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Tokō Ishoku and The Reform of the Act on Organ Transplants in a Medical Anthropological Perspective

In Japan, the redefinition of human death as brain death in relation to transplantation has been at the centre of a heated debate. While in North America and Europe the redefinition of death remained confined to the debate within a narrow circle of medical experts, legal scholars and bioethicists, in Japan the so-called “brain death problem” became a matter of wider social and public concern. Scholars and public commentators have widely discussed the issue, casting an important light on aspects of the redefinition of death that had gone largely unchallenged in other countries.

The local cultural attention towards death as a social event rather than a biological fact cast a light on the reductionist logic underlying the concept of brain death, and highlighted the arbitrariness of reducing the process of “becoming dead” to a single moment in time. Furthermore, grass-roots opposition to brain death, as well as the work of legal scholars like Bai Kōichi, called attention on the rights of patients and the next of kin, which had gone largely unchallenged in other countries, elaborating an analysis of brain death that complicates in many respects the simplistic notion of individual autonomy at the base of bioethical reasoning. Like Morioka Masahiro famously argued, brain dead bodies are in fact brain dead people made up of networks of social relationships, and any failure of conceptualizing these relationships is a loss of precious intellectual resources that can greatly enrich the bioethical debate on end-of-life care. But the Japanese debate didn’t simply problematize the social and ethical implications of the new death; it also produced significant insights into the formulation of brain death as a medical category. In light of culturally specific notions of the body, the Japanese debate pointed out how the notion of brain death is not an objective description of human physiology, but one informed by a socially and historically contingent view of the body. Brain death, in other words, rests as much on scientific knowledge as on the tacit reification of the ethno-centric Cartesian dualism of body/mind. The cultural sensibility towards different notions of the body contributed to a critique of the very scientific foundations of the diagnostic category of brain death. In this way, with his best selling book *Nōshi*, journalist Tachibana Takashi effectively anticipated many of the issues that would have later come to the attention of neuroscientists in North America and Europe. Indeed, the Japanese brain death problem has attracted the attention of Western scholars as well, and as anthropologist Margaret Lock famously showed, it offered a precious cross-cultural critique of the hidden assumptions at the basis of a concept that plays a major role in contemporary bioethics.

In fact, the brain death problem has been so significant as to become a sort of essentialised fact. By this, I mean three things. First, the brain death problem has in fact functioned as a powerful gatekeeper of popular representations and

academic analysis of organ transplantation in Japan. Organ donation from the brain dead was legalised in 1997 and although Japan has one of the lowest donation rate in the world, transplants are routinely carried out. Organ transplantation in Japan has its advocates, not only among medical professionals but also in the form of grass-root activism and patients' organizations, and their role in the regulation of this technology has been maybe more incisive and influential in Japan than it was in many other countries. Yet, regardless of these factors, organ transplantation in Japan is still largely synonymous of brain death, especially in the English language literature. In this perspective, little has been said about how transplantation is technology is managed, and not just objected, how it affects the lives of those most directly involved with it, and what this tells us about the role of this medical technology in contemporary Japanese society more at large.

Second, and closely related to this point, is the fact that little attention has been paid to Japan's place in the global economy of organs. Isolated in the uniqueness of its debate on brain death, Japan has remained effectively off the map of international transplant mobility. Research by Japanese scholars, like Shimazono, Yamazaki, and Tomomatsu, has partly filled this gap by investigating instances of so-called tokō ishoku. Even so, however, tokō ishoku remains poorly known outside of Japan. Or better said, while Japan's involvement in illegal organ trafficking, in particular in neighbouring Asian countries, is fairly attested tokō ishoku towards North America remains poorly analysed, despites offering significant theoretical implications for social sciences and bioethics.

Finally, consequent upon these previous two points, there is a problem of representation. As I discussed briefly at the beginning, the critique of brain death in Japan potentially offer precious insights to reflect back on this concept in a cross-cultural perspective. Yet the framework of the cultural critique can also very easily offer its cheek to the reification of sterile ideas of "cultural differences" that reproduce divisions rather than promote mutual understanding. When it comes to Japan, this approach has, unfortunately, proven particularly popular.

Japan is a field where the essentialisation of an ideal of culture has been arguably very successful, for reasons that I don't have the space to discuss here. For long, a distinctive ideal of Japanese cultural uniqueness and difference with the rest of the world has functioned as the gatekeeper of representations and self-representations of Japan in the better part of academic literature as well as media and popular accounts. The legacy of this has been a sort of crisis of representation in, and therefore of relevance of, Japanese studies. Japan was either too much like the West to attract the attention of disciplines, like anthropology, interested in the study of the "Other", or too different than anywhere else in the world to be of any relevance to those outside the field of Japanese studies. Knowledge about, as well as from, Japan lost in this way its potentiality of providing a critique that could really challenge ethno-centric representations and understanding of problems, like brain death and transplants, that increasingly have a global dimension and relevance.

In the remaining of the presentation I am going to briefly illustrate some of the findings from my ethnographic fieldwork, which I conducted between 2011 and 2012 in relation to my PhD thesis on organ transplant in Japan. In particular, I am going to focus on the experience of Japanese transplant recipients and their

families, describing two related cases. The first is the fundraisings for tokō ishoku involving young patients in need of a heart.

A few months into my fieldwork, I heard through one of my interlocutors, that a new case of fundraising was about to get started to send six years old Mai-chan (the name is fictitious) to America for a heart transplant. The following weekend, I join the Mai-chan Sukuukai for the first day of the bokin katsudō, at a JR station in West Tokyo.

These public fundraisings are practically synonymous with paediatric organ transplant. The reason why this is so is in the legacy of the brain death problem. Largely as a result of the controversy on brain death, Japan is, to date, the industrialized nation with the lowest rate of deceased organ donation per million population, and this local shortage is especially severe when it comes to paediatric organs. In 1997, the Act on Organ Transplants (*Zōki no Ishoku ni Kansuru Hōritsu*) legalized organ donation from the brain dead. In the wake of the heated polemic on the redefinition of death, the law didn't go as far as giving a uniform definition of brain death as human death; instead, it stipulated that brain death was to be considered equivalent to the death of the person, only when the patient had expressed valid consent to organ donation by signing a donor card. In this way, however, children younger than fifteen were de facto ruled out as potential donors, because under the age limit to express valid legal consent to organ procurement. As a consequence, paediatric transplantation, in particular cardiac transplant, became effectively impracticable, for organs from adult patients cannot be used in young recipients.

Under the circumstances, families of young Japanese patients in need of an organ have increasingly come to resort to travels overseas, mostly to the US. The acceptance of foreign patients is to the discretion of the single transplant programs, and the issuing of a medical visa is conditional upon the payment of a first installment of the overall costs of the operation, which are also calculated by individual hospitals. Adding to these medical fees the expenses of travel and staying in the country for several months while awaiting for and recovering from the operation, the overall costs of a heart transplant in the US can be up to one hundred million JPYN, sometimes even more. The public fundraisings are, therefore, the most common and rapid way to collect such money, for none of the costs is refundable through national insurance schemes.

The fundraisings are forms of charitable donation to strangers that escape traditional forms of gift giving based on reciprocity. What more, they sponsor causes that are exceptional, in the sense that they highlight needs that institutionalized systems of health care do not or cannot take charge of. They identify “uninsured lives”. These are lives with no entitlements, which cannot claim rights, and can only beg for help. In this perspective, along with raising money, the bokin katsudō is primary a way to raise sentiments of empathy towards the patients in need and to construe them as appropriate and worthy recipients of support.

The images of the young children on the hospital bed, with the oxygen tube in their nose, and the parents' desperate cry for help for this only way to save their children call attention to the scandal of deaths that shouldn't be, not at those conditions, and not without doing anything to help. Through the fundraising campaign public attention is called towards this life in need, while also setting up the conditions to compensate for it by institutionalizing circuits of giving,

receiving. In this way, the fundraising identifies a form of what Davies calls “pathological mortality”, that is a form of mortality that is in surplus respect to what society can tolerate. Through the fundraising, patients and families share the burden of this pathological mortality, by creating and mobilizing networks of moral obligations towards their cause.

In 2009, the problem of tokō ishoku rose to the attention of the general public in relation to the reform of the Act on Organ Transplants. After more than ten years of unsuccessful petition by transplant advocates to have the law revised, it was the cause of the young tokō ishoku children that effectively mobilized public attention and made brain death again into a matter of public debate. This happened after that the Istanbul Declaration and the WHO principles on organ donation urged governments to promote self-sufficiency in organ procurement at a national level to counter the raising phenomenon of transplant tourism and traffic. The mutated international situation risked affecting the practice of tokō ishoku, compromising the only chance at life of Japanese children in need of a transplant. Against this background the cause of tokō ishoku young patients exerted a crucial leverage to have the law on brain death revised for the first time since the debate on the “brain death problem”.

Like the fundraising, policies for organ procurement and allocation are in fact social institution to share the burden of death. Similarly to what just described in relation to the bokin katsudō, policies on organ procurement and allocation function by socially stipulating networks of moral obligations along which things –in this case organs, not money– are given, received, and shared. The process is one that entails the very redefinition of the parameters of life and death, as the controversy on brain death in Japan shows very clearly. In this sense, as the fundraisings highlight a form of “pathological mortality”, or what I called earlier a surplus of mortality, so the redefinition of brain death stipulates where the line can be drawn after which too little life can count as good as death. As the first called attention to lives that need to be saved, so the second stipulated that certain lives can be let go.

In this way, the fundraising and the public policy on organ donation function in similar way, one on a level of informal economy and the other through legal regulation, as practices through which society distributes the burden of death. Both the fundraising and the policy on organ donation are, in other terms, socially organized processes of defining the parameters of life and death through the negotiation of networks of mutual obligations within a community.

When opening up the perspective from the contestation of brain death to include other aspects of the problem, the significance of the controversy over the redefinition of death is thus fully revealed its complexity. In this perspective, attention is called the actual consequences of the definition of death, and not just its theoretical implications. These consequences, as the case of tokō ishoku demonstrates, increasingly takes shape on a trans-national scale, requiring to think Japan in a global perspective. As patients, organs, and money increasingly move across national and jurisdictional boundaries, so our analysis must find a language and frame to reconcile the local specificities of the ethical dilemma of defining death, with the problems of structural conditions of access to care on a global level. In these regards, exploring the specificities of the case of Japan, can

offer precious theoretical insights to humanities and social sciences to articulate a contribution to the analysis of contemporary problems concerning the use of medical technologies, one that can move beyond the ideal of the cultural critique and map the actual implications of how bioethical principles and definitions are worked out in practice, how they achieve the purposes they serve, and what outcome they produce in the process.