Transplantation, Biobanks and the Human Body, volume 3 of About Bioethics

by Nicholas Tonti-Filippini

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Transplantation, Biobanks and the Human Body is the third volume in Dr. Nicholas Tonti-Filippini's About Bioethics series. Here Tonti-Filippini expounds on a subject with which he has extended experience, not only as an ethicist, professor, and bioethical consultant but in profoundly personal ways as well. Tonti-Filippini has long been dependent on hemodialysis as a patient with renal disease. In this volume, he writes about the transplantation of human organs and tissue from a perspective that is solidly grounded in sound theological and philosophical tradition, with a broad understanding of both medical practice and public policy and a practical familiarity with many of the matters he presents for our consideration. The result is a book that not only applies sound and balanced moral science to the questions at hand but also provides insight into the complex moral psychology of one to whom such questions are addressed as real-life deliberations.

Tonti-Filippini begins by defining his target readership: "This book," he says, "is written for people who want to reflect on whether to be an organ and tissue donor, donate the organs and tissue of a relative after death, receive an organ transplant, or participate as a health professional in transplantation or biobanks" (vii). His purpose is to inform such people about how donated tissues might be used and what organ transplantation involves. He is particularly interested in the practice of transplanting organs after the death of the donor. In the book's preface, as he recounts his many years of involvement in ethical matters relating to organ and tissue donation, it is the issues related to postmortem donation on which he focuses. He recalls that, in the early 1980s, when the diagnosis of death by the brain criterion (so-called "brain death") became legally accepted, he had reservations about how it was applied in practice. His reservations included concerns about "the way in which the families of organ donors were treated, and the move towards diagnosing death by the clinical testing of brain stem reflexes and the apnoea test alone" (x). The process of organ donation, he observes, was becoming "more like *taking and getting* organs rather than *giving and receiving*" (xi).

Although he supports organ transplantation, Tonti-Filippini has refused to put his name on a list for a kidney transplant: "I felt then, and still feel, that I could not seek to make changes to the practices and to advocate for ancillary testing if I were to be a beneficiary of the process" (xi). In particular, he urges adherence to the original whole-brain criterion for determining death—that is, the irreversible loss of all brain function. He treats these matters extensively in chapters 3 and 4 of the book.

In his introductory chapter, Tonti-Filippini lays out many of the subjects he will consider in the subsequent chapters. In addition to donation after death (chapter 3) and questions about the diagnosis of death (chapter 4), these include the protection of living donors (chapter 2), for-profit trade in human organs and tissue (chapter 5), xenotransplantation (chapter 6), the use of human stem cells for research and transplantation (chapter 7), the development of artificial organs and tissues (chapter 8), and the experience of being a donor or recipient and the dilemmas with which donors and recipients are confronted (chapter 9).

He begins with a brief reflection on attitudes toward the human body and how the human body is related to the human self. After a brief summary of religious and secular understandings of human life and death, he poses suggestive questions about particular bodily organs—the brain and genital organs—and human identity: "I often ask my

students that if my brain were switched with one of their bodies, who would go home to my wife—my brain in someone else's body, or my body with someone else's brain?" (2). The sensitivity to the bodily constitution of human identity that underlies this question is the subtext of this entire book. In every issue he considers, Tonti-Filippini raises questions about how the treatment of the human body in the practice of organ and tissue transplantation does or does not do justice to the human person.

In chapter 2, Tonti-Filippnni takes up the subject of living organ and tissue donors. Under particular consideration here is the donation of non-regenerative tissue, such as the donation of a kidney by a person who has two healthy kidneys and can maintain healthy functioning with only one. This kind of donation involves significant risks to the donor: both the risks of undergoing invasive surgery and the increased risk of renal failure in the future. Tonti-Filippini considers these risks and how they are to be evaluated by potential donors as well as the medical teams involved. He also considers how taking reasonable risks for the sake of another person's health can be a great gift. He emphasizes the act of giving, not only as something praiseworthy but also as something necessary in the practice of organ donation. Later, in chapter 9, he will contrast giving and receiving with taking and getting. Here in chapter 2, he approvingly quotes Pope John Paul II: "Any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable, because to use the body as an 'object' is to violate the dignity of the human person."1 Tonti-Filippini will return to the issue of trade in human organs and tissue in chapter 5. Here he continues to consider what he calls the "altruistic" gift of an organ on the part of a living person: "Because the decision must be an altruistic decision," he says, "consent of the donor is essential" (21).

Consent is essential to authentic donation; it is also hard to ensure. "A difficulty can arise," Tonti-Filippini warns, "when the donor's decision is affected by emotional

pressure and the strong wish of other family members that the donation occur" (21). This issue is close to his experience. He writes, "Having been dependent on haemodialysis for more than 20 years, and had renal disease for 35 years, the possibility of being a recipient of a kidney from someone else has been very real" (21). He tells us how he has received several offers "from friends and acquaintances, as well as from complete strangers," that he has chosen not to accept. He explains, "In my mind has been the thought that family members may have felt a strong sense of obligation, because they are the most likely to be tissue matched. I have not wanted to exploit that sense of obligation and have wondered whether such a choice can ever be considered entirely free" (21-22). He goes on to reflect insightfully on the family dynamics and unspoken pressures that could influence a person's decision to incur such risks.

I do not wish to cast doubt on the influence of such factors, and I do not question the very generous personal decisions that Tonti-Filippini has made. But I also wonder whether the question might be turned around. No choice is ever entirely free from external influence. But as a clinical psychologist friend pointed out to me, to deny someone the opportunity to make such a gift could also be a way of restricting freedom.

In chapters 3 and 4, Tonti-Filippini returns to the subject of organ donation after death. He begins his treatment of the subject by taking note of the strong support of Popes John Paul II and Benedict XVI for the practice. He also echoes their concerns that donors provide fully informed consent and that donors' deaths be established with certainty before organs are removed.

Tonti-Filippini first examines the concerns about consent. He considers the ways in which consent is obtained from potential donors or members of their families and the lack of information on which that consent is often based. Already in the preface, he pointed out the "problem with organ donation decisions being made without knowledge of what is involved, especially that organ

donation involves harvesting organs while the heart still beats" (xi). In chapter 1, he described how "being an organ donor will change the experience [of the donor's death] for the family": when a patient's organs are to be transplanted, "the family make their goodbyes while the heart still beats, usually in the intensive care unit and prior to the patient being taken to the operating theatre" (7).

In chapter 3, Tonti-Filippini points out the confusion and misinformation that exist concerning the ways in which the death of potential donors is diagnosed. Although the laws in the majority of western countries identify death by brain criteria with the irreversible loss of all brain function, that standard, Tonti-Filippini says, is not generally upheld in the "current practice in Australia and other English-speaking countries[, where] the practice in most instances is not to diagnose 'brain death' by testing for blood flow to the brain. Instead the clinical tests for some brain stem functions are considered sufficient" (41). He concludes, "Consent by potential donors or their families is clearly not informed consent if they do not understand the way in which the diagnosis [of death] is to be made" (43).

In chapter 4, Tonti-Filippini considers the understanding of death from religious and philosophical perspectives and the ways in which these views do or do not intersect with contemporary secular and scientific views. He focuses especially on the Christian and Aristotelian understanding of death as the separation of body and soul and how that view has been reconciled with the notion of brain death. He notes the approval of the neurological criterion for death expressed by Pope John Paul II, quoting the Pope's teaching that "the death of a person is a single event, consisting in the total disintegration of the unitary and integrated whole that is the personal self"2 and paraphrasing the Pope's conclusion that once all brain function has ceased completely, the soul has separated from the body and death has occurred (53).

The convergence between the understanding of death as the separation of the soul from the body, resulting in bodily disintegration, and the idea of death as being diagnosable from the irreversible loss of brain function has itself begun to disintegrate. Tonti-Filippini summarizes in this chapter the objections of Alan Shewmon to the notion that total loss of brain function results in the loss of all bodily integration. He relates how, in 2009, on the basis of Shewmon's evidence, the "US President's Council on Bioethics rejected the loss of integration explanation for death by brain criterion" (54). Instead of calling for stricter criteria for the diagnosis of death, however, the council opted "for what it calls a 'mode of being' view in which it is acceptable to diagnose death if the living being (sic) is no longer receptive to stimuli, cannot act upon the world to obtain what it needs, and is not driven by basic felt needs" (54). Tonti-Filippini critiques Shewmon's findings, suggesting that some of the bodily integration Shewmon observed in "brain dead" patients may occur only in those who are diagnosed by less strict clinical criteria, which "are not sufficient" to show the loss of all brain function (60). He also questions whether some of the integrative functions Shewmon cites are "really activities of the organism as a whole in the sense that Pope John Paul II meant when he referred to the unitary and integrated whole that is the personal self" (61).

Tonti-Filippini likewise rejects the President's Council's mode-of-being view in favor of the traditional integrationist understanding, which he believes is consistent with the diagnosis of death by the irreversible loss of all brain function. He points to the "need to evaluate the philosophical explanation offered by the US President's Council" (67) and proceeds to examine the mode-of-being view as it relates to other philosophical explanations of human death. Although he claims to "have argued that the integrationalist view can be defended philosophically" (72), he himself does not offer much of a critique.

In this short, accessible book, Tonti-Filippini raises and thoughtfully considers these and many other subjects. Indeed, the breadth of his treatment of transplantation and the harvesting of human tissue is among the book's most commendable features. The

reader is likely to find that there are more things meriting ethical consideration than he imagined. He will also find these matters treated in a way that is entirely consistent with Tonti-Filippini's Catholic faith while bringing a range of ethical, scientific, and political perspectives into the discussion. I highly recommend this book to anyone who is seeking to gain a better understanding of transplantation, death and dying, and the uses to which the human body may or may not be put. I would especially recommend it to those for whom transplantation presents

practical dilemmas and who seek, like the author himself, to approach these decisions with sensitivity and wisdom.

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¹John Paul II, Address to the Eighteenth International Congress of the Transplantation Society (August 29, 2000), n. 3.

² Ibid., n. 4, original emphasis.

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