocation policies are consistent and coherent with the community preferences outlined above, such as higher priority for younger patients, patients who have spent a long time on the waiting list, and patients with high medical urgency (Browning & Thomas, 2001). However, several factors that the public views as important—such as donor status, lifestyle, number of previous transplants, and whether the recipient has dependents or caring responsibilities (Howard et al., 2015) are not taken into account. Regarding the quality of life, overall, people are utilitarian, implying that they would rather give an organ to a patient who would achieve maximum utility from the transplant. But given two patients who would generally benefit equally, public preferences seem to skew in favor of the patient who is currently suffering more. This observation seems to imply that the public regards achieving a satisfactory level of quality of life as a critical criterion for transplantation. Still, once this criterion has been fulfilled, other factors come into play (Stahl et al., 2008). People attribute importance to the context in which preferences are sought (Ratcliffe, 2000).

Table 1 presents a comparison between formal legislation and public views regarding kidney allocation.

Table 1

COMPARISON BETWEEN FORMAL LEGISLATION AND PUBLIC VIEWS REGARDING KIDNEY ALLOCATION POLICY

	Formal guidelines/legislation	Community preferences
Maximum benefit/Capacity to survive and benefit	Allocating better-deceased donor kidneys to waitlist candidates who have longer life expectancy after transplantation	A most crucial parameter in the selection of transplant recipients
Time spent on the waiting list	The points system adds points for waiting time	Key factor. Longer waiting times are given higher priority
Age	Longevity matching-allocating more deceased donor kidneys to younger adult	Influential factor prioritizes the young over the elderly
Moral deservingness	Decisions depend on medical evaluations. Clinicians decline patients when they believe they are abusing their body, non-compliant, and likely to have a poor medical outcome	Less preference is given to candidates who are engaged in socially undesirable behaviors
Social valuation	Illegal under equal opportunity legislation	There is no preference based on the patient's occupation, socioeconomic status, employment status, citizenship, or ability to pay. Nevertheless, priority is given to patients with 'family responsibilities'
Prejudice	Not admissible	Not acceptable
Medical urgency	Priority allocation of kidneys based on medical urgency is limited to patients developing severe complications or where dialysis can no longer be reliably performed	The allocation should preferentially be determined by medical urgency

Patient's Perspectives and Preferences

On top of considering the general public's preferences, decision-makers should take into account the perspectives of specific key stakeholder groups when evaluating the acceptability of an allocation policy. Dialysis patients and transplantation candidates are critical stakeholders in this regard and can provide relevant, practical, and compelling standpoints (Geddes et al., 2005; Gibbons et al., 2017; Tong et al., 2012).

In a survey of 232 patients with chronic kidney disease, Geddes et al. (2005) found that patients value reducing waiting time while on dialysis therapy more than they value the estimated benefit of allocating kidneys to patients not yet on dialysis therapy. Moreover, patients regard reducing time on dialysis as a more salient benefit than minimizing HLA (human leukocyte antigen) mismatches. The researchers also found that, contrary to current policies, patients believe that age should not be used to determine the designated adult recipient.

In a survey of multiple stakeholder groups, including 908 patients with renal disease, (Clark et al., 2012) found that patients value prioritizing candidates with close tissue matches and give significant value to additional factors, such as long waiting times, younger age, and people with dependents. Patients considered the severity of the disease to be a relevant factor in allocation decisions; notably, they prioritized disease severity differently across different types of conditions. The researchers noted that both times spent waiting and the donor/recipient tissue match's quality are significant to health workers and patients alike.

In a recent qualitative study based on interviews with UK patients who either had received or were awaiting kidney transplants, (Gibbons et al., 2017) discovered that patients instinctively attributed primary importance to donor-recipient matching (human leukocyte antigen and/or blood). Non-medical aspects were considered secondary to having a well-matched kidney. Patients further expressed the perception that those who have the most medical need for a transplant should be prioritized. They also acknowledged that kidneys should be assigned to those who have the best prognosis of surviving and maintaining a functioning graft. Patients were more inclined to prioritize younger recipients, especially children, based on the anticipation of increasing life expectancy. Although patients did not rate any variable as unimportant, the following variables were rated as the least important considerations for kidney transplant allocation: being older than 60 years, having other medical conditions, and having children or dependents.

An Australian study involving focus groups of patients with kidney disease revealed four main themes underpinning patients' rankings of the factors that should influence allocation decisions: (1) enhancing life (improving quality of life, increasing life expectancy, minimizing graft loss, and estimating the better chance of survival); (2) medical priority (medical urgency and time on dialysis); (3) recipient valuation (priority to younger patients, and avoidance of unwarranted discrimination); and (4) deservingness (longer time on the waiting list, significance of treatment adherence, and lifestyle choices repercussions). According to that study, patients believe that the extent of matching or compatibility is the essential factor to be considered in allocation.

Tong et al. (2012) suggest that patients priorities are not based on utilitarian considerations-a desire to achieve the graft's best possible outcome. On the contrary, respondents' preferences were influenced by their own illness experiences, strong empathy and

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compassion, aspiration to gain justice for other patients (equity), and close interaction with the healthcare system. For example, even though patients prioritized graft–recipient compatibility, their approach was not motivated by a concern for organ wastage, but rather by distress regarding the emotional trauma that graft rejection would ensure.

The studies outlined in this paper yield two additional noteworthy findings: First, in principle, patients believe that young people should be prioritized; however, in reality, they are unwilling to sacrifice a chance for an organ and disagree that older recipients should be disadvantaged. Second, patients believe that priority should be given to waitlisted recipients who will respect and take care of their grafts; this preference is based on a desire for fairness rather than maximization of utility.

As in community preferences, some of the patient perspectives are compatible with current organ allocation policies, whereas others differ in several aspects. Additionally, patient and public preferences share some similarities, such as social deservingness and recipient valuation in allocation protocols Patients' willingness in the studies mentioned above to share their point of view in a time of suffering and agony illustrates that, if given an opportunity, they will be eager to participate and contribute to discussions about how to balance the different parameters (Louis et al., 1997).

Differences in Preferences among Medical Professionals and Other Stakeholder Groups

In the previous sections, we briefly alluded to the commonalities and distinctions between current criteria for organ allocation and the criteria that the general public, and patients, believe should be prioritized. Given that medical professionals' opinions largely shape these allocation policies, it is of interest to identify how these professionals' preferences diverge from those of other stakeholder groups and whether different groups of medical professionals hold different opinions.

According to a survey by (Neuberger et al., 1998), there are considerable differences in priorities and preferences among members of the general public, family physicians, and hospital clinicians. In the survey, respondents representing the general public prioritized age, transplant outcome, and time on the waiting list, whereas family physicians indicated that transplant outcome, age, and likely work status after transplantation were the most important criteria. Hospital clinicians rated transplant outcomes, work status, and non-involvement of substance abuse as the most significant factors. However, all three groups agreed that anti-social behavior and substance abuse should hamper entitlement to transplantation. Notably, these views diverge somewhat from the official positions of the American Medical Association (Davis & Wolitz, 2006) and the Australian National Health and Medical Research Council, which state that factors such as the ability to pay, contribution to society, perceived obstacles to treatment like alcohol abuse, transport difficulties, anti-social personality, the contribution of the patient to the medical condition, and past use of medical resources, are unacceptable criteria for selecting organ transplant patients. It can be concluded from the (Neuberger et al., 1998) that neither the general public nor the medical profession fully shares these principles and standards Kedudukan Undang-Undang Pemerintahan Daerah Dalam Sistem Pemerintahan. Seminar Sistem Pemerintahan Indonesia Pasca Amandemen UUD 1945 (Clark et al., 2012).

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Findings extend Observations showing that healthcare professionals' opinions regarding which criteria should be prioritized are significantly different from those of patients. In a survey they administered, observed that professionals assessed prioritizing better tissue matches less than patients but valued prioritizing those with dependents more. Professionals also prioritized patients with no diseases over moderate diseases predominantly affecting life expectancy, whereas patients did not. Furthermore, healthcare professionals were more likely than patients to prioritize those with severe diseases over those with moderate diseases affecting their quality of life. These disparities suggest that if healthcare professionals' inclinations and preferences prevail in transplant decision making, allocation decisions might inadequately reflect patient perspectives (Cleemput, 2018).

Ultimately, we propose that an optimal allocation system must strive to find a balance that considers and respects community values and patient perceptions while preserving sustained clinical effectiveness (Johri & Ubel, 2003).

CONCLUSION

Our analysis converges towards a proposition that, we suggest, can improve the current line of thought that dictates allocation policies. Specifically, we propose that key stakeholders including healthcare clinicians, patients, their families and carers, donor representatives, and the general public are most likely to perceive an allocation system as efficient and equitable if the scheme considers those stakeholders' ideas regarding which criteria yield efficiency and equitability. Though it is infeasible for a complex system to reflect all stakeholders' priorities perfectly, it is notable that decision-makers do not explicitly consider the community's preferences when devising allocation policies, mainly since donor organs are a community resource. We suggest that formal consideration of the community's values and beliefs would go a long way towards improving organ donation and transplantation programs' effectiveness.

The conclusion of echoes this central idea. The researchers claim that transplantation policy should not blindly reflect the perception and specific standards of transplantation professionals or healthcare researchers, who generally come from different backgrounds than most general public members. Nor should such policies solely reflect the attitudes and morals of the general public. Instead, efficient and equitable policies arise when policymakers allow public input to inform their decisions

We suggest that this literature review can be used as a foundation for future studies aiming to identify optimal kidney allocation policies. The study highlights the significance of incorporating diverse stakeholders' preferences and stresses that this method might yield a more efficient and equitable system than currently available policies.

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