Ralf J. Jox Galia Assadi Georg Marckmann *Editors* 

# Organ Transplantation in Times of Donor Shortage

**Challenges and Solutions** 



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### Chapter 1 Organ Transplantation in Times of Donor Shortage. An Introduction

Galia Assadi, Ralf J. Jox and Georg Marckmann

Organ transplantation is an exceptional success story of modern medicine. From 1954, when Joseph E. Murray conducted the first living kidney donation among twins, to 2013, when 6866 transplants<sup>1</sup> were conducted within the Eurotransplant<sup>2</sup> region, the new discipline of transplantation medicine has been confronted with a long list of different challenges and obstacles. In the beginning, medical difficulties were in the foreground, e.g. tissue typing or the matching of donors and suitable recipients. One of the major problems, the allogeneic rejection caused by antigen differences, was able to be solved in the course of the 1950s. Due to the groundbreaking discovery of the French hematologist Jean Dausset, who in 1958 discovered that Human Leukocyte Antigens (HLA) function as body markers indicating whether a tissue is own or foreign, it became possible to develop immunosuppressive drugs which counteract rejection. Based on the development of more specific and effective immunosuppressants, transplantation technology could expand. Thereby the 1960s became the decade of transplantation success with the first post-mortem kidney transplantation in 1962, the first liver and lung transplantations in 1963, followed by the first pancreas and the first heart transplantations in 1966 and 1967, respectively.

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<sup>&</sup>lt;sup>1</sup> Eurotransplant, http://www.eurotransplant.org/cms/.

<sup>&</sup>lt;sup>2</sup> Eurotransplant, a collaboration of eight European countries cooperating to heighten the amount of available organs and optimizing the allocation process, was founded in 1967.

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While the major medical obstacles to transplantation could be overcome by pioneer scientists and physicians, the emerging discipline faced another challenge that is still unresolved today. Due to the growing effectiveness of transplantation and the increase of organ failure in aging societies, the problem of organ shortage became prominent. In order to close the gap between an accelerating demand and a rather staggering supply, many responses have been conceptually invented and practically tested. Yet, despite all the efforts that are being undertaken to resolve the problem, every year thousands of potentially curable patients die while waiting for an organ transplant. Health authorities, medical professionals and bioethicists worldwide point to the urgent problem of organ shortage, which will be further intensified due to increasing life expectancy, particularly in newly industrialized, emerging countries with huge populations. Even though the practical problem seems to be well known, the search for suitable solutions is often constrained by disciplinary and national borders. In addition, organ transplantation is surrounded by numerous ethical and emotional problems that stir public discussions, e.g. brain death, consent for post-mortem and living organ donation, organ allocation, and implantation of animal organs in humans—just to name a few.

This book approaches the relevant ethical questions of organ transplantation by investigating and critically rethinking the moral and ethical foundations of current solutions. Taking these as a starting point, the contributions engage in the development of new approaches, which can be viewed as fruitful concepts to inform the public discourse. As the topic of organ transplantation has come to the fore of the broader public, due to scandals happening e.g. in Germany, a public debate is needed in order to gain new orientation and restore trust in the transplantation system. Contributing to this debate was the aim of an international conference that brought together young scholars and experts in spring 2013 at the University of Munich, Germany, funded by the German Ministry for Education and Research. The presentations and ensuing discussions at this conference laid the basis for the articles collected in this volume, refined by several rounds of peer review.

The goal of this book is twofold. First, it analyzes and critically reviews the currently established solutions to alleviate the problem of organ shortage (e.g. consent procedures, moral obligation of donating organs, organ procurement practices). Second, it presents innovative, creative and applicable solutions for the problem of organ shortage (e.g. financial incentive schemes, living advocates for organ donation, organizational innovations, xenotransplantation). In order to achieve these aims, we split the publication into four different sections that will be summarized by us.

The diversity of contributions presented in this volume can be interpreted as a sign for the diverse, controversial, enthralling discussions surrounding the ethics, politics and legal regulation of organ donation worldwide. We consider the international plurality of reflections undertaken, solutions practiced and experiences gained to be a fruitful humus of ideas and a permanent inspiration for improvement, and we are therefore grateful to be able to enrich this international endeavor.

Many people have helped us bring this book into existence. In order to make their contribution explicit and visible, we want to thank Dorothee Wagner von Hoff for providing competent language and translation support and Carolin Lorenz and Johannes Pömsl for their engaged assistance with formatting and correspondence. Furthermore, we want to express our gratitude to the German Ministry for Education and Research that rendered the whole publication possible in the first place and to our kind and patient editor at Springer, Christopher Wilby, and to Prasad Pramod for organizing a smooth production of this book. We also thank all authors and reviewers for their intellectual contributions and their sustained patience during the production of this book.

Ralf J. Jox is a medical ethicist, neurologist and palliative care specialist working as Assistant Professor at the Institute of Ethics, History and Theory of Medicine at the University of Munich, Germany. His research activities focus on transplantation ethics, neuroethics, end-of-life care ethics, and clinical ethics consultation. He has published extensively in leading journals in medical ethics and clinical medicine, such as J Med Ethics and The Lancet Neurology. He is also the principle editor of an international book on the Vegetative State. Dr. Jox received multiple awards, among them the Young Investigator Awards of the European Association for Palliative Care (2011) and the German Academy of Ethics in Medicine (2004). In 2012, he was Caroline Miles Visiting Fellow at the Ethox Centre, University of Oxford.

**Galia Assadi** studied Social Work at the University of Applied Sciences Munich and mastered in Sociology at the LMU. Subsequently, she completed her PhD in Philosophy at the LMU. Her main research interests lie on the intersection of sociology, philosophy and politics. Her focus is on the critical reflection on normative orders of modern society and feminist theory. Following the works of Michel Foucault, she is currently investigating the connection between modern economical, philosophical, political and psychiatric thinking.

Georg Marckmann studied medicine and philosophy at the University of Tübingen (Germany) and received a master's degree in Public Health from Harvard School of Public Health (Boston, MA). He was a scholar in the Postgraduate College "Ethics in the Sciences and Humanities" in Tübingen from 1992 to 1995. He received a doctoral degree in medicine in 1997. From 1998 to 2010, he was Assistant Professor at the Institute of Ethics and History of Medicine at the University of Tübingen and since 2003 served as vice director of the institute. Since 2010, he is full professor of medical ethics and director of the Institute of Ethics, History, and Theory of Medicine at the Ludwig-Maximilians-University of Munich. His main research interests include ethical issues of end-of-life care, distributive justice in health care, ethical issues in organ transplantation and public health ethics.

# Part I The Ethics of Organ Donation: Foundations and Challenges

The contributions of the first Part raise the question of actual and potential ethical foundations of organ transplantation both on a theoretical and an empirical level. Starting with a critical investigation of the ethical obstacles that need to be overcome in order to increase the amount of organs available, the contributions not only develop a critique but go on to provide a variety of innovative – and sometimes controversial – perspectives on the ethics of organ donation.

Tobias Eichinger's contribution broaches the intensely debated issue of brain death in an innovative way. Instead of arguing in favor or against brain death as a matter of law, he shifts the question and reframes the whole discussion by conceptualizing a third category between life and death – a category that puts humans in a new and ambiguous realm between life and death, in accordance with the requirements of the transplantation practice and with fundamental moral commitments. Thus, brain-dead patients whose bodies – or relevant parts of their bodies – retain good functions, but whose brains are irreversibly damaged would be considered neither still living nor already dead, but rather seen as both already dead and still living at the same time. By presenting philosophical reflections on the necessity and possibility of a third category and adding some considerations about the interplay of film and societal issues, Eichinger approaches the topic in an innovative way. In order to illustrate the philosophical and societal potential of films, he argues that the metaphorical figure of the zombie could help to raise awareness of emotional abysses and personal fears, which are evoked by brain death and post-mortem organ donation.

Adrian Viens critically investigates the role of the physical integrity of the body in individual decision making as well as for policies and collective practices. He explicates ideas of bodily integrity in decisions regarding organ transplantation and explores some of the potential problems related to the endeavor to increase the supply of high-quality organs for transplantation. He first provides an overview of the concept of bodily integrity itself and how ideas about the importance of the physical integrity of the body come into play in the context of organ donation. Second, he examines the extent to which the beliefs and attitudes of individuals and their families

about bodily integrity act as an empirical barrier to their willingness to be involved in organ donation. Third, he raises some issues with respect to the extent to which bodily integrity should also be seen as a normative barrier for different practices and policies surrounding organ donation. He concludes by arguing that the idea of bodily integrity admits different conceptions and interpretations.

Investigating the influence of body concepts on the willingness for organ donation, Sabine Wöhlke, Julia Inthorn and Silke Schicktanz present the results of an empirical survey conducted among students of medicine and economics. The authors start with the puzzling observation that various opinion polls suggest that the majority of German citizens are in favor of organ transplantation, but the number of citizens that possess an organ donor card is very low compared to other Western countries. By switching the commonplace perspective and questioning the impact of (hidden) cultural factors such as body image, concepts of death, and personal identity on attitudes towards organ transplantation, they make an important contribution to a yet scarcely investigated area. By focusing on the role of body concepts and the impact of attitudes towards brain death on the acceptance of organ donation, they prove the ethical relevance of lay anthropologies that are often neglected by the academic, legal, and ethical discourse, especially in the analytical and liberal tradition. They argue that philosophical or anthropological considerations are a necessary condition to develop consistent bioethical theories without comprehensively reflecting the positions represented in society. Therefore, public bioethics and policies, which aim to develop ethically justified models based on democratic norms, should not only consider consequentialist arguments to increase social benefit by increasing the number of available organs, but should also consider citizens' rights to have particular concepts about death and about their bodies. They conclude by encouraging the development of better ethical models of consent and donation by considering more concretely how to deal with plurality and moral uncertainty over such difficult issues.

Katherine Mendis' article focuses on developing an ethical foundation of a duty to donate organs based on the Kantian theory as well as the social contract theory. She argues that inventing an alternative ethical foundation could help to avoid the controversy and denial evoked by proposals designed to increase the supply of cadaveric organs (e.g. confiscation of organs, an "opt-out" system, and various methods of compensation). The view that people are not obligated to make their organs available after death is based on Kantian respect for autonomy and a notion of rights derived from social contract theory. Mendis looks to both Kant and contractarian views of free-riding to argue instead that making one's own organs available for donation after death is in fact a moral duty. According to the Kantian concept of a duty of mutual aid, we have a duty to respond to the true needs of rational beings when fulfilling such needs places little burden on us. In addition, a refusal to donate organs entails the kind of indifference to interdependency that characterizes morally problematic free-riding. Mendis concludes by showing that accepting cadaveric organ explantation as morally obligatory avoids the concerns that other proposals, such as confiscation, an opt-out system, or some sort of donor or family compensation systems, have – namely that they violate rights or fail to respect autonomy. It

also avoids the criticism that these more *aggressive* policies would disadvantage vulnerable populations.

Taking a different approach to the problem of the ethical foundation of a duty to donate organs, *Diana Aurenque* examines to what extent altruism arguments are likely to increase willingness to donate organs. Her working hypothesis is that altruistic arguments are unsuitable for this purpose. In order to demonstrate this, Aurenque first elaborates the concept of altruism. In a second step, she investigates the motivational nature of altruistic actions and presents this as a problem in the face of organ shortage. Due to the ethical and political challenge to tackle organ shortage – in order to enhance the survival of seriously ill patients or to improve their quality of life – she points to the urgent need for binding measures. In a third step, she suggests that solidarity instead of altruism is the key to promoting organ donation. For that purpose, Aurenque argues that a model based on the values of solidarity and responsibility is suitable to justify other policy interventions that might increase donation rates. Finally, she draws attention to the meaning of justice (as fairness) for the success of these actions.

Instead of searching for a different ethical foundation of voluntary organ donation, *Christoph Schmidt-Petri* investigates the ethical legitimacy of organ confiscation as a radical way to resolve the problem of organ shortage. His argumentation is based on an analogy: if inheritance taxes and mandatory autopsies are legitimate, then so is organ confiscation. Therefore, he starts by exposing that neither the widely accepted practice of inheritance taxes nor the practice of mandatory autopsies requires prior consent of the dead. Both are typically performed in order to benefit other citizens, and autopsies also involve opening the body of the deceased. Therefore, he argues, these practices do not really differ from transferring body parts. Subsequently, he discusses objections against this proposal based on concerns about the brain death criterion. He concludes by arguing that, given the legitimacy of inheritance taxes and autopsies, routine salvaging of organs is also legitimate; or, to put it more cautiously, if inheritance taxes and mandatory autopsies are (considered) legitimate, then so should routine post-mortem salvaging of organs.

Investigating organ transplantation under a theological-ethical perspective, *Konrad Hilpert* discusses the theological challenges arising from organ donation against the background of the German situation, where an opt-in system is practiced and fraudulent manipulations of the waiting list for liver transplantations have recently agitated the public. Hilpert sketches three tasks that appear to be necessary for pastors and theologians: first, accepting that the donor is not just a vehicle for salvaging valuable human material and respecting the legacy of an individual whose dignity is to be appreciated after death; second, remaining honest and humble, not only by contextualizing the success of the greater spectrum of possibilities and power within high-tech medicine, but also by recognizing boundaries, fears, dependencies, and the possibility of failing; third, providing spiritual guidance for the donor's relatives as well as the organ recipient, who will have numerous questions both before and after the transplant.

Barbro Fröding and Martin Peterson switch the perspective and expand the range of the ethical discussion surrounding organ transplantation by focusing on the