

18. Considering the Role of Public Health

Organ Shortage, Global Justice, and the Paradox of Prevention

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1. Introduction

What are the chances that a 13-year-old child with end stage renal disease (ESRD) will undergo a kidney transplant, or at least be treated with dialysis? Sadly, the answer is not only clinical but also sociological in nature, deeply rooted in economic, political, and social structures. If, for example, this child lives in a lower- or middle-income country, her chances of being diagnosed in time to receive such care are low (Muralidharan/White 2015; Muller 2016). However, if this child was born in a Scandinavian country, she would have a good chance of receiving a transplant that would lengthen her life by many years.

The gap between organ demand and available supply, even in countries where it has been reduced slightly in recent years, is abysmally large. Patients across the globe die every day awaiting a needed organ. In the United States, for example, a significant disparity between organ supply and demand remains, even as a record number of transplants have been performed. Data from early 2020 provided by The United Network for Organ Sharing indicates that 112,605 Americans are in need of an organ transplant. But in 2019 there were only 39,718 successful organ transplantations (from both living and dead donors). Supply is not meeting, nor will meet, demand (UNOS 2020).

We all know that health disparities exist. In transplant medicine, however, disparities and equity are generally discussed by bioethicists in terms of access to transplantation for ESRD and other chronic health conditions that lead to transplant. In this paper, we show why transplant bioethics alone cannot solve many of the problems facing transplant medicine, and we turn instead to public health for answers. In general, public health employs policies of prevention to address conditions *before* they develop into chronic or fatal diseases. We believe there is an unmet need to discuss prevention in the context of organ transplantation and to explain how public health ethics approaches could both contribute to reducing the organ shortage and provide moral guideposts for such an approach. As public health practitioners, we also believe our moral obligation is to assist those with inherited, chronic, and acute conditions *before* transplants become necessary. Thus, in this paper we argue that the field of transplant medicine will be better able to address its challenges if it incorporates prevention

modalities and public health ethics into an overall approach that seeks to reduce the costs and health burden of diseases associated with the need for organ transplant.

2. Background: Public Health Ethics

Public health emerged as an organized discipline during the 19th century with the goal of improving the health of the nation (Porter 1999; Berridge/Gorsky/Mold 2011). While its initial interests focused on infectious diseases, sanitation, and hygiene, over time, its scope has grown to include health promotion and address the rise of chronic diseases and health inequalities. Yet, emerging and re-emerging infectious diseases – from HIV to SARS to SARS-CoV-2 – constantly remind us that the battle against contagious diseases is far from over. In many parts of the world, the ‘double burden’ of both infectious and chronic diseases imposes a growing burden especially upon low- and middle-income countries, which have limited resources and struggle to meet the challenges of long-existing problems associated with infectious diseases and the rapid rise in cardiovascular diseases, diabetes, cancers and obesity-related conditions (Bygbjerg 2012).

Furthermore, low- and middle-income countries are also burdened by the interaction of poverty, scarce health-related resources, and a high burden of chronic disease. For example, according to estimates from the Global Burden of Disease study in 2015, globally more than 2 million people died in 2010 because they had no access to dialysis, mostly among the poor (Crews/Bello/Saadi 2019). Such statistics point to a major crisis of chronic kidney diseases (CKD) globally, including the uneven distribution of CKD among poor people. A public health approach can broaden the discussion to include a focus on prevention efforts, which are a less costly and more sustainable approach to the transplantation crisis.

It should go without saying that this is not a solution for many patients currently in need of and waiting for organs. It is, however, about the need to include a public health perspective to improve investment in programs that seek to reduce the burden of disease in conditions ranging from diabetes to cirrhosis to hypertension – in order to alleviate the downstream need for transplantation itself. A public health approach is beneficial because it adds to quality of life, it is easier and less costly to accomplish than cure, and it reduces health inequalities. Take the example of diabetes: it can lead to CKD, and primary prevention campaigns targeting populations at-risk for diabetes may have the beneficial impact of preventing diabetes itself and thereby reducing the further downstream need for organ transplantation. We would rather approach populations this way, instead of treating those with high rates of chronic kidney diseases (which are significantly more prevalent in low socioeconomic groups) and can lead to end stage renal failure and alter organ transplant (especially in low-socioeconomic populations) (Nicholas et al. 2015).

The ethical challenges of organ donation have become more pressing as transplantation has become more efficient (Jonsen 2012; Veatch 2000). But despite the efforts of academic bioethicists and policy makers to assuage the public's fears about being a donor, organ donations around the world remain low. This is due to several factors, including fears about risks from the procedure (Sanner 1994) and widespread concerns about how to measure brain death prior to organ harvesting (Belkin 2014). These con-

cerns are compounded by imperfect policies for both increasing donorship and fairly selecting the individuals to receive a donor organ (Chatterjee et al. 2013).

Answers to these challenges may lay outside of traditional bioethics and clinical discourse. Here, we turn to public health ethics and practice for guidance on novel strategies to address organ shortages and global disparities in transplant. Viewing organ transplantation through a public health ethics, rather than a clinical ethics lens, helps bring to the fore very different ethical concerns, and calls into question why most organ transplant-related resources go to costly medical solutions instead of upstream prevention efforts.

There is very little literature examining how prevention efforts related to kidney, liver, and heart disease, as part of wider public health efforts, could help reduce demand for organs. Leading journals on organ transplantation rarely publish on this topic. Existing literature on organ transplantation and prevention yields mainly articles discussing prevention of post-transplant complications, showing that even prevention-focused discussions are almost exclusively focused on clinical aspects.

Current discussions have not adequately served the public's health, nor has the public health ethics and prevention discourse. We believe that this has severely constrained popular and policy discussions about transplantation. The bottom line is this: prevention is necessary in order to reduce organ shortage and the inequalities that often accompany the scarcity of resources; we can address the fundamental problem of scarce resources by preventing the need for transplant itself. As we describe below, such a shift has implications not only for academic debate, but for how policy makers and the general public understand and prioritize the challenges currently facing transplantation and organ procurement.

2.1 Normative Framework of Public Health Ethics

Public health is a function of the complex relationship between the social actions of the state, institutions, and groups of citizens, and is best conceptualized by understanding the socio-philosophical basis of the relationship between the individual and the state. The liberal approach to public health focuses on the right of an individual to defend his/her freedom in the face of coercive state actions, even when these actions are carried out in the interest of the greater good (Bayer/Fairchild 2004; Kass 2001). On the other hand, a communitarian approach views public health care as part of community welfare (cf. Walzer 1983). The authority of the state in public health is broad, permitting extensive interventions in the private sphere. Hence, critics view public health care as open to exploitation by the state, which can engage in coercive practices, trampling on individual rights. Traditional issues of contention have included measures such as vaccination, quarantine, medical examination of immigrants, forced sterilization, and other eugenic measures. (Alberstein/ Davidovitch 2011). Mutual trust between the public and health systems has long been recognized as integral to the long-term success of policy initiatives. Yet, trust cannot be assumed, and trust building should be a fundamental part in planning and program implementation (see also chapter 4 in this book). The view of health systems as socio-political entities, or even tools to achieve social justice, underscores the importance of trust in obtaining equality and equity in health promotion (Ezezika 2015).

The allocation of resources is one of the central aspects of public health ethics, with values such as equity and cost-effectiveness playing key roles, and different potential public health programs competing for limited public resources. How can we balance efficiency with equity and individual rights with the public good, and what institutions are the most appropriate to carry out the public health agenda? The distribution of organs for transplantations faces these very ethical challenges, including understanding organ shortage as not just an individual problem but a societal one, and addressing overall organ supply and demand through a prevention-driven approach that reduces the need for transplant by improving the public's health. Framing organ shortage this way forces us to also consider the fundamental causes of chronic diseases, their uneven distribution within and between societies, and the greater burden this uneven distribution (or health disparity) places on poor people and low- and middle-income countries.

While prevention provides a novel approach to thinking about how to improve care for patients and populations, we must also turn to public health ethics for theoretical justifications as to why we should take such an approach. As we have already stated and is widely described in the literature, bioethics tends to privilege the individual, insuring, for example, the protection of those enrolled in research studies, of patients in clinical settings, and of the fair distribution of organs for transplant. By contrast, public health ethics provides a moral foundation to protect the health of populations. For example, a public health ethics approach can help institutional review boards weigh potential harms to populations in research that may be associated with outcomes that fuel stigma and discrimination. Public health ethics can also give practitioners and policy makers alike a way to consider how to balance individual rights with the need for collective sacrifices in cases such as quarantine or mandatory public health laws, including requirements for vaccination, use of motorcycle helmets, and automobile seatbelts.

The ethical principle of justice – which, according to Gostin and Powers, emphasizes “the fair disbursement of common advantages and the sharing of common burdens” (2006: 1053) – is central to a public health ethics approach to reducing the burden of disease, especially if that disease or condition disproportionately impacts vulnerable communities globally. Focus on such “fair disbursement” (*ibid.*) creates obligations for public health actors to work towards ameliorating health inequities by addressing determinants of health. Ideally, this would happen in multiple domains, including local, state, and federal government efforts, NGO engagement on these issues, and through communities who fight to redress public health disparities. There are disparities between rich and poor nations in terms of transplant infrastructure; a woman in Pakistan, for instance, has less access to dialysis treatments or to transplantation than a woman at same age with the same medical condition in the West (Ghods 2015). There are also disparities between rich and poor countries in terms of the burden of chronic and infectious disease that can lead to transplant (Sakhujia/Sud 2003). Such disparities are rooted in health determinants, including poverty, health infrastructure, environmental hazards, education, and culture, among others.

Approaching transplant through the lens of prevention raises several important practical and ethical issues that are rooted broadly in public health ethics, specifically in the concept of justice. First, in this context prevention itself must be seen as a public good. If diseases are prevented in the first place and people are thus healthier – for

example, a reduction in diabetes and hypertension that can lead to kidney transplant, a reduction in alcohol consumption and/or the prevalence of hepatitis B and C may lead to a decrease in liver failure, and a reduction tobacco use can lead to a decrease in coronary artery disease – then prevention has had the desired effect of both reducing the individual burden of disease and preventing illness in the first place, thus reducing the demand for organs. Because many of the diseases that can lead to organ failure and transplant are not evenly distributed within populations and between societies, the prevention of illnesses that can lead to transplant is satisfying a justice-based approach.

We can also look to more granular aspects of public health ethics, including the role of human rights and social justice theory, in considering how public health ethics can inform our approach to the ethics of transplantation. A human rights approach, for example, offers a universal framework to advance justice in public health, elaborating the freedoms and entitlements necessary to realize dignity for all and create, as Jonathan Mann once wrote, “what are the societal (and particularly governmental) roles and responsibilities to help promote individual and collective well-being” (1996: 924). Indeed, preventing disease that leads to transplant will protect and promote the pre-conditions of human health, as it is focused on social and economic determinants of health.

With international law evolving to address threats to health, a rights-based approach transforms the power dynamic that underlies public health. Moving from human rights to social justice is crucial because social justice is viewed central to the mission of public health. It has been described as the field’s core value: “The historic dream of public health [...] is a dream of social justice.” (Beauchamp 1999: 105) Two aspects of social justice – promoting health on the population level and fair treatment of the disadvantaged are fundamental aspects of public health. This understanding leads us to consider the multiple causal pathways to numerous dimensions of social inequities. These include poverty, substandard housing, poor education, unhygienic and polluted environments, and social disintegration. Thus, to understand prevention and its implication for transplantation, all these should be taken into consideration.

Global statistics shine a light on the impact of social inequalities on transplant medicine. For example, a major challenge for low-income countries is the complete lack of transplant infrastructure. Only twelve per cent of low-income countries worldwide report, for example, any kidney transplant infrastructure, and all transplants in those countries come from live donors. Furthermore, the global burden of chronic kidney disease – which can have both infectious and non-communicable causes ranging from diarrheal diseases to malaria to pre-term birth – have unequal impacts on populations between low- and middle-income countries and wealthy nations because of the lack of transplant infrastructure (Luyckx et al. 2018)

The Sustainable Development Goals, rooted in a justice approach to public health and adopted by all United Nations member nations, seek to redress persistent disparities multiple domains, including health, education, and the impact of climate change. (United Nations 2020). Sustainable development goal three specifically addresses health – “ensure healthy lives and promote well-being for all at all ages” (ibid.) – and can be applied to the social and environmental determinants of health that lead to both the inequities that produce the unequal burden of infections and non-communicable diseases globally, and the conditions that lead to poor or non-existent organ transplant

infrastructure in low- and middle-income countries. Only by developing specific policies that addresses these disparities can we begin to reduce the burden of diseases that lead to a need for organ transplant, thus reducing the demand. This justice-based approach to organ transplant is not a solution to this crisis; however, preventing the need for a significant number of transplants would be a step in the right direction. (Luyckx et al. 2018) Further research is needed to quantify how prevention would both improve the health of populations impact by communicable and non-communicable disease, but also concomitantly how the demand for transplant would change.

2.2 The Paradox of Prevention

Finding the right balance between the more individual-focused, clinically oriented model of health care and public health prevention and community-based approaches, with strong emphasis on social, economic and political determinants of health, remains a global challenge that impacts resource allocation and availability. While many declare that prevention is better than cure (as it adds quality of life, is easier to accomplish, and is often cheaper), in practice prevention is regularly marginalized and deprioritized, and it is generally the first to face cuts during times of fiscal austerity. Harvard's former dean of their School of Public Health, Harvey Feinberg, described this as the 'paradox of prevention' (Feinberg 2013).

As Feinberg points out, the paradox is driven by several challenges, including that prevention's successes are generally invisible, that prevention lacks drama and immediacy, and that it generally requires time-consuming investment with delayed success. Such barriers have, in large part, occluded the application of prevention and public health principle to organ donation. Saving one person's life by transplant will always look more appealing than preventing kidney failure, when apparently nothing 'happened': the transplant is not needed and there is no drama. The current challenge is how to leverage the public's awareness of, and personal connection to, conditions that necessitate transplantation and move both the public and policy makers to develop ethical strategies to subvert the paradox of prevention.

Despite the potential benefits of a population-based prevention approach, it remains the least common strategy and an example of Feinberg's 'paradox of prevention'. The need for prevention-based strategies in transplant medicine are obvious: organ transplants are very expensive. In 2017, *Fortune* magazine, following the consulting firm Milliman, estimated the cost of kidney transplantations to be 415,000 USD and a heart transplant to be 1.4 million USD (Rapp/Vendermey 2017). In a more recent review, Fu et al. (2020) suggest that associated rise of transplantation costs, certain patient groups may not benefit from transplantation in a cost-effective manner compared with dialysis. Their analysis underscores that transplantation is indeed expensive, but it is cost effective, especially for young people on dialysis. The huge cost of transplants has led to the creation of inequalities related to who has access to transplantation care. It has also led to black markets for organs, both within and between countries (Scheper Hughes 2000). The burden of organ demand on low- and middle-income countries is particularly acute, considering that non-communicable diseases that can lead to organ failure, such as diabetes, are on the rise, especially in poor populations (Crews et al. 2019). Without fundamental structural change, and a change in priorities, the public health and ethical dilemmas related to organ transplant cannot

be adequately addressed. The paradox of prevention is more than just a heady concept; it is a barrier to reducing suffering and establishing the best care for patients and populations globally by preventing the need for transplantation.

The principles of public health – distinct from those of clinical medicine, which are more focused on medicalized treatments of individuals in clinical setting – are based on a population approach, an approach to health that aims to improve the health of the entire population and to reduce health inequities among population groups. In order to reach these objectives, this approach looks at and acts upon the broad range of factors and conditions that have a strong influence on our health. Its components include: (1) a focus on primary care prevention and health promotion; (2) targeted studies of the economic, political, and environmental factors that may affect populations and cause diseases; and (3) implementing and translating these studies into policies and ways in which the modification of social and environmental variables may promote public health aims (through active social and political involvement) (Scutchfield/Keck 2009).

3. The Social Determinants of Supply and Demand in Organ Transplants

Organ shortage is a universal problem, its severity varies across countries, and it is influenced by social, cultural, economic, and political factors between nations. A public health approach to organ shortage maps these differences and seeks ways of limiting the demand in the first place. Above we have described general differences between a bioethics approach and a public health ethics approach. Below we propose how to analyze organ shortage from the perspective of public health ethics, and how this perspective sheds light on two limitations in the current transplant ethics discourse: how the global burden of disease drives up demand in kidney transplantations, and how different socio-cultural approaches to brain death impact the supply side of organ transplantation.

3.1 The Global Burden of Kidney Diseases

The International Society of Nephrology estimates that 850 million people worldwide suffer from CKD. It is hard to assess how many of them will develop ESRD and will need to undergo a transplant or use dialysis machines in order to sustain their life. It is clear, however, that preventing CKD patients from becoming ESRD is a primary mission for public health. Li et al. (2020) define three lines of prevention of CKD. First, intervention before the onset of renal disease; second, diagnosing and prompt treatment before the condition worsens; and third, managing an existing condition to prevent disease progression and complications. Following this categorization of primary, secondary and tertiary lines of prevention, it is possible to focus on different factors of, and tailor a prevention policy for, CKD in each country or global region.

Li et al. evaluate the risk factors for de novo CKD and pre-existing CKD progression as follows: around 50 per cent suffer from diabetes, approx. 25 per cent have hypertension, and ten to 20 per cent are obese. Less than ten per cent have polycystic kidney disorder, a direct heredity condition of CKD that can lead to ESRD. Most of CKD could

have benefited from a prevention policy that would create structural changes that encourage them to conduct a healthy way of life (Li et al. 2020).

Studies have shown the low awareness of people with CKD to their condition. This finding was significant in both publicly funded health systems such as in Quebec, Canada (Verhave 2014), as well as in privately funded health systems, including the US health care system. Ene-lordache et al. (2016) found low awareness of CKD symptoms in six different regions of the world. In low-income countries, they found risk factors to be human immunodeficiency virus (HIV) infection, tuberculosis, and exposure to toxins. These factors comprise up to 40 percent of CKD patients, and they are different from the risk factors that Li et al. (2020) found in high-income countries. These differences call for a different line of prevention in different global contexts. Whereas prevention would focus on boosting awareness of the hazards of salt and sugar-rich diets in high-income countries, other preventive measurements are needed in regions the main causes of CKD are from infectious diseases. Yet in both contexts, however, not only are risk factors different, but they tend to be unevenly distributed across low and high socio-economic status.

Prevention of CKD is in large part a matter of raising awareness of risk factors for CKD. It is not clear who bears the responsibility of addressing this awareness and what role health systems, and more broadly the state, have in boosting this awareness and helping populations to make healthy choices. The questions of awareness and responsibility entail a much more detailed and longer discussion than we can develop here. The importance of awareness and prevention, however, is clear: it can save the lives of many on today's lengthening transplantation waiting lists. Identifying risk factors and populations at risk and develop healthy policies to strengthen primary prevention could reduce the burden of waiting lists and the need for transplantation (Li et al. 2020; Ene-Lordache et al. 2016). Prevention strategies should also include secondary prevention (early detection of illnesses) and tertiary prevention for those target populations that are not yet on the waiting lists but are prone to develop conditions that might lead them to end-stage diseases. The paradox of prevention lies in the understanding that prevention is advisable both from clinical, social and economic perspectives, yet prevention is generally less prioritized. It is only when face organ shortage that we start to think of prevention.

3.2 Social Solidarity and Organ Donation

Whereas prevention can help reduce the demand for organ transplantations, public health measures can also help to boost the supply of organ donations. In contrast to many other medical therapies, organ replacement cannot be performed without the cooperation of the public. Advanced and sophisticated as it is, transplant medicine cannot do without a collective willingness to donate organs. This is the point where public health can ease the burden of organ shortage by focusing on how to increase organ donations rates.

These efforts vary from one social context to another; each context poses its own difficulties and challenges. Generally, scholars point to the controversy over brain death (Youngner et al. 2002), bodily conceptions (Schweda/Schicktan 2009), and lack of information (Rady et al. 2012) as central factors hindering organ donation. Researchers have also identified that these barriers are more evident in specific social

groups such as racial and ethnic minorities (Johal et al. 2018; Li et al. 2019; Suliman et al. 2019) and are also impacted by socioeconomic status (Shah et al. 2018). These sociological features pose a challenge to policy-makers to encourage less inclined populations to donate organs. The premise is that if such social and cultural barriers could be removed by educational campaigns, there will be less reluctance to organ donation within these populations. We suggest that a public health approach to problems of organ donation should prioritize fostering social solidarity, thus creating a different context in which organ donations decisions are made, before addressing the specific barriers to donation itself.

Although seemingly self-evident, social solidarity is an ambiguous concept within public health (Dawson/Verweij 2012). Prainsack and Buyx (2011) define it in terms of costs that one pays for the sake of a collective good and point to organ donation as an act that builds social solidarity. Durkheim, on the other hand, defined solidarity as “pre-contractual,” (2014 [1893]: 158) that is it precedes rational acts towards the collective good. For both definitions, the link between solidarity and acts on behalf of the collective might be tautological, deserving further analysis. It is not clear whether social solidarity is simply ‘out there’; if not, how can it be fostered? Is it an explanation for altruism and voluntary acts, or is it a different separate concept?

Nonetheless, researchers have suggested that social solidarity as a motivation for organ donation must be built on reciprocity (Schweda/Schickltanz 2009). Siegal and Bonnie (2006) have called to replace altruism with social solidarity, which they also base on the concept of reciprocity. For them, solidarity defines one’s group belonging, and within this belonging one can expect reciprocal acts. These acts are not oriented toward a complete stranger, as in pure altruism, but rather to someone who shares some social characteristics with the donor.

In more than one sense, such reciprocity already exists in the ethical repertoire of organ donation. Organ donation from family members reflect the same logic: one donates to her kin member only due to their family connections. A public health approach would expand this feeling of a family to the community, thus fostering solidarity. This requires an ethical shift, since such donations will be based on a much closer resemblance between the donor and recipient than in blind altruistic donations.

Such an approach can already be found in organ donation prioritization policies (Lavee/Brock 2012), in donations in return to a future prioritization of a family member in need of an organ (Martin/Danovitch 2017), and in private agencies that match recipients according to the donors’ grouping conditions. These initiatives, however, run the risk of being more exclusive than inclusive, turning organ donation to something akin to a club membership.

We believe that a public health approach to social solidarity in organ donation should consider first the public’s good in terms of equity and equality. Although the state or any public agency cannot enforce organ donations, just as it cannot authorize organ sale, we do believe that social solidarity, alongside altruism, is a productive concept to work with in organ donation. Social solidarity’s benefit lies in a stronger commitment of the group’s members towards each other. In a model promoting both solidarity and altruism, where social solidarity leads to donations within the in-group members, and altruistic donations to strangers are allocated according to shorter waiting lists, it is possible to increase the supply of organ donations. Such a model can be multi-level: a communal-oriented approach to encourage donations among commu-

nity members, where solidarity might be stronger, and a nation state-level approach to encourage altruistic donations towards strangers in need.

4. Conclusion: Reassessing Organ Transplantation from the Viewpoint of Public Health

This paper began with a claim: that to reduce organ shortage, policy makers must shift from understanding transplant needs as largely clinical in nature to an alternative view rooted in public health approaches. This shift can help draw attention to the relationship between chronic and infectious disease that disproportionately burdens lower- and middle-income countries (and people living in poverty more generally), the impact that such diseases have on the need for transplantation, and how we should approach their prevention from a social and economic determinants of health perspectives. A separate but parallel discussion using concepts from public health ethics can also inform the discussion on reducing organ shortage needs by developing alternative models for procuring organs for transplant.

Organ shortage is a product of concrete factors that can be addressed directly by focusing on fundamental causes rooted in the social, environmental, economic and political determinants of health. Framing organ donations and organ shortage within such a context can help us to develop an understanding of why certain questions are being asked instead of others, and to develop mechanisms to build alternative approaches based on public health ethics frameworks. Such an approach has the potential to reduce the burden of suffering, promote primary prevention and other public health-oriented activities, and thus enrich current discussions of organ donation shortage and lead to more deliberate actions.

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