Exploring the Ethical Issues in Organ Transplantation
Ongoing Debates and Emerging Topics

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If you have not made up your mind yet about organ donation, a brief scan of the literature, internet, and media inundates you with messages. A huge variety of books, journal articles, social media campaigns, and TV shows convey information on transplantation medicine. Across this broad array of media, facts about transplantation medicine as well as individual cases of donors, donor families, health professionals, and recipients are presented to a wider audience. All this information is in one way or another linked to implicit, or sometimes explicit, moral statements: why donate, or why not. Some scholars and policies universally refer to organ donation as an act of altruistic gift giving. However, transplant rates vary widely across the globe, and so do ethical discussions. Additionally, regulations demand fair allocation of a scarce resource to those in need. Many countries invest an enormous amount into public education in this field (Hansen et al. 2018; Hansen et al. 2021).

This volume provides a systematic orientation to the main ethical questions concerning organ transplantation: Where to source the organs? How to allocate a precious resource? How do people experience their life with an organ transplant? What are the alternatives to current practices? The first two questions have been intensively discussed in research, policy, and the media in last three decades, but the latter two have not yet received the attention they deserve. Therefore, our aim in this volume is to reevaluate old debates, and consider new ones, to provide guidance to readers from moral philosophy, bioethics, health care science, social science, law, and the humanities.

Our volume has a clear international focus. Rather than confine themselves to ethical debates in specific national contexts, all contributions seek to address the main ethical issues discussed globally, but they sometimes also point out cultural specificities or discuss local solutions to delicate ethical questions. For instance, while, the English recently adopted a so-called ‘opt-out’ policy (without explicit objection one automatically becomes an organ donor) in May 2020 (Iacobucci 2020), some countries such as the US and Germany remain firmly in the ‘opt-in’ (requiring explicit consent) camp despite many attempts to change their policies (Glazier/Mone 2019). In most countries such policy changes are subject to intensive public, media, or academic debate. To be considered acceptable, they must prove both their practicability and legitimacy, which requires solid empirical exploration of the medical and social effects as well as normative reflection regarding the implications for both citizens' rights and duties as well as patients' needs or exposure to harm.

Beginning as an experimental practice, organ transplantation already provoked debates in the 1960s (Woodruff 1964; Murray 1964); and the many technical advances and legal standardizations of this practice have led to increasingly complex ethical dilemmas and debates (Diethelm 1990). Since the 1980s, organ transplantation has evolved worldwide to become a broadly established medical practice, offering a cure for chronic illness, often extending lives for many years and improving patients and their families' quality of life (Blumstein/Sloan 1989; Caplan 1989). However, despite these benefits, the clinical consequences, policy implications, and ethical relevance of organ donation have been debated right from the beginning. And although it is already subject to numerous regulations, organ donation still stimulates lively discussions in these fields of inquiry (Miller/Truog 2012; Veatch/Ross 2015).

In contrast to most other medical treatments, transplantation ethics must consider and balance not only the interests and rights of patients and physicians, but also those of donors and their relatives. Representing high-tech medicine, organ transplantation also serves as a paradigmatic case for medical progress and for controversies in bioethics (Bailey 1990). First, essential topics of discussion include brain death, organ allocation, and organ sale. Additionally, the intervention into healthy bodies for the sake of others, as in the case of living organ donation, continuous to be controversial (Garwood-Gowers 1999). Second, alternative approaches such as the use of animal organs for humans (xenotransplantation) triggered both high hopes and concerns in the 1990s and 2000s (Daar 1997) – and they are now being revived again in the context of new technological possibilities, such as genome editing (Ekser et al. 2017). Third, new topics such as face or uterus transplantation and organ printing elicit totally new debates that have yet to be sufficiently addressed. There are even more future options, such as organ allocation through artificial intelligence (Briceno 2020) or the treatment of organ failure with organoids that will require more scrutiny by ethicists (Hyun et al. 2020). However, such possibilities are not included in this volume because we felt it was too early to speculate about their ethical dimensions when their application is still very vague. But we should all keep an eye on these developments. A fourth cluster of themes we consider includes still rather marginalized topics that are, however, highly relevant to understanding the whole picture. These includes prevention, the role of old age in allocation, and the role of the family for consent.

Whereas the importance of normative theoretical problems remains unquestioned, we are convinced that the ethical challenges of transplantation medicine cannot be addressed without taking into account concrete lifeworlds with their practices, solutions, and contradictions. All these topics must therefore be examined with reference to socio-empirical, cultural, and anthropological considerations. Consequently, many invited contributions of this anthology provide an overview of the ethical debate while also considering specific socio-empirical lifeworlds through anthropological and empirical analysis. We have thus selected authors who have long-standing expertise in combining empirical methods and ethical analysis. In fields such as transplantation medicine, this is particularly important because such empirical work helps to correct false claims and assumptions about affected groups (Schweda/Schicktanz 2014; Schweda/Schicktanz 2009). Moreover, insights from medical anthropology, the social sciences, and empirical bioethics help to sensitize us to the many layers of judgements and often hidden anthropological assumptions regarding the body, the meaning of death, the social meaning of donation and the self-conception of living with a transplanted organ (Joralemon 1995; Schicktanz et al. 2017).

Various medical and scholarly insights demonstrate how the consequences, or even the idea of organ transplantation itself, challenge concepts of personal identity, the family, and the body (Lock/Crowley-Makota 2008). Such diverse attitudes seem to relate to stable sociocultural and anthropological concepts, but also to normative ideas of reciprocity and gift-giving, which influence medical and non-medical actors alike. Consequently, and often intertwined with the ethical debate, medical sociology and anthropology have accompanied developments in this field with critical observation of cases and systematic overviews (Scheper-Hughes 2008; Fox/Swazey 1992). Empirical-ethical work has scrutinized the influence of cultural concepts like identity, the family, and embodiment at the intersection of morality, anthropology and medicine, often through comparative analysis (Schicktanz/Wöhlke 2017). Thereby, we also take into account that organ donation is a field of extensive discussion, because it involves many profound challenges of our anthropological conditions. What we consider to be 'self' and 'other', 'alive' and 'dead', or 'human' and 'non-human' are contested through this medical procedures. Thereby, organ transplantation challenges many presumptions regarding what we consider as 'natural' or 'artificial'.

Such a contextualization allows us to locate such different arguments in 'grey zones' between universalism and relativism, and to examine further ethical concepts such as relational autonomy, responsibility, and trust. These ethical concepts add an important dimension to the more prominent ethical principles of autonomy, well-being, or fairness in allocation, and they therefore also feature prominently in many of our contributions.

While transplantation is now a global phenomenon, it evokes questions (and might require answers) that are very specific to certain regions and local contexts. Bringing together international perspectives allows us to make intercultural comparisons, and to learn from successes and pitfalls from around the world. Informed by empirical data, we consider the relevance of particular cultural differences and universal norms, which intersect in the field of transplantation medicine in various ways.

For instance, various models of consent exist in different countries. Still, the core ethical problem is the same everywhere: how to respect the morally autonomous decision of the potential donor. Internationally, the global exchange of organs continues to be debated, which is important due to ongoing mobility of patients as well as of organs and tissue. Other topics, such as non-heart-beating donation and models of unspecified donation, or old age, are managed and addressed in culturally different ways.

The fact that this volume revisits a long-standing discussion within bioethics and beyond is also grounded in our own research on the different forms of uneasiness and critique directed towards organ donation (Pfaller et al. 2018). Such forms of discomfort and criticism, however, are not only based on a lack of information or expertise (Hansen et al. 2021), but result from critical reflection and hidden anthropological meanings. Therefore, we see them as considered judgments and discuss them as legitimate forms of critique which ethicists, practitioners, and policy makers should consider while attempting to find and establish ameliorative strategies. In order to continue these lively debates, the book is divided into five sections, each comprising several chapters, which mirror the sequence of transplantation decisions: (i) donation of organs and tissue, (ii) human organ sources, (iii) organ allocation and transplantation systems, (iv) organ recipients, and (v) alternatives.

(i) Donation of Organs and Tissue

Anja MB Jensen and Klaus Hoeyer (Denmark) begin our anthology with a major question centered on the constant global need for organs: What motivates donor families and potential organ donors to decide for donation? Based on both an analysis of the debates on altruism, duty to donate, and incentives for organ donation as well as a decade of anthropological research in Denmark among donor families, hospital staffs, and registered organ donors, their chapter argues that deciding to donate organs is a meaning-making practice centered on consoling family members. They show that organ donation is therefore a way to make sense of death that can reflect a wish to create a legacy for the deceased. It can also be a comfort in the usability of the organs, and expose wider relations to the body, the family, and society in general.

Alberto Molina-Pérez, Janet Delgado, and David Rodríguez-Arias (Spain) systematically analyze how models of consent, autonomy, and the role of the family are intertwined in various policies. The ethics of deceased organ procurement is supposedly based on individual consent to donate, either explicit (opt-in) or presumed (opt-out). The authors propose a novel and comprehensive taxonomy of the models of consent. Depending on the country, the family may be allowed to take different kinds of actions in different situations, which may be grounded in law or simply by traditions of clinical practice. By comparing different models of consent, they show that these models rely on different concepts of autonomy, and they discuss the ethical debates surrounding two policy approaches: presumed consent and family veto.

Douglas MacKay and Katherine Saylor (USA) provide an overview of the ethical considerations relevant to nudging in organ donation policy. They first outline the different ways in which jurisdictions use nudging to facilitate the donation of organs before exploring and evaluating the ethical objections to nudging, including the claim that nudging is a form of manipulation and thus disrespectful of people's autonomy. Finally, they consider the benefits that governments may realize through the use of nudges to promote organ donation and consider whether these benefits can be great enough to outweigh any moral objections.

Solveig Lena Hansen and Katharina Beier (Germany) analyze normative implications of trust in transplantation discourses and debates on tissue donation for research. Comparing the practice of organ and tissue donation, they critically analyze how both public and academic discourses evoke a certain paradigm of trust. This paradigm follows a logic in which the application of adequate practices and regulative frameworks results in a well-informed public, thus leading to trusting donors who ultimately support donations in practice. The emergence of trust, however, is more complex than this paradigm suggests. In addition, the willingness to donate organs for transplantation and tissue for research depends not only on trust but also on other factors, such as concepts of the body, understandings of death, acceptance of research in general, as well as notions of altruism and solidarity.

(ii) Human Organ Sources

Dieter Birnbacher (Germany) observes that there is a lingering uneasiness about whether brain death is a satisfactory criterion of death. Though all legislatures identify, explicitly or implicitly, brain death with human death, sections of the public as well as a number of academic anthropologists continue to hold reservations about whether it is morally acceptable. The chapter examines the arguments for and against the identification of death and brain death, both from theoretical and ethical perspectives. Taking a pragmatic position, he argues that abandoning the brain death definition of death would seriously limit the highly beneficial practice of organ transplantation, which, in the absence of alternative methods of treatment, would be ethically undesirable.

Anne L Dalle Ave (Switzerland), *David Shaw* (Switzerland), and *James L. Bernat* (USA) analyze protocols for donation after the circulatory determination of death (DCDD). According to their analysis, this system forces physicians to decide exactly how death should be determined following the cessation of respiratory and circulatory functions. In DCDD, death is determined by the permanent cessation of circulation and respiration but before those cessations become irreversible. During this time, vital organs could regain function if circulation were restored by resuscitation. Because the cessation of brain functions is essential for the determination of death, and because the brain may regain functions with reperfusion, death cannot be determined unless brain circulation has permanently ceased. The authors conclude that organ procurement should be initiated only after the possibility of auto-resuscitation has elapsed, and after ensuring that the functions of the brain have permanently ceased.

Dominique E. Martin (Australia) examines the ethics of directed living organ donation. By permitting a healthy person to undergo an invasive surgical procedure that is both medically unnecessary and nonbeneficial to the physical health of the donor, and that further poses immediate and potentially longer term risks to their health and wellbeing, living organ donation challenges fundamental norms of health ethics. Nevertheless, living donation of kidneys and partial livers is now widely accepted, and in some countries it has become the primary source of organs for transplantation. Evaluating the proportionality of risks and benefits of donation to living donors and justifying the acceptance or non-acceptance of prospective donors remains clinically and ethically complex. The author argues that ethical concerns about living donation should be recognized as reflecting routine ethical considerations in health care, but they also require exploration in the broader context of prospective donors' lives and relationships.

Greg Moorlock and *Heather Draper* (UK) focus on ethical aspects of unspecified living donation. They first provide a brief overview of the practice, the international context, and regulation before discussing the principle of 'first do no harm'. They explore how this potential obstacle has been overcome by adding the principle of autonomy as addition to established accounts of benefits and harms. Finally, they analyze whether the medical profession should promote this practice.

(iii) Organ Allocation and Transplantation Systems

Søren Holm (UK/Norway) analyzes how postmortal organs, a rare non-fungible resource, should be allocated among potential recipients and investigates the ethical and pragmatic criteria used. The weightings of criteria used in existing organ allocation schemes are to some extent arbitrary. In addition, the chapter discusses the use of organ allocation schemes as mechanisms for incentivizing organ retrieval, and whether geographical restrictions within a country or transplant organization can be justified. Finally, while organ shortage might be hypothetically solved by replacing material scarcity with financial scarcity, the quest for fair allocation would remain.

Peter Sykora (Slovakia) analyzes the underlying moral assumptions of the current system of organ procurement, which is based on the notion altruistic organ donation but is considered by many to be 'a qualified failure'. Based on a discussion of kidney exchange programs, he argues that instead of seeing the solution in an organ market, a new approach based on indirect reciprocity holds promise.

Zümrüt Alpınar Şencan (Germany) scrutinizes how the scarcity of organs and the growing ease of internet communications have led to the rise of commercial organ transactions. The chapter presents an overview of the moral arguments in favour of and against this trend. In particular, critics to organ sale relate to various approaches, ranging from of harm and benefit, exploitation and justice, autonomy and coercion as well as social values. These arguments are either (a) guided by generally adopted principles of biomedical ethics or moral concerns without further inquiry, or (b) mostly founded on contingent factors, which are adjustable. The chapter addresses a further concern regarding the practice: a dignity-based objection to organ selling. It argues that according to a social account of dignity, the practice of organ selling, independent of whether the subject chooses to act autonomously and regardless of the external conditions, threatens human dignity by implying that some people have less value than others.

Mark Schweda and *Sabine Wöhlke* (Germany) analyze how questions of old age and generational relations are increasingly receiving attention in the field of transplantation medicine. Demographic ageing contributes to a growing demand for transplantable organs, thus intensifying the problem of 'organ scarcity' and fueling concerns about the efficient use and fair distribution of donor organs. At the same time, older people are being discovered as potential organ donors in postmortem and living organ allocation. In all these contexts, positions and arguments regarding organ donation are interwoven with morally loaded ideas of (old) age, the life course, and intergenerational relations. Against the backdrop of current research in transplantation medicine, the authors provide an overview of the social role and ethical implications of age and generational relations in organ donation, indicating open questions and the need for further empirical research and ethical debate.

(iv) Organ Recipients

Paweł Łuków (Poland) analyzes the role of embodied personal identity and conceptions of good life and how this is relevant for assessing organ transplantation. He argues that embodied identity has a central place in every conception of a good life. Instabilities in a patient's present identity, and in their conception of a good life, can prevent them from developing a sufficiently stable and instructive future identity, and therefore from having a good post-transplant life. An adequate response to such challenges may involve not only reciprocal adaptation of the patient's post-transplant identity but also a reframing of the very concept of the good life when applied to life after transplant surgery.

Rhonda M. Shaw (New Zealand) discusses insights from a large set of qualitative studies to critically examine the gift-discourse. Her analysis is based on 127 face-to-face, in-depth interviews and fieldwork undertaken in New Zealand between 2007 and 2013 with medical professionals, living organ donors, donor families, and transplant recipients. The study findings indicate that while the gift-of-life discourse is the dominant cultural script available for people to articulate their experiences of organ donation and transplantation, it is not always aligned with people's testimonies of organ transfer. To address this gap in understanding, the author draws on the philosophical concept of epistemic injustice to show why the inclusion of perspectives from organ donors, donor families, and transplant recipients is ethically needed and justified. The chapter emphasize the importance of qualitative social science research in bringing these views to bear on our collective understanding of organ donation and transplantation processes.

Sayani Mitra (UK) offers an ethical analysis of uterus transplantation (UT) using a normative critique of the existing ethical and legal debate from a feminist standpoint. By referring to a reproductive justice approach, the chapter identifies and analyses three ethical issues that require a gender-sensitive explanation. The first ethical issue revolves around the designation of UT as a 'non-vital' transplant procedure that simply improves the quality of life and the impact of this categorization on uterus retrieval procedures. The second issue concerns the strategy of uterus allocation and listing and the gendered position of the donor in the process. The third issue revolves around the questions as to whether UT needs to be regulated as another transplant procedure, like the other vascularized composite allograft organs (VCAs), or needs to be recognized as an assisted reproductive technology (ART).

(v) Alternatives

Tatjana Višak (Germany) analyzes the ethical debate on xenotransplantation, the transplantation of animal organs to humans. Her analysis features two main lines of argumentation: anthropocentric and sentientist. Anthropocentric arguments focus on harms and benefits for humans: the potential improvements to the welfare of organ recipients and their loved ones. However, the extent of this benefit is still unclear, since it depends on the quality of the organs and on the required public safety measures. The main costs for humans are the opportunity costs: the lost benefits that would have occurred if scarce health care resources had been invested in other, more cost-effective, projects. Other costs include the risk of zoonoses, namely the transfer of animal viruses to humans, a topic that due to the Coronavirus-crisis in 2020 has received new attention. By contrast, sentientist arguments consider the interests of all sentient beings on an equal basis. These arguments allow for animal rights, which are meant to protect animal interests and function as constraints against killing and injuring animals for research purposes or as organ sources. From a sentientist perspective xenotransplantation may be unacceptable.

Charlotte Burnham-Stevens and *Niki Vermeulen* (UK) discuss case studies from the field of 3D bioprinting, a future prospect for transplantation medicine. The potential of 3D bioprinting in transplantation medicine tends to focus on its promissory power; its ability to 'solve' a number of key problems associated with traditional organ transplantation and revolutionize modern medicine. Whilst the nascent technology could indeed have some future benefits, it also raises social and ethical issues around its embedding in health care systems, including regulation, ownership, and access. For instance, organ bioprinting may risk further commodification of our bodies, or sustain or increase existing health inequalities, while its promises may heighten expectations and desires for 'ideal health'. In the context of emerging ethical debates, this chapter combines bioethical and legal scholarship with insights from Science and Technology Studies (STS), using hypothetical narratives for further exploration of ethical issues.

In the final chapter, *Hagai Boas* (Israel), *Nadav Davidovitch* (Israel), and *Michael Yudell* (USA) provide broad reflections on the public health ethics of organ transplantation. The gap between organ demand and available supply is large, and patients across the globe die every day awaiting a needed organ. The authors argue that transplant bioethics alone cannot solve many of the problems facing transplant medicine, and turn instead to public health for answers. Hereby, they discuss the critical paradox of prevention as well as how a global perspective can challenge some assumptions regarding brain death and donation policies.

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