



THE STRAUS INSTITUTE
for the ADVANCED STUDY
OF LAW & JUSTICE

The NYU Institutes on the Park

THE JOSEPH AND GWENDOLYN STRAUS INSTITUTE FOR THE ADVANCED STUDY OF LAW & JUSTICE

*Professor J.H.H. Weiler
Director of The Straus Institute*

Straus Working Paper 01/12

Andrea Büchler

**Regulating the Sacred
Organ Donation and Transplantation:
Autonomy and Integrity of the Person or Social Responsibility of the Body?**

NYU School of Law • New York, NY 10011
The Straus Institute Working Paper Series can be found at
<http://nyustraus.org/index.html>

All rights reserved.
No part of this paper may be reproduced in any form
without permission of the author.

ISSN 2160-8261 (print)
ISSN 2160-827X (online)
Copy Editor: Danielle Leeds Kim
© Andrea Büchler 2012
New York University School of Law
New York, NY 10011
USA

Publications in the Series should be cited as:
AUTHOR, TITLE, STRAUS INSTITUTE WORKING PAPER NO./YEAR [URL]

REGULATING THE SACRED
ORGAN DONATION AND TRANSPLANTATION:
AUTONOMY AND INTEGRITY OF THE PERSON
OR SOCIAL RESPONSIBILITY OF THE BODY?

By Andrea Büchler*

Abstract

Organ transplants are a hugely complex field of human endeavour with highly contentious legal, ethical, religious and societal ramifications. The paper unravels the legal threads that run through this field, formulates questions and theses to highlight the fundamental issues involved, and promulgates some assumptions in the process. The focus lies on aspects of autonomy which appear to be fundamental to the understanding of current legal developments. I want to investigate possible shifts from autonomy to social responsibility for the body in organ transplant laws and policies and how these laws and policies correlate with the nature of the relationship between the person and his or her body. Furthermore, I am interested in understanding the role played by human dignity within the legal framework and how it relates to autonomy in the context of cultural and religious pluralism. The scope of the paper, however, will permit only a few cursory observations of “what may be going on”; my objective is to provide some appreciation of what may be occurring underneath the obscuring mantle of technical, medical, religious and legal discourse.

* Professor for Private and Comparative Law at the University of Zurich, Law Institute, andrea.buechler@rwi.uzh.ch

Introduction

The no man's land between life and death, and indeed the ambiguity of these two terms, has deep cultural roots. In the industrialised Western world, new criteria for defining death have been evolving over the past 30 years, and these have focused on the brain. In the cross-cultural context, however, this reinvention of death¹ has elicited strong reactions.² The definition of death is of direct relevance to questions surrounding the donation and transplant of organs. A modern miracle to some, and a false promise to others, organ transplants are a hugely complex field of human endeavour with highly contentious legal, ethical, religious and societal ramifications. Organ donation and transplantation has been described as "a unique way to affirm and share our humanity".³ Removing organs from one individual human being and placing them in the body of another is a twentieth century invention which has developed, with extraordinary speed, from an experimental and unproven strategy to become the treatment of choice for a great many diseases and conditions today. Ironically, and unfortunately, transplantation has become a victim of its own success. The critical shortage of donor organs is the greatest impediment facing transplant programmes around the world. According to the World Health Organisation, 106'879 organs were transplanted worldwide in 2010, accounting for less than 10 per cent of the estimated need.⁴ The demand for donor organs far exceeds their available supply. It is this shortfall which has given rise to intense public debate about possible legislative and administrative measures to foster organ donation. How can we generate an adequate volume of organs for transplantation without offending ethical principles? That is the question facing legislators and policy makers in numerous countries. Many of the organisational factors or clinical considerations accounting for the organ shortage are, by their very nature, beyond direct legal regulation or influence. On the other hand, norms governing the consent to organ removal or the involvement of family members certainly can have an impact on the availability of organs for transplant.

¹ LOCK.

² BOWMAN/RICHARD, 211.

³ YOUNGNER/ALLEN/BARTLETT/CASCORBI/HAU/JACKSON/MAHOWALD/MARTIN, 313.

⁴ Cf. WHO, Organ Donation and Transplantation Activities 2010, [<http://issuu.com/o-n-t/docs/2010adgodt?mode=window&pageNumber=1&layout=http://publicaciones.ont.es/issuu/godt/layout.xml>].

Organ donation and transplantation have forced ethicists and lawyers to deal with issues which break new ground in a number of areas: the re-definition of death, the feasibility of adopting a donation regime, or indeed one based on the presumption of willingness to donate (with an opting out privilege), the acceptability of payment for body parts, the possibility of donations by minors, or the rights of relatives to override the wishes of a deceased or dying relative to donate organs. Indeed, what is truly distinctive about the whole process of organ donation and transplantation is not technology, but ethics, which is why these procedures are uniquely and utterly dependent on public participation in the debate if they are to maintain any viability as therapeutic options. Many of the legal and ethical problems surrounding transplantation are nothing other than concrete manifestations of fundamental questions of legal philosophy. This can already be said of the question as to the extent to which the moral convictions of the individual or society at large should determine the provisions of the law and, by extension, the restrictions it places on individual freedom. Then, for example, the objective criteria applied to cadaveric organ donation are necessarily linked to our definition of the person. Does protection of an individual's right to personal integrity extend beyond death? Issues surrounding subjective criteria for organ removal are closely related to the right to self-determination and how that right interacts with possible social responsibilities as far as the body is concerned. If the rights of relatives in these matters are taken into consideration, then issues of piety and of belonging to a community or family also become relevant. Regulations governing tissue removal from living donors are concerned with the limits to legitimate paternalism. Those regulating commerce in organs revolve around the question of whether the opening up of financial avenues to the socially disadvantaged amounts to compulsion akin to usury and can thus be seen as an infringement of personal freedom. A further issue here is whether, and if so why, any commerce with the human body should necessarily be viewed as injurious to human dignity. Finally, the allocation of scarce organs to those in need of them for survival or a better life raises questions of distributive justice. How should such criteria as urgency, effectiveness, fair treatment, social utility criteria and market principles be weighted?

In most countries, extensive revisions to the legal system have taken place in order to ensure its fairness and continued relevance in the age of biomedical technology. The comparatively recent enactment of laws regulating organ donation and transplantation was preceded by more or less controversial discussion about the beginning and the end of life, the body and the person. It is certainly true that what is technically feasible and what is morally or ethically defensible are not one and the same thing. Modern bioethics first came into being in the United States in the late 1960s, as rapid advances in medical science and research and the biotechnological innovations they brought in their wake gave rise to novel ethical questions. Early contributions to scholarship in bioethics emerged from within theological frameworks.⁵ Yet in a pluralistic society, with a constitutional separation of church and state, the discipline soon assumed a predominantly rational, secular mode of thought and philosophical analysis, the objective being to develop universally applicable norms. In the 1970s, Georgetown University philosophers TOM BEAUCHAMP and JAMES CHILDRESS published the first edition of their book “Principles of Biomedical Ethics”,⁶ marking a transformative moment in the discipline. In this influential work the authors elaborate on four prima facie ethical principles – autonomy, beneficence, non-maleficence and justice. Respect for patients’ autonomy and their right to make their own decisions became one of the central tenets of bioethics. Exactly what constitutes autonomy in this context and how it should be balanced against older, more traditional principles of medical ethics such as beneficence, non-maleficence and justice remains a source of on-going debate. BEAUCHAMP and CHILDRESS’s principles, presented as the basis for a common morality to guide biomedical research and clinical practice worldwide, became integral to the evolution of bioethics in American society and they were rapidly exported to other countries in the world. Today, this so-called principlist approach has become dominant in bioethics discourse. Indeed, it is the declared goal of principlist bioethics to serve as a model for moral reasoning that is useful and intelligible to individuals from different cultural backgrounds, to provide a vocabulary and a set of concepts that are applicable beyond the domains of a particular religious or philosophical tradition and to make

⁵ Paul Ramsey, Joseph Fletcher, and James Gustafson, for example, all wrote as theologian, see TURNER, 205.

⁶ The 6th edition of the book has been published in 2009.

available a shared rhetoric and conceptual framework for use in both the clinical setting and larger policy debates.

Of course, the universalist aspirations of principlist bioethics are open to criticism.⁷ First, there is the question as to whether the very premise of modern bioethics – that there exists a universal bioethical perspective and a core morality shared by all human communities (what BEAUCHAMP and CHILDRESS refer to as a common morality⁸) – is theoretically and empirically valid. LEIGH TURNER, for example, states critically, “Given the pluralistic, multicultural, multifaith character of most contemporary societies, I suspect the contribution of bioethicists to the resolution of many moral debates will be quite limited”.⁹ As a comparativist legal scholar, my main interest is in understanding whether and, if so, how these principles translate into norms across countries and legal cultures. Second, many alternatives (such as virtue ethics, casuistry and narrative ethics) have been put forward to challenge the principlist approach to modern bioethics. In response to the increasing global influence of ethical principles based on secular traditions, efforts are also being made to identify Islamic, Jewish or Christian bioethical principles which conform to the parameters set by the religious law in question by drawing on scripture and traditions. Opponents of principlism also include those who claim that its principles do not represent a theoretical approach – the four principles being disengaged from any particular theory –, and those who believe that its principles are too far removed from the concrete particularities of everyday human existence.

Third, autonomy, as a principle of first order significance in its own right, is being questioned both from a communitarian and a utilitarian perspective. For liberal critics, on the other hand, the principle of autonomy is not being applied rigorously and consistently enough. Their view is that, in a secular pluralistic society, authority for actions involving others is derived from their permission. Indeed, if one further assumes that it is not possible to define what is good on anything but a secular basis, all ethics has to flow first from the respect for autonomy.¹⁰ Contemporary biomedical ethics relies

⁷ CLOUSER/GERT, 221 ss.

⁸ Cf. 2 s. and 401 ss.

⁹ TURNER, 207.

¹⁰ LAWRENCE, 35.

on a contractual model that focuses on the legal rights of the parties involved in medical interactions. Autonomy, however, may not be perceived and valued in all cultural settings as the intellectual and moral foundation of healthcare. For many, focusing on autonomy and the rights of the individual may overlook the social and moral implications of personal interconnectedness. Indeed, challenges to the individualistic, rights-based view of bioethics can have their origin in what might be described as a post-modern perspective. If the individual (*the subject*) is a product of technical intervention and discursive construction and communication,¹¹ then his or her suitability as the starting point and the pivot of deliberation about the prospects and limits of medical intervention is necessarily in question. Or: If the body is increasingly seen as an entity existing at the intersection of society and medical practice, does this inevitably imply its social responsibility? Particular mention should also be made, finally, of the objection, formulated in the Foucaultian tradition, that if autonomy is reified as a bioethical principle outside the context of discourse, it may only complement the hegemonic power of biomedicine – and bioethics would become an extension of biomedical discourse.¹²

Of course, organ donation and transplantation operate within the broader prevailing cultural and societal contexts of various distinct jurisdictions, and ethical and religious pluralism exists not only between sovereign states but also within them. In pluralistic liberal democracies today we find multiple cultural, religious and philosophical traditions which inform our understanding of life, death, the body and the person. Potential donors or recipients of organs inhabit distinctive social worlds, and are guided by multiple understandings of moral practice. Different concerns are addressed, defined, defended and evaluated from a diverse array of interpretive constraints.¹³ Religious contributions inevitably enter the policy debate; and religious interventions regularly play an important role in normative deliberation. It would therefore seem logical to assume that religious perspectives and beliefs have substantially influenced transplant laws and policies in various societies.

¹¹ JEAN LUC NANCY.

¹² MCGRATH.

¹³ TURNER, 202.

The vast majority of countries now have laws governing organ donation and transplantation. Numerous guidelines have been promulgated, such as WHO's Guiding Principles on Human Cell, Tissue and Organ Transplantation 2010, and the field of biomedicine is also subject to supervision by a number of institutions and committees. Because the challenges posed by the rapid development of biomedicine are global in nature, international organisations have made significant efforts over the last few decades to establish common bioethical standards, a more recent example being the Universal Declaration on Bioethics and Human Rights adopted by UNESCO in 2005. The international legal framework in this area can be viewed as an extension of international human rights law into the field of biomedicine. The European Convention on Human Rights and Biomedicine adopted in 1997 by the Council of Europe is a notable example of these endeavours.¹⁴ Along with the Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin, 2002, this convention promulgates a set of requirements relating to organ transplants which can be regarded as setting a minimal ethical standard.

My intention is to unravel the legal threads that run through this field. I will start by describing the broad area of organ transplant law by referring to a limited number of central legal issues and making some comparative observations. In so doing, I will formulate questions and theses to highlight the fundamental issues involved, promulgating some assumptions in the process.

The field of study is vast and the questions multifaceted. I intend to focus on aspects of autonomy which appear to be fundamental to the understanding of current legal developments. I want to investigate possible shifts from autonomy to social responsibility of the body in organ transplant laws and policies and how these laws and policies correlate with the nature of the relationship between the person and his or her body. Furthermore, I am interested in understanding the role played by human dignity within the legal framework and how it relates to autonomy in the context of cultural and religious pluralism. This will entail an analysis of the essential character of the different

¹⁴ ANDORNO 2005.

legislative regimes concerned and an examination and prioritisation of the values and interests involved in organ donation and transplantation. Biomedical laws and practices will be analysed to determine whether they shed light on the complex interaction between biomedical knowledge, ethical values and religious beliefs which is integral to the understanding, negotiation and regulation of the sacred – the body, life and the person. Of course, the scope of the paper will permit only a few cursory observations of “what may be going on”; my objective is to provide some appreciation of what may be occurring underneath the obscuring mantle of technical, medical, religious and legal discourse.

From the heart to the brain

The contemporary criteria for determining the end of life clearly demonstrate the influence which advances in biomedicine have had on legal, ethical and religious discourse. In most Western countries there are two sets of medically and legally acceptable criteria for determining and pronouncing death: (1) An individual may be diagnosed and pronounced dead on the basis of the cessation of heartbeat and breathing – i.e. of the circulatory and respiratory functions. These are long-standing, traditional indicators that the medical profession has used as definitive signs of death; (2) A person may also be “defined” as dead on the basis of the irreversible cessation of all functions of the brain, including the brain stem (whole brain). The criteria for determining brain death were given substantive, symbolic and legal impetus by the publication of the report of the Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death in 1968. For the first time, this committee proposed that death be defined as irreversible coma. The necessity for this new definition of death was justified as follows: “(1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged (...); (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.” Indeed, cardiac transplantation can only be carried out with a live, still-beating heart. Clearly, this is incompatible with a definition of death based upon the cessation of cardiac function.

The irreversible cessation of brain-stem function occurs a short time before the termination of cardiac activity. Under this definition, the still-beating heart is thus removed from a dead donor, not a live one.

Brain death is legally recognised in the great majority of jurisdictions. The majority of authorities in Jewish and Islamic law also now recognise the concept of brain death. In 1986, the Chief Rabbinate Council of Israel issued a decision permitting heart transplants and laying down the tests required for establishing irreversible destruction of brain-stem function, one condition being that a representative of the Chief Rabbinate who was also specialised in Jewish law would be part of the team which established the death of the donor. It based its decision upon the criterion of lack of breath as in the Talmudic discussion of mounting a mission to rescue people trapped in the rubble of a collapsed building on the Sabbath day.¹⁵ However, an important factor in the Chief Rabbinate's decision was the tremendous improvement in the success rate of cardiac transplant operations. In the light of the excellent recovery statistics, the Chief Rabbinate was confident that its decision would lead to the saving of many lives, thereby helping to fulfil the paramount *mitzwah* of preserving human life. Israel, however, legally validated the concept of brain death only with the Brain-Respiratory Act 2008, with resistance to the new Act coming from several rabbinic authorities.¹⁶ In 1986, the Academy of Islamic Jurisprudence held a meeting in Jordan to debate the permissibility of the criteria for brain death under the *sharia*. The Academy approved the brain-death criteria, though there are continuing concerns expressed by a minority of Islamic scholars to this day. Iran passed the "Deceased or Brain Dead Patients Organ Transplantation Act" in 2000,¹⁷ while Pakistan passed the Transplantation of Human Organs and Tissues Act – which recognises the brain-death criteria – in 2010.

Overall, there is widespread acceptance of a brain-oriented definition of death – and thus of shifting the borders of life. At least among legal scholars and policy makers this is the case, since they rely mainly on scientific description and medical judgment. Opinions differ as far as diagnostic criteria are concerned, as well as on standards with

¹⁵ SINCLAIR, 236.

¹⁶ Cf. SPERLING.

¹⁷ AKRAMI/OSATI/ZAHEDI/RAZA.

regard to concept, aetiology, the minimum observation period required before clinical testing, what medical personnel can confirm death, the repetition of tests, apnoea tests, or the role of confirmatory investigation. Indeed the variability of operational guidelines in these areas is remarkable.¹⁸ Nevertheless – and somewhat surprisingly in view of this global consensus on the concept of death – there are still extensive philosophical and ethical controversies surrounding brain death.¹⁹ Critics point out that human personhood cannot be determined at a purely diagnostic and empirical level, that dying is a process and that equating any specific moment or physical event with death is somewhat arbitrary. It is argued that the scientific, medical determination of whole brain death in a human being is a symptom of death, but not death itself. The question of what death is, the argument goes, cannot be answered by natural science, since she belongs to the sphere of philosophical and theological consideration.

There is also some evidence that while the brain-oriented definition of death has established itself in law and thus made organ procurement possible, it has not completely won the day at the emotional level. The fear of being pronounced dead prematurely at the behest of organ transplant medicine is widespread, and it is this fear which explains public resistance to the brain-death criterion and to organ donation. Proposals can be found in the literature recommending that the plurality of views in this area be accommodated by introducing the possibility of choosing among different criteria for death or at least by allowing the physician contemplating a pronouncement of death to exercise some discretion in cases where there are family objections to a brain-oriented definition of death.²⁰ Allowing for such options could allow for accommodation of religious and cultural diversity by granting recognition to differing understandings of the nature of death. More importantly, this proposal could potentially contribute to the deconstruction of the fact versus values dichotomy by acknowledging that while death is indeed a biological factum, its localisation in terms of space and time is a cultural construct which is open to judgment. This is part of a larger issue: In defining fundamental concepts such as life, the person, will, responsibility or gender it is

¹⁸ Cf. WJLDICKS/GARDINER/SHEMIE/MANARA/OPDAM.

¹⁹ Cf. YOUNGNER/ARNOLD/SHAPIRO (ed.).

²⁰ VEATCH 1999, 156 ss.

important to consider to what extent it is appropriate for the law to rely on biological and medical realities, however imperfectly these may be understood. Is it right, in other words, for the law to delegate the definition and determination of these fundamental concepts to medical science and the medical profession? It is certainly the law's task to perform certain duties, such as maintaining confidence in the norm canon by sanctioning its violation, ensuring predictability of outcome and, also, guaranteeing social stability. To fulfil those functions, the law needs to draw on legal concepts which are independent of science – the idea of free will and individual responsibility in criminal law, which is constantly being called into question by neuroscientific findings (or speculations?), being but one prominent example.²¹ Of course, scientific orthodoxy constructs its legitimacy around formal concepts, dispassionate observations and rational objectivity.²² Cultural or religious perspectives, on the other hand, are considered to be empirically untrue, and based on authoritarian dogma or sentiment. And yet, what knowledge, exactly, have we gained from science? What, for example, does it mean to say that the establishment of the criteria of brain death is value-neutral because it is scientifically proven? The discussions surrounding the definition of death provide exemplary evidence that scientific knowledge cannot be understood outside historical, social and political contexts. The problems arising from the law's dependence on medicine, particularly with regard to the concepts applied to defining life, cover a wide area – and one which requires further investigation elsewhere.

Cadaveric organ transplantation: (Whose) autonomy and (whose) consent? Issues and legal regimes

As a form of clinical therapy, cadaveric organ transplantation essentially came into being in the 1960s. From its very inception it has raised a plethora of challenging legal and ethical issues, not to mention the clinical and organisational obstacles which needed to be overcome. The very first question to address, however, is how cadaveric organ transplantation itself, and any limitations placed on it, can be justified in the first place. As far as the bioethical principle of autonomy is concerned, removal and transplantation of cadaveric organs can be justified in cases where the deceased, during his or her

²¹ Cf., however, GAZZANIGA.

²² MOAZAM, 1.

lifetime, expressly gave their consent to such procedures. Here already objections can be raised on the grounds that human beings have no right to dispose of their bodies as they please, since the human body is a gift from God. Taken in conjunction with the view that the human body is sacred and at one with the soul, and cannot thus be injured, this position effectively results in organ removal being regarded as completely impermissible. The idea of the human body as a gift from God can however also be interpreted as implying a religious duty – on altruistic grounds – of making organs available for saving other human lives after death. An initial review of classical religious positions on this matter reveals an unexpectedly uniform picture. From the Christian standpoint, organ donation is seen as a sign of love for one's fellow human beings and solidarity with the sick which is deserving of particular appreciation. Under this interpretation, while life and, by extension, the human body are gifts given by the Creator of which humans cannot dispose as they wish, resurrection is primarily associated with belief in God and not necessarily with the intactness of the body.²³ In the Islamic and Jewish literature, organ donation and transplantation have been the subject of lively controversy, reflecting a concern among religious scholars about the dilemmas arising from rapid advances in medical science and biotechnology. Key arguments against cadaveric organ donation and transplantation are structured around the premise that humans do not own their bodies to use as they please; that the body is held in trusteeship from God and therefore must not be desecrated; that the body needs to be treated with dignity and respect and buried after death.²⁴ The majority views do now support cadaveric organ donation, however, and a practice which was once forbidden is increasingly being seen as a praiseworthy, exceedingly meritorious and highly dignified act, sometimes even as a religious obligation that will be rewarded in the hereafter. Since organs obtained from cadavers are directly designated for saving the lives of others, and since to give life is the most honourable of all deeds, the suspension of the

²³ Cf. Organ Transplantation, Statement of the German Conference of Catholic Bishops and the council of the protestant church, 9 and 16 s. [http://www.dbk.de/fileadmin/redaktion/veroeffentlichungen/gem-texte/GT_01.pdf].

²⁴ For a review of Islamic positions of Muslim *ulema* from South Asia, which are generally far more circumspect and conservative in their deliberations and rulings on organ transplantation than the *ulema* from Arab countries: MOOSA; AASI; for a review of the halakhic considerations in the use of cadaver donors: SINCLAIR.

traditional treatment of corpses is seen as being justified.²⁵ The vast majority of Islamic Arab countries now have organ transplant programmes and some of them have specific legislation regarding organ donation and transplantation.²⁶ Extensive reviews of the situation in Iran can be found in the literature. Indeed it was *fatwas* from the country's highest shi-ite religious authorities that largely paved the way for the enactment of Iran's Organ Transplantation and Brain Death Act 2000, whose provisions include regulation of cadaveric organ transplantation.²⁷ In 2010, Pakistan, too – whose legislation in this area had for many years been informed by *fatwas* decrying organ transplantation as un-Islamic – enacted an organ transplant law permitting transplantation from deceased donors. Israel did not pass its Organ Transplant Law until 2008, in response to the dearth of organ donors and the long list of patients on the transplant waiting list.²⁸

To whom does the body belong according to secular thought? Who is granted access to the body and in what way are they permitted to alter it? As far as cadaveric organ transplantation is concerned, the central issue is that of the right to dispose of the dead body. A review of the literature reveals a broad consensus that there are no property rights to a corpse, be it in favour of third parties or the person who is now deceased. However, there is also a consensus across all jurisdictions that a cadaver deserves proper and decent treatment. Conceptions of respectful and decent treatment are infused and intertwined with religious beliefs that the body is the handiwork of God and hence entitled to reverence.²⁹ In purely secular terms – whose applicability I would however dispute in this instance – respectful treatment of a corpse is not a duty *towards* the dead (because the corpse no longer enjoys personal protection since it is no longer a person), but rather *regarding* the dead,³⁰ and this relates essentially to the protection of the memories and sense of piety of the relatives of the deceased, and thus to the personal rights of the relatives rather than to any property-based interests. Following

²⁵ About the Jewish perspective: SINCLAIR.

²⁶ For a review of the legislation: ATIGHETCHI, 183.

²⁷ ATIGHETCHI, 186 ss.

²⁸ JOTKOWITZ relates how surveys conducted at the time showed that the willingness among the Israeli population to donate organs was very low by international standards.

²⁹ Federal Court, *Kohn v. United States* 1984.

³⁰ CHADWICK, 57 s.

this line of argument, the interests of the potential recipients of organs would have to be balanced only against the position of the relatives. In other words, the interests of the living would inevitably assume precedence. This is the assumption made by certain jurisdictions in cases where the deceased did not express any opinion on the matter of organ donation while he or she was alive. What is the approach, however, in cases where the deceased, when alive, clearly expressed a wish against organ donation? What is the rationale for giving his or her wish precedence over the interests of the living?³¹ The literature emphasises the right to self-determination of the ante-mortem individual, which clearly would be fundamentally compromised by procurement of organs as a matter of routine. The knowledge that our wishes will be respected after death may well give us a fuller sense of personal autonomy. It seems to me, however, that this is an argument which cannot be made to stand without recourse to the idea that the corpse is the representation of its living predecessor. This argument is intimately wedded to perceptions of the interconnection between the body and the self, as a nexus that survives death. Even in death, the body is clearly regarded as more than a mere piece of matter, albeit a valuable one. Indeed, article 18 of the Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Transplantation of Organs and Tissues of Human Origin 2002 states, “Respect for the human body. During removal the human body must be treated with respect and all reasonable measures shall be taken to restore the appearance of the corpse”, which suggests that the often-mentioned sacredness of the human body lends it inherent value in its own right.

There seems to be a broad consensus that there is a need for some form of consent to organ removal for a cadaver, however that need is justified. Two questions dominate the current discussion: first, does the consent of the deceased have to be explicit or can it be presumed; second, to what extent is the family of the deceased entitled to object to the deceased’s decision or to make a decision in his or her place. The differing answers to these questions in turn reflect the diversity of understandings and appreciations of self-determination, belonging and obligations to society. A comparative perspective reveals considerable variability in the legal procedures applied to donor consent. As far as I can

³¹ E.g. article 19 section 2 of the Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Transplantation of Organs and Tissues of Human Origin 2002: “The removal shall not be carried out if the deceased person had objected to it”.

determine, all jurisdictions at present explicitly require either the express consent of the deceased (through an opting-in regime) or his or her presumed consent (through an opting-out regime) or, in some instances, the express consent of a relative³² as a prerequisite for legitimate organ removal from a cadaver for transplantation purposes. Most of the early laws passed in this area were of the express consent variety. In Europe that picture soon changed and regimes of presumed consent are now widespread, which raises the question of the extent to which silence can really be assumed to be tantamount to consent. Why is organ donation either so unequivocally beneficial or so unequivocally desirable, particularly when the empirical evidence provided by existing rates of donation clearly does not bear this out? And what makes us think that bodily invasion is such an easy sacrifice to make that a communitarian-based obligation to facilitate saving the lives of others is justified?³³ It would seem that it is society's need for organs that is making it acceptable to lower the threshold required with regard to the reliability of the evidence of willingness on the part of the donor. Presumed consent can be seen as a reflection of the perception that the interest of the collective as potential recipients should prevail over that of the individual dead body. The 'injury' to the corpse resulting from organ removal must serve a therapeutic objective, however.³⁴ If one assumes that the dead themselves are beyond harm, then, from a consequentialist point of view, it is certainly desirable – if not indeed compulsory – to use corpses to prolong the lives of others; at the same time there is no apparent conflict with a deontological perspective or more precisely with the Kantian doctrine requiring that the individual must not be used solely as means to further the ends of others.

Most statutory transplant regimes prioritise the aspirations of the deceased over those of relatives and others. However, there are legal regimes in which organ removal is only permissible with the consent of both the deceased and members of the family. This applies particularly in jurisdictions where the law is to some extent religiously informed, as is the case in Iran or Israel. Moreover, in many jurisdictions medical staff do, in practice, grant relatives discretion to override the deceased's express wish to donate (as is generally the case in the US). Different regimes (from consent to non-objection to

³² As evidenced, for example, in section 3 of the Uniform Anatomical Gift Act 1987.

³³ Cf. the discussion in PRICE 2000, 148 ss.

³⁴ PRICE 2000, 149.

non-involvement of family members) reflect the dominant conceptions not only of the role accorded to the family but also of views regarding rights to dispose of the body or the legal weight accorded to the feelings of relatives who may be offended by certain forms of interference with the corpse of the deceased (in bioethical terms, these relate to the duty of non-maleficence owed to relatives).

Legislative efforts are also being undertaken to raise the number of organ donations by focusing attention on potential recipients. Israeli legislation in this area, the only one of its kind in the world, exemplifies the attendant ethical issues. The view seems relatively unanimous that where access to an organ is not governed by the ability to pay, the distribution of organs should be based upon medical factors. Indeed this is required by bioethical principles of justice. The new Israeli plan, which took effect in 2010, differs from others in that it accords allocation priority both to those who sign donor cards and to their first-degree relatives should they ever be in need of an organ transplant themselves, thus applying non-medical criteria to the organ allocation process. Prioritising donors in this way necessarily raises a number of significant moral and ethical issues.³⁵ This particular form of reciprocal altruism, “each partner helping the other while he helps himself”³⁶ certainly needs further consideration.

To sum up, the emphasis in cadaveric organ donation appears to be shifting from a traditional understanding of the rights of the deceased and his or her family to determine the way in which the corpse is disposed of towards a presumption that those who, in principle, are entitled to make decisions in this matter consent to the organs being used for the collective good or the good of others. VEATCH (1989) tellingly summarises the arguments against this as follows, “If the body is essential to the individual’s identity, in a society that values personal integrity and freedom, it must be the individual’s first of all to control, not only over a lifetime, but within reasonable limits after that life is gone as well”, adding, “If the state can assume that human bodies

³⁵ LAVEE/ASHKENAZI/GURMAN/STEINBERG.

³⁶ TRIVERS.

are its for the taking (...), what will be the implication for less ultimate, less-sacred possessions?”³⁷

Living organ donation: (when) does consent outweigh the principle of non-maleficence?

Living organ donation raises other questions than those posed by cadaveric organ donation. While Western jurisdictions continue to approach living organ donation with a degree of reticence, religious arguments appear to find it more approachable than post mortem donation, which is still subject to reservations on religious grounds. The biblical injunction, “thou shalt not stand up against the blood of thy neighbour” (Leviticus 19:16) exemplifies man’s religious duty to help members of the community. The main halakhic question then is the degree of danger to the recipient of the transplant operation weighed against the chances of a successful outcome. Different rabbinic authorities provide differing answers to the question of whether a person is permitted, or obliged, to put himself or herself in some danger in order to save the life of another person who is in grave danger. The answers range from prohibition on the grounds that this is too dangerous, to permission as an act of piety, to an act that is expressly required, the dominant opinion being that it is a most pious act, provided that it does not endanger the volunteer’s life.³⁸ Islamic-law discourse exhibits a similar structure: as long as no serious harm accrues to the donor, and the medical professional believes that such a transplant is necessary to save the life of the patient, living organ donation is allowed. This, at least, is the opinion of some *ulemas*.³⁹ In fact, Iran was one of the first countries in the world to implement a living unrelated donor programme in 1988, with cadaveric organ transplantation following much later. While this is a matter on which religious authorities admittedly express a wide range of views, and some of the individual arguments are painstakingly formulated and difficult to follow, a widespread position seems to be that donor and recipient form a community of believers and that membership of that community implies certain obligations.

³⁷ 213.

³⁸ GRAZI/WOLOWELSKY.

³⁹ MOAZAM, 5 ss.

Modern bioethics has a different focus: the individual and his or her autonomy. As far as living organ donation is concerned, the requirement of donor consent is self-evident; to compel a person to submit to a violation of his or her bodily integrity “would change every concept and principle upon which our society is founded” (Mc Fall v. Shimp 1978 with regard to the extraction of bone marrow). While it seems reasonable to assume that this holds true for many jurisdictions, legal systems which incorporate more communitarian, collectivistic values and require individuals to take reasonable steps to assist or rescue a person whose life is in danger are also conceivable. Yet even if a refusal to donate – bone marrow for example – is morally indefensible, forced removal cannot be justified in law (PETER SINGER, however, sees it as an ethical obligation of beneficence to prevent evil where this can be done without sacrificing anything of comparable moral importance,⁴⁰ a straightforward consequentialist approach that seems unduly demanding). For these reasons, living organ donation by incompetent persons or persons without full decision-making capacity is also highly controversial. Nevertheless, consent is a necessary, though not always sufficient, condition for justifying medical intervention. In the context of conventional legal frameworks, even legitimising living organ donation by fully competent adults is contentious. The removal of organs for transplantation purposes clearly involves a degree of physical damage of the body of the donor. Typically, apart from consent, some further legitimating feature is required to justify acts by third parties which infringe upon the physical integrity of the body if a certain degree of harm is exceeded. Otherwise, the *primum non nocere* maxim applies. When it comes to medical procedures, it is the purpose of the infringement to the body – i.e. the benefit to the person concerned – which justifies the act, provided that the benefits are perceived as outweighing the risks. It is precisely because living organ donation is a non-therapeutic medical procedure for the donor that it is so problematical.⁴¹ How then can the predominant scheme of laws which allow living organ donation if the harm done to the donor is not serious be justified?⁴²

⁴⁰ SINGER, 229.

⁴¹ PRICE 2000, 242 ss.

⁴² Cf. article 11, Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin, 2002.

The ethical and legal issues relating to the principle of non-maleficence have resulted in a number of jurisdictions, and transplant clinics, preferring cadaveric organ donation over living organ donation, and living related organ donation over living unrelated organ donation. All things being equal, in many countries cadaveric organ donation has statutory precedence.⁴³ However, recent policies have largely come to embrace living organ donation as a standard therapy, a policy shift which can be attributed first to the fact cadaveric donation is failing to meet the growing need for organs, and, second, to the fact that living organ transplantation produces consistently better results.⁴⁴

As far as the benefit to the donor is concerned – which is a prerequisite for justifying any procedure – a distinction is now drawn between living related organ donation and living unrelated organ donation. Living related organ donation serves to help a person who is close to the donor. Often it involves fulfilling a moral duty. This aspect alone, coupled with an interest in the well-being of people for whom one feels strongly, perhaps even the prospect of improved status within the family, may well explain the benefit for the donor. A question often raised in the literature, however, is whether consent to living related organ donation can ever really be free.⁴⁵ What does the requirement of the act being voluntary mean, for example, in the case of a mother wishing to donate a lobe of her lung to a child who would not survive without it? In principle, voluntariness is more than a choice between alternatives; the consent has to be free of coercive moments.⁴⁶ Do the internal pressures to which the mother is subject undermine her voluntariness? Does she even feel she has a choice? I would contend that as long as she is acting of her own free will, and provided that the determining or predominant will is not that of another person, we can assume she is acting voluntarily. This, of course, is a field in which cultural and religious values and commitments play a fundamental role. The will is the product of various different expectations – expectations our environment places on us, as well as expectations we place on ourselves. Each of us has our own idea of what

⁴³ Cf. article 19 of the Council of Europe on Convention on Human Rights and Biomedicine, 1997.

⁴⁴ PRICE 2010, 196.

⁴⁵ This is why clinical and medical staff often give a „medical excuse“ to the relatives of transplant patients, i.e. a “fabricated anatomical or physiological reason given to a donor (with or without the donor’s request) that immediately shields the potential donor from coercive pressure by family and friends”; see MCKOY/MCKOY, 391.

⁴⁶ PRICE 2000, 290 s.

is right and what is wrong, and these are ideas which, of necessity, have evolved in the context of particular cultural and religious circumstances. Clearly, it is not always easy to define the borderlines between coercion (which prevents autonomy of choice), internal and circumstantial pressures (which are inherent to living related donation) and cultural traditions and expectations (which are the foundations on which a person's own commitments and partiality are based and which determine who they are and what they believe in). While the pressures and expectations placed on an individual can be structural in nature, the members of the society formed by those structures have made them their own. This is reflected, for example, in the gender imbalance which is well documented in living organ donations. Considerably more women than men put themselves forward as living organ donors. This partly reflects role expectations which are congruous with a person's own individual expectations and plans for the future. Since they tend to be internalised without conflict, it is not possible to say that the expectations of society are the controlling factor.⁴⁷

If we allow for living unrelated organ donations (directed and non-directed), the pool of potential donors is very large. Nevertheless, policy statements have invariably been either negative or ambivalent in this regard.⁴⁸ It would seem that our intuitions are somewhat divided as far as self-sacrifice is concerned. The suspicion seems to be that people donating organs to people to whom they are not even related either receive some (illegal) financial benefit for so doing or are in a troubled state of mind and thus not capable of giving valid consent. This means that whilst in living related donation it is the closeness of the relationship which is the source of concern (because an emotional connection might be contaminating what should be a rational free choice), in living unrelated donation it is precisely the absence of such a relationship that is perceived as being the problem. Indeed, the rhetoric itself is inconsistent. On the one hand there is

⁴⁷ Cf. BILLER-ANDORNO 2002.

⁴⁸ Cf. WHO Guiding Principle 3, 2010: "Donation from deceased persons should be developed to its maximum therapeutic potential, but adult living persons may donate organs as permitted by domestic regulations. In general living donors should be genetically, legally or emotionally related to their recipients"; article 10 Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin, 2002: "Organ removal from a living donor may be carried out for the benefit of a recipient with whom the donor has a close personal relationship as defined by law, or, in the absence of such relationship, only under the conditions defined by law and with the approval of an appropriate independent body".

an insistence that organ donation should be altruistically motivated, which means that no personal advantage for the donor should be involved. On the other hand, anonymous living organ donors are the most altruistic donors of all, and that is exactly what arouses suspicion about their motivation. What constitutes a good motive and results in a positive reward or satisfaction is not an objective matter. Motives of living unrelated donors are probably as diverse, complex and maybe even as unintelligible as human beings themselves. The motivation may be the idea of a duty to oneself; an independent moral force of interest in the faith of others; a sense of belonging to a community; the longing for a heightened self-esteem that would also lead to an increased quality of life; or the manifestation of altruism itself.⁴⁹ The benefit is something for the donor to weigh up, the clinic can only make sure that the patient has the capacity and all the information necessary for making a realistic assessment of the risks and the burden involved. Good clinical outcomes have led to increased acceptance of donations by genetically unrelated donors. As far as broadening the range of living donor sources is concerned, this is a critical development. However, in some countries it is still prohibited altogether (e. g. Germany, France), in others the law is silent but many clinics are unaccommodating to such donations. According to the comparative work carried out by PRICE, 2010, “the ‘bar’ nevertheless appears to be lifting incrementally as far as acceptable risk is concerned. (...) (T)he ethical and legal ceiling of living organ donation is uncertain”.⁵⁰

Finally, there is a widespread assumption that donor voluntariness is called into question if the real incentive for the donation is monetary gain. Therefore, the general ethical policy is that payments for organ donation should not be allowed, unless it is compensation for financial losses incurred as a direct result of organ donation.⁵¹ Indeed, there is a broad and intense controversy concerning the threats of the commoditisation and commercialisation of the body and its parts. The various positions on this are well

⁴⁹ PRICE 2010, 216.

⁵⁰ 210.

⁵¹ Cf. WHO Guiding Principle 5, 2010: “Cells, tissues and organs should only be donated freely, without any monetary payment or other reward of monetary value. Purchasing, or offering to purchase, cells, tissues or organs for transplantation, or their sale by living persons or by the next of kin for deceased persons, should be banned”; article 21 the Council of Europe on Convention on Human Rights and Biomedicine, 1997: “The human body and its parts shall not, as such, give rise to financial gain”.

known: arguments against a market for organs include the vulnerability and weak agency of potential donors, and unequal access to the market; arguments in favour of paid organ donations are utilitarian considerations – financial incentives would lead to an increase of the number of people willing to donate –; or the libertarian view, according to which the ban on organ sales amounts to an illegitimate infringement of personal liberty. One common argument made is that the advantages of a transparent market outweigh those of its prohibition (and the resulting black market), also with regard to considerations of justice.⁵² An interesting case in this regard is Iran. In 1988, Iran adopted a compensated and regulated living unrelated donor renal transplant programme and is currently is the only country in the world without a kidney transplant waiting list.⁵³ It is not my intention to engage here in a complex debate that also has to take economic theories and perspectives into account. Of greater interest in the context of the current project is the fundamental and frequently made claim that – irrespective of the outcome of any cost/benefit analysis balancing the benefits and risks of a market for organs – attaching a commercial value to organs would violate human dignity and the intrinsic value of every human – consistent with the Kantian, non-consequentialist position that „In the kingdom of ends everything has either a *price* or a *dignity*“.⁵⁴ Or in the trenchant words of Justice Arabian in the leading *Moore v. Regents of the University of California* case⁵⁵: „Plaintiff has asked us to recognize and enforce a right to sell one's own body tissue for profit. He entreats us to regard the human vessel – the single most venerated and protected subject in any civilized society – as equal with the basest commercial commodity. He urges us to commingle the sacred with the profane. He asks much“.

From a comparative perspective, one can observe a substantial diversity with regard to the normative frameworks of living organ donation. Whilst consent to donation is a universally accepted necessity, precisely how the capacity to consent should be assessed involves different interpretations of the meaning of autonomy. In fact, the different protocols and operational standards used to assess a person's decision-making capacity,

⁵² RADCLIFFE RICHARDS, 381 ss.

⁵³ LARIJANI/ZAHEDI/TAHERI; GHODS.

⁵⁴ 1785/GREGOR (ed.) 1996, 4:434.

⁵⁵ 51 Cal.3d 120, Supreme Court of California July 9, 1990.

the screening of donors' motives and attitudes, and the corresponding court decisions, should offer very useful insights into one of the most complex and controversial issues of living organ donation: whether and how to contextualise autonomy – the theoretical basis for consent which is both free and informed. How and to what extent do the situational context (the characteristics of a particular case, its medical risks, benefits and therapeutic options), the cultural and religious context (such as the importance of the social role of family ties or religious belonging), the emotional context (affective dimensions), and the relational context (i.e. the specific relationship between the recipient and the donor)⁵⁶ inform or even pervade both the concept of autonomy and the individual's decision-making process? Each assessment presents us with a complex ethical question that hinges on the underlying understanding of autonomy.

First observation: From the autonomy of the person to the social responsibility of the body

To date, the policy underpinning almost all cadaveric organ transplant regimes has been one of autonomous donation. Routine procurement of organs from a dead person, without at least some form of (alleged) consent to their removal is (very) rarely considered as a viable approach. There is an ongoing debate as to whether express or presumed consent regimes are the preferred legal response, the premise being that the latter will result in a greater volume of organs being available for transplantation. However, a legal presumption of vital consent to organ donation in all cases where such presumption has not been expressly challenged is dogmatically controversial; the same is true of a possible controlling authority being exerted by the surviving family. Some participants in the debate consider that the presumed consent regime is the first step on a slope towards a corpse automatically being understood to be at the state's disposal, or seen as a societal resource left to the medical community to be deployed as needed. Whilst this fear is certainly exaggerated, legal frameworks and the public discourse nevertheless indicate a shift towards presumed consent. This development may well reflect more than mere strategies designed to cope with the scarcity of donors on the one

⁵⁶ Cf. for a comparative study of three cases in Germany, the United States and India BILLER-ANDORNO/AGICH/DOEPKENS/SCHAUENBURG.

hand and the increasing demand for organs on the other. International conventions clearly prioritise the interests of the individual over social or academic interests.⁵⁷ Is that really so? Or have new forms of mutual dependence emerged which presuppose or entail other structures of obligations or collective understandings of what group or community a corpse “belongs to“?

A very similar question can be asked in the context of living organ donation. Admittedly, from an orthodox legal perspective, living organ donation appears as a transgression of the medical ethic – since, by necessity, the intervention does not benefit the donor in his or her physical integrity. Yet there are many advocates of a broader theory of harm and benefit, one which is not limited to the donor’s position but which encompasses other people’s humanity as well. In this context it seems sensible to ask what moral obligations the advances in organ transplantation technology impose on those contemplating donation. If we are the owner of a good which can prolong or improve other people’s lives, the perspectives may shift from an individualistic to a more collective definition of the benefits. Moreover, obligations may arise from the increasing reliance of society on organ donation. What may once have been a very charitable standard and ideal is becoming an expectation. Clearly, there is a universal duty not to harm the physical integrity of a person, but what of a person’s duty to save another if the risks to the former’s physical integrity are minimal? Does the individual’s body have to succumb to the collective need – unless he or she has compelling reasons for not agreeing to this? And what do individuals’ and society’s increasing reliance on organ donation mean for conceptual assumptions about autonomy – the concept to which bioethical analysis gives the centre-stage position? My observation would be that the rapid progress being made in transplantation medicine wields considerable influence on the conceptualisation of autonomy, and that body-related duties of solidarity will have a significant impact on private and public discourse on organ transplantation. Religious norms do not in any way contradict this. To the contrary, I believe that, in this context, religious and scientific narratives produce convergent messages – despite radically different assumptions, forms of reasoning and perceptions. The precepts of religion can

⁵⁷ Cf. article 3.2. Universal Declaration on Bioethics and Human Rights, 2005: “The interests and welfare of the individual should have priority over the sole interest of science or society”.

even be interpreted as supporting an ethical framework favourable to organ donation and transplantation, and scientific developments can be seen as carrying religious weight. Reducing the question of (limits to) organ donation and transplantation to one of resolution of conflicts between the interests of donor and recipient, or to cultural narratives of liberal individualism, progress and the market, or to focus on the narrow context highlighted by achievements in medical technology does not fully appreciate the intimate, societal and cultural struggles being waged over the body. Evaluations of this field have to take into account cultural, societal and religious preoccupations with the body, as well as individual and community-oriented ethics of responsibility and compassion.

Second observation: Whose body? Is it me or is it mine? The dialectic tension between being and having

The sometimes excitable discussions being conducted on organ utilisation actually stem from a limited number of fundamental legal questions regarding obligation and the individual's autonomy over his or her own body – even though the organ transplant debate does not always explicitly refer to them. The body is the most innate form of personal expression. Since time immemorial, the law has always implicitly assumed congruence between the person and the body. Indeed that congruence was fundamental to the very concept of humanity itself (Kant argued that the „body is part of the self; in its togetherness with the self it constitutes the person“⁵⁸). The scope for technological appropriation of the human body and its bio-industrial exploitation clearly challenge the historical identity between the person and the body. There is a shift in the way the self is viewed. Whereas we were previously corporeal beings (*wir waren Leib*), now we also have a body (*und haben nun einen Körper*). The historically old question of who owns the body (dead or alive) is now becoming dramatically accentuated. The array of possible answers – the tradition of viewing the cadaver as *res nullius*; judicially created ambivalent concepts of the quasi-property rights of relatives over the body; Lockean notions of self-ownership; the transformation from person to object that then falls into

⁵⁸ KANT ed. 1963, 124.

'limbo' after removal from the body; property rights vested in the source of the material alone – all reflect the deep conceptual issues arising from secular ideas of possession imbued with the notion of sacredness of the body, and all are incapable of easy resolution. At present, there is a widespread statutory and judicial reluctance to apply property rights to human body parts (or attitudes in this area are at the very least ambivalent); scholarship is, ultimately, organised roughly along the common and civil law divide: in the Anglo-American legal culture the relationship between the person and his or her body is interpreted more as one of possession, in the continental European perspective more as one of being.

New medical technologies have resulted in a tacit reconsideration of the fundamental question of the nature of the relationship between the person and his or her body. Human organs and tissues can be appropriated and put to use by third parties. Since these organs and tissues can now be made available to others outside the confines of the person, they have become fundamentally different from other personal rights such as honour, freedom or life. The possibility of organs and tissues being made available to others, and thus commercialised, suggests that they are structurally akin to property. Theory is thus called upon to state who is entitled to lay claim to controlling, using and deriving benefit from these goods. In pulling the different strings of this discussion together, I would argue for different views to be taken of (1) our own living body (an individual's right to his or her own body is a personal right, one which offers protection against incursion by others. This therefore invalidates the establishment of property rights to the human body and to the parts of it which are inalienably associated with it); (2) the parts of the human body which have been severed from the whole; and (3) the dead body or parts thereof. Whilst the person is embodied, and the body is me, we are also more than the sum of our parts.⁵⁹ The parts removed or separated from the body as a whole – e.g. donated organs – are capable of being the subject of property rights (the factual distance becoming a normative distance – for there is a corporeal object to which we can refer, which is distinct from its owner and to which human will can be applied) without the notion of embodiment (I am my body, my body is me) being called into question. I would like to expand this perspective by adding that the fact that excised

⁵⁹ PRICE 2010, 240.

body parts can be the subject of property rights does not prevent them from also being subject to personal rights. An organ is a partial portrait of the individual who previously bore it, and that previous bearer therefore maintains a protected interest in it and a personal right to it. To that extent, I believe that property and personal rights must necessarily co-exist in this regard. One problem about thinking of the body as property is the potential of subjecting parts of it to commercial arrangements. However, the existence of property rights does not preclude the potential outlawing of commercial transactions. Treating the body and body parts as *res nullius* is not the only way to preserve the altruistic spirit of the donation and remove them from the commercial sphere. In fact, the justification for arguing that despite its becoming more available to biotechnological science, the human body and its constituent parts should remain subject to a commercialisation embargo is not all that self-evident. The right to be able to exercise control over certain goods through a process of approval generally also implies that it is possible to ask for money to granting such control. Would the possibility of requiring emolument in exchange for an organ donation really compromise an individual's free will and thus his or her self-determination?

A profound approach to thinking about the body in the light of biomedical procedures such as organ transplantation, must, however, necessarily go beyond rigorous legalistic reasoning and take into account the complexities which result from embodiment. In order fully to comprehend the challenges posed by organ donation and transplantation, we need to appreciate how the body is conceived of within cultural and religious frameworks, and what values are ascribed to it. We need to appreciate that the body is at the intersection of nature and culture, of the individual and society, and that it is the material substrate of our existence and has a special place in our lives. Through a holistic lens – one that includes the “experiential realities” – we may have difficulty in discerning the secular and the religious – not only in private discourse, but also in public deliberation and in legal texts dealing with transplantation. Organ transplantation revolves around bodies and their meaning. Associated with the body there is a sense of sacredness that transcends the secular/religious divide. Empirical findings suggest that the unwillingness to donate an organ is often due to the conviction

that body should be kept whole.⁶⁰ It is a given that religious convictions shape individual approaches to organ donation and transplantation and that they inform personal decision-making. In debating bioethical issues, and in perhaps reaching normative conclusions, religious responses inevitably enter the conversation. Finally, and this is not surprising, organ transplantation laws are perceived as embodying deep religious values.

Third observation: Individual autonomy or universal dignity? The challenges posed by societal pluralism

There is an assumed tension between increasing universal bioethical standards,⁶¹ the global nature of the need for organ transplants and the intrinsically personal, even intimate, cultural and religious aspects of the matter. Current bioethical theory sets out to be universal, since it assumes a common morality, embodied in a few principles. This kind of universalism and the principlist methodology have drawn criticism. The presumption is that too little attention is paid to the pertinence of religious pluralism, cultural differences, and ultimately to the moral diversity which pervades our society. DANIEL CALLAHAN frames the question as follows, “How are we as a community, dedicated to pluralism, to find room for the different values and moral perspectives of different people and different groups? How, that is, are we to respect particularism, by which I will mean a respectful interest in the values and ways of life of different cultural and ideological groups and commitment to taking those differences seriously”.⁶² On an abstract and theoretical level, the question of universalism or particularism is hardly answerable and yet not particularly exciting. CALLAHAN himself answers it as follows: “There cannot and should not ordinarily be any decisive victory for particularism or universalism. They should over the long run fight to a draw, existing in tension with each other, with context and circumstance determining their relative weight”.⁶³

⁶⁰ Cf. STEPHENSON/MORAGAN/ROBERTS-PEREZ et. al.

⁶¹ In fact, supranational instruments are progressively used to determine global standards, while invoking the vocabulary as well as the tradition of human rights; for a critical appreciation of this aspect of the European Convention on Human Rights and Biomedicine: HOTTOIS.

⁶² 37.

⁶³ 37 s.

In fact, the alternative of universalism and particularism is simply too blunt given the moral complexity of everyday life as it unfolds within a system of cultural parameters. What seems more promising, yet is largely unexplored, are approaches that aim to overcome limitations of comprehensive moral theories – in the sense that they arbitrarily impose moral commitments on others – in order to come to grips with the fact of a plurality of moral worldviews. AINSLIE argues persuasively for a Rawlsian approach to bioethics as an adequate response to pluralism: “My suggestion is that bioethics should be seen as freestanding in relation to comprehensive moral doctrines, just as Rawls thinks that political philosophy is. In each case, the norms that are to apply to all members of society – whether as citizens or as participants in the delivery of health care – are justified not by appeal to any particular comprehensive doctrine, but in terms that those with conflicting yet reasonable doctrines can accept”.⁶⁴ AINSLIE calls for a bioethics of everyday life – needed for the different moral options to be accommodated in a pluralistic society.

In today’s dominant bioethical discussion, autonomy provides a parenthesis accommodating a variety of perspectives. Autonomous decisions allow individual beliefs and preferences to be expressed. Two points remain moot, however. First, it is questionable whether autonomy genuinely enjoys the same recognition across all religious and cultural contexts – whether, in other words, autonomy can accommodate religious and cultural diversity. Second, it is debatable whether the decision by the person concerned can allow an autonomous, self-determined perspective to be expressed in the first place. We have seen the decisive influence which tightly knit networks, family structures, societal expectations and religious reasoning exert on matters relating to organ donation. It would thus seem essential that autonomy is not granted an entirely free rein.

In the recently adopted international instruments dealing with biomedicine and bioethics, respect for human dignity holds a prominent position; according to ANDORNO it can even be seen as the overarching principle of international biomedical law.⁶⁵ The concept of dignity, however, has often been criticised as being too vague or having

⁶⁴ 13.

⁶⁵ ANDORNO 2009, 227.

insufficiently defined content. There is certainly a lack of consensus on the substance of human dignity considerations.⁶⁶ Indeed, dignity is not only much more suited than autonomy to capturing (individual or collective) notions of the sacredness of the body and the person, but also makes the transcendent more accessible. In the Kantian understanding of dignity - often found in legal texts on organ donation and transplantation - a human being should always be treated as an end and not as a means. The prohibition of property rights in body parts or paid organ donation⁶⁷ is justified by the argument that allowing such practices would compromise human dignity.⁶⁸ In this sense dignity trumps the principle of autonomy, constraining the individual's freedom to pursue his or her autonomously chosen goals. Finally, insofar as it is understood as a high-ranking status afforded equally to all human beings,⁶⁹ dignity – as a universal concept – also ensures respect for all people. These are all valid reasons supporting the importance of dignity in organ donation and transplant laws in a culturally and religiously diverse society.

Concluding remark

These three observations are intended to capture some of the shifts and movements in the field of organ donation and transplant law. Whether these movements can be explained solely by the scarcity of donated organs, or whether medical and technological feasibility is the key determining factor, is something I cannot judge. What I can say is that this entire issue provides a good illustration of how the various types of discourse – medical, religious and legal – are interwoven with each other.

⁶⁶ MCCRUDDEN exposes that there are no coherent interpretations of human dignity in national or transnational jurisprudence.

⁶⁷ E. g. Convention on Human Rights and Biomedicine, 1997, Explanatory Report, according to which property rights would compromise human dignity.

⁶⁸ For a different view and challenging the traditional understanding of the Kantian idea BEYLEVELD/BROWNSWORD: “Dignity belongs to my person/agency, not to my body, unless I conceive of myself as my body (...). My body is a thing generically instrumental to my agency, not my being as an agent or person itself, and not therefore an end-in-itself. Whereas to use my body as a mere means to the ends of others would be to violate my person as an end-in-itself, for me to will use of my body as a means is not for me to treat myself as a mere means, for to treat a person as an end in itself is basically to respect the will of that person”, 95 s.

⁶⁹ WALDRON.

Bibliography

Ghulam-Haider Aasi, *Islamic legal and ethical views on organ transplantation and donation*, 38 ZYGON, at 725 (2003)

Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A definition of irreversible coma*, 205 (6) JAMA, at 337 (1968)

Donald C. Ainslie, *Bioethics and the Problem of Pluralism*, 19 (2) SOCIAL PHILOSOPHY & POLICY FOUNDATION, at 1 (2002)

Seyed Mohammad Akrami, Z. Osati, F. Zahedi & M. Raza, *Brain Death: Recent Ethical and Religious Considerations in Iran*, 36 (10) TRANSPLANTATION PROCEEDINGS, at 2883 (2004)

Roberto Andorno, *The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law*, 2 (4) JOURNAL OF INTERNATIONAL BIOTECHNOLOGY LAW, at 133 (2005)

Roberto Andorno, *Human Dignity and Human Rights as a Common Ground for a Global Bioethics*, JOURNAL OF MEDICINE AND PHILOSOPHY, 34 (3), at 223 (2009).

DARIUSCH ATIGHETCHI, ISLAMIC BIOETHICS: PROBLEMS AND PERSPECTIVES (2009)

TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS, (6th ed. 2009)

Deryck Beylevel & Roger Brownsword, *MyBody, My Body Parts, My Property?*, 8 (2) HEALTH CARE ANALYSIS, at 87 (2000)

Nikola Biller-Andorno, *Gender imbalance in living organ donation*, 5 (2) MEDICINE, HEALTH CARE & PHILOSOPHY, at 199 (2002)

Nikola Biller-Andorno, George J. Agich, Karen Doepkens & Henning Schauenburg, *Who shall be allowed to give? Living organ donors and the concept of autonomy*, 22 THEORETICAL MEDICINE AND BIOETHICS, at 351 (2001)

Kerry W. Bowman & Shawn A. Richard, *Culture, brain death, and transplantation*, 13 (3) PROGRESS IN TRANSPLANTATION, at 211 (2003)

Daniel Callahan, *Universalism & Particularism, Fighting to a Draw*, 30 (1) THE HASTINGS CENTER REPORT, at 37 (2000)

Ruth F. Chadwick, *Corpses, Recycling and Therapeutic Purposes*, in LAW AND ETHICS AT

THE END OF LIFE, at 54 (Robert Lee & Derek Morgan ed., 1994)

K. Danner Clouser & Bernard Gert, *A Critique of Principlism*, 15 (2) JOURNAL OF MEDICINE AND PHILOSOPHY, at 219 (1990)

David Gardiner, S. Shemie, A. Manara & H. Opdam, *International perspective on the diagnosis of death*, 108 (S1) BRITISH JOURNAL OF ANAESTHESIA, at i14 (2012)

MICHAEL S. GAZZANIGA, WHO'S IN CHARGE? FREE WILL AND THE SCIENCE OF THE BRAIN (2011)

A.J. Ghods, *Changing Ethics in Renal Transplantation: Presentation of Iran Model*, TRANSPLANTATION PROCEEDINGS, 36, at 11 (2004).

Richard V. Grazi & Joel B. Wolowelsky, *Nonaltruistic Kidney Donation in Contemporary Jewish Law and Ethics*, 75 (2) TRANSPLANTATION, at 250 (2003)

Gilbert Hottois, *A Philosophical and Critical Analysis of the European Convention on Bioethics*, 25 (2) JOURNAL OF MEDICINE AND PHILOSOPHY, at 133 (2000)

Alan Jotkowitz, *Notes on the New Israeli Organ Donation Law – 2008*, 40 (10) TRANSPLANT PROCEEDINGS, at 3297 (2008)

Immanuel Kant, *Groundwork of the Metaphysics of Morals*, in PRACTICAL PHILOSOPHY, at 43 (Mary J. Gregor ed., 1996) (1785)

IMMANUEL KANT, LECTURES ON ETHICS (Louis Infield trans., John MacMuray ed., 1963)

Bagher Larijani, F. Zahedi & E. Taheri, *Ethical and legal aspects of organ transplantation in Iran*, 36 (5) TRANSPLANTATION PROCEEDINGS, at 1241 (2004)

Jacob Lavee, Tamar Ashkenazi, Gabriel Gurman & David Steinberg, *A new law for allocation of donor organs in Israel*, HEART TRANSPLANTATION UNIT, DEPARTMENT OF CARDIAC SURGERY, SHEBA MEDICAL CENTRE, TEL HASHOMER, ISRAEL (2009), available at PubMed, File No. 20022099

Dana J. Lawrence, *The Four Principle of Biomedical Ethic: A Foundation for Current Bioethical Debate*, 14 JOURNAL OF CHIROPRACTIC HUMANITIES, at 34 (2007)

MARGARET M. LOCK, TWICE DEAD: ORGAN TRANSPLANTS AND THE REINVENTION OF DEATH (2002)

June M. McKoy & Judith M. McKoy, *Caveat Patiens – Ethical Dilemmas in Decision-making*, CENTRAL EUROPEAN JOURNAL OF MEDICINE, 3(4), at 390 (2008).

Christopher McCrudden, *Human Dignity and Judicial Interpretation of Human Rights*, EUROPEAN JOURNAL OF INTERNATIONAL LAW, 19 (4), at 655 (2008).

Pam McGrath, *Autonomy, Discourse, and Power: A Postmodern Reflection on Principlism and Bioethics*, 23 (5) JMED PHILOS, at 515 (1998)

FARHAT MOAZAM, BIOETHICS & ORGAN TRANSPLANTATION IN A MUSLIM SOCIETY: A STUDY IN CULTURE, ETHNOGRAPHY, AND RELIGION (2006)

Ebrahim Moosa, *Interface of science and jurisprudence: Dissonant gazes at the body in modern muslim ethics*, in GOD, LIFE AND THE COSMOS; CHRISTIAN AND ISLAMIC PERSPECTIVES, at 329 (Ted Peters et al. ed., 2002)

JEAN-LUC NANCY, ÊTRE SINGULIER PLURIEL (1996)

Janet Radcliffe Richards, *NEPHRARIOUS GOINGS ON, Kidney Sales and Moral Arguments*, 21 (4) THE JOURNAL OF MEDICINE AND PHILOSOPHY, at 381 (1996)

DAVID PRICE, HUMAN TISSUE IN TRANSPLANTATION AND RESEARCH. A MODEL LEGAL AND ETHICAL DONATION FRAMEWORK (2010)

DAVID PRICE, LEGAL AND ETHICAL ASPECTS OF ORGAN TRANSPLANTATION (2000)

DANIEL B. SINCLAIR, JEWISH BIOMEDICAL LAW (2003)

Peter Singer, *Famine, Affluence, and Morality*, 1 (3) PHILOSOPHY AND PUBLIC AFFAIRS, at 229 (1972)

Daniel Sperling, *Israel's New Brain-Respiratory Death Act: One Step Forward or Two Steps Backward?*, 20 (3-4) REVIEWS IN THE NEUROSCIENCES, at 299 (2009)

Michael T. Stephenson, Susan E. Morgan, Samaria D. Roberts-Perez, Tyler Harrison, Walid Afifi & Shawn D. Long, *The role of religiosity, religious norms, subjective norms, and bodily integrity on signing an organ donor card*, 23 (5) HEALTH COMMUNICATION, at 436 (2008)

Robert Trivers, *The evolution of reciprocal altruism*, 46 (1) QUARTERLY REVIEW OF BIOLOGY, at 35 (1971)

Leigh Turner, *Bioethics in pluralistic societies*, 7 (2) *MEDICINE, HEALTH CARE AND PHILOSOPHY*, at 201 (2004)

Robert M. Veatch, *The Conscience Clause, How Much Individual Choice in Defining Death Can Our Society Tolerate?*, in *THE DEFINITION OF DEATH*, at 137 (STUART J. YOUNGNER, ROBERT M. ARNOLD & RENIE SCHAPIRO ed., 1999)

Robert M. Veatch, *The Newly Dead. Mortal Remains or Organ Bank?*, in *DEATH DYING, AND THE BIOLOGICAL REVOLUTION*, at 213 (1989)

Jeremy Waldron, *How Law Protects Dignity*, *NEW YORK UNIVERSITY PUBLIC LAW AND LEGAL THEORY WORKING PAPERS*, Paper 317 (2011), http://lsr.nellco.org/nyu_plltwp/317

Eelco F.M. Wijdicks, *Brain death worldwide: Accepted fact but no global consensus in diagnostic criteria*, 58 (1) *NEUROLOGY*, at 20 (2002)

STUART J. YOUNGNER, ROBERT M. ARNOLD & RENIE SCHAPIRO, *THE DEFINITION OF DEATH*, at xiii (1999)

Stuart J. Youngner, Martha Allen, Edward T. Bartlett, Helmut F. Cascorbi, Toni Hau, David L. Jackson, Mary B. Mahowald & Barbara J. Martin, *Psychosocial and Ethical Implications of Organ Retrieval*, 313 (5) *NEW ENGLAND JOURNAL OF MEDICINE*, at 321 (1985)