

BIOETHICS FROM BELOW: A Perspective from the Disadvantaged and Vulnerable



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THIS PRESENTATION

- Need for a framework to address issues in bioethics affecting disadvantaged and vulnerable segments of the population.
- Why a distinct framework?
 - The disadvantaged and vulnerable have urgent needs requiring special attention
 - They are exposed to injustice and discrimination when subjected to the same standards that are thought to apply equally to all without qualification
 - The injustice and discrimination is easy to overlook when we don't pay attention to economic, social, cultural and power differences among individuals



THE DISADVANTAGED AND VULNERABLE: 1: The exploited paid donor

- ✚ Earns 25,000 rials a day (but not everyday)
- ✚ Donated a kidney to someone he did not know
- ✚ Expected payment
- ✚ Was paid enough money to buy a television set, a DVD player and good food for a few weeks
- ✚ Still earns 25,000 rials a day
- ✚ He & his family rarely have enough to eat
- ✚ No medical insurance
- ✚ Emergency care only at government hospital -- they have to wait for hours; facilities and health care staff are not enough
- ✚ Unable to buy prescribed medicines



THE DISADVANTAGED AND VULNERABLE: 1: The exploited paid donor

- ✚ Poor and ignorant
- ✚ Exploited by others
- ✚ Prohibited from receiving material compensation
- ✚ Regarded as a law-breaker
- ✚ Forced to the underground
- ✚ Left at the mercy of commercial transplant agents



THE DISADVANTAGED AND VULNERABLE: 2: The poor but altruistic organ donor

- ✚ Earns 25,000 rials a day (but not everyday)
- ✚ Donated a kidney to a well-off community leader who has done good things for their neighborhood
- ✚ Did not expect payment or reward
- ✚ Was not paid or rewarded
- ✚ While the organ recipient now enjoys a happy life, the donor continues to subsist on 25,000 rials a day
- ✚ He & his family seldom have enough to eat
- ✚ No medical insurance
- ✚ Emergency care only at government hospital -- they have to wait for hours; facilities and health care staff are not enough
- ✚ When they are prescribed antibiotics, they can only manage to buy the pills (if at all) for a day or two



THE DISADVANTAGED AND VULNERABLE: 2: The poor but altruistic organ donor

✚ Hasn't the poor but altruistic organ donor been exploited?



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THE DISADVANTAGED AND VULNERABLE: 3: The poor but (un)lucky(?) organ recipient

- ✚ Confined with ESRD at the charity ward of a government hospital while waiting for a transplant donor
- ✚ Lucky to get a kidney from an accident victim
- ✚ Unfortunately, he could not buy the immunosuppressants that were required to make the transplant work
- ✚ He died after 9 months when the transplanted kidney was rejected by his body
- ✚ Until recently, the hospital has had a policy of allocating cadaver kidneys alternately to full paying patients and to charity (non-paying) patients
- ✚ Now, hospital is rethinking the policy since the poor who get kidneys are not likely to get full benefits from the transplants anyway



THE DISADVANTAGED AND VULNERABLE: 4: The poor exploited brothers

- ✚ Having no regular job, the first brother, Edwin, decided to donate a kidney in exchange for \$2,000 (18 million rials)
- ✚ Six days after the surgery, Edwin was sent home in a taxi
- ✚ He was given cash and was told to use part of the money to buy the medicines listed in a prescription
- ✚ He did not buy - or take - all the medicines prescribed.



THE DISADVANTAGED AND VULNERABLE: 4: The poor exploited brothers

- ✚ Soon after, Edwin's brother, Rico, decided to try to make money the same way
- ✚ Their mother felt bad about the whole thing but because she could offer no alternative to her children, she did not object
- ✚ Both brothers were told that once they were discharged they were not to go back to the hospital
- ✚ When the National Kidney Institute conducted a survey of paid former kidney donors, the brothers did not respond



THE DISADVANTAGED AND VULNERABLE:

5: The missing poor donors

- ✚ In addition to the brothers, many other paid kidney donors were absent from the survey conducted by the National Kidney & Transplant Institute
- ✚ Only Living Related Donors replied to the questionnaires
- ✚ The poor have also been missing in other ways related to organ transplantation
 - From medical follow ups because they have been told to hide
 - From their neighbours, who tend to view them with stigma
 - From employers, who think they take great risks in employing organ donors
 - As organ recipients -- as a group, poor people make up the vast majority of donors but almost no one can hope to receive a donated organ if he needs it



THE DISADVANTAGED AND VULNERABLE: 5: The missing poor donors



- ✚ During our own survey, we found many “missing” poor donors living in this area



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THE DISADVANTAGED AND VULNERABLE: 6: The Proud Donor -- Received Payment but Did not Sell(?)



Photo courtesy of Lalaine H. Siruno & Sarah Toledano, University of the Philippines

- ✚ He received money through an agent when he donated a kidney
- ✚ During an interview, a researcher referred to him as an "organ vendor"
- ✚ Upon hearing the term, he reacted angrily, insisting that he donated, and did not sell his kidney
-- even if he admits having received money



THE DISADVANTAGED AND VULNERABLE:

6: The fortunate donor

- ✚ He learned about a neighbor who was given medical and economic assistance by a Non-Profit Foundation established to ensure the well-being of organ donors
- ✚ Decided to make one of his kidneys available for transplant
- ✚ Was given thorough medical check up before and after the transplant
- ✚ Matched with a suitable recipient, who thus managed to transcend his diseased condition
- ✚ After the transplant, the donor was given advice on making a proposal for start-up business
- ✚ When his proposal was approved, he received capitalization
- ✚ He was guided every step of the way until his business became profitable
- ✚ One year after the transplant, he still receives guidance
- ✚ His progress in health and business is monitored closely



THE DISADVANTAGED AND VULNERABLE: 6: The fortunate donor

- Having started as a pedicab driver earning about 20,000 rials a day, he now owns a fleet of pedicabs and earns about 450,000 rials a day by renting out the pedicabs to other drivers
- His sacrifice as an organ donor has enabled him to transcend the economic poverty that severely constrained his life options



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THE DISADVANTAGED AND VULNERABLE: 6: The fortunate donor

- ✚ If we stick without qualification to the common and dominant view that a human organ is sacred and could only be donated without receiving something in return, we will not have an opportunity to consider issues from the perspective of the poor & vulnerable (“bioethics from below”).



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Is that so?

- ✚ An unmarried young lady living near the marketplace gets pregnant.
- ✚ People are left wondering who the father of the child is.
- ✚ The lady says the religious leader in their community is responsible.
- ✚ The religious leader does not deny the accusation and merely says: Is that so?
- ✚ He then proceeds to prepare everything necessary for the coming birth, as a dutiful father.



Is that so?

- ✚ After the child is born, the religious leader continues to care devotedly for the child and the mother.
- ✚ He is very successful and the mother and child are very happy
- ✚ Realizing how good and uncomplaining the religious leader has been, the thankful woman eventually confesses to her parents that it was someone else and not the religious leader who was really responsible for getting her pregnant.
- ✚ Her parents rush to the religious person to offer their apologies and beg for forgiveness. The religious person listens attentively before giving his reply:
- ✚ Is that so?



Is that so?

- ✚ How would you explain the attitude taken by the religious person?
- ✚ Among the characters in this short narrative, who has the biggest problem of all?



Is that so?

Some questions to remind us of “bioethics from below”:

1. Who are going to be affected by the decision under consideration?
 - a) Beneficially
 - b) Negatively
2. Who are going to be affected negatively the most?
3. Among those who are going to be affected negatively the most, who are the most vulnerable (who need help the most)?



BIOETHICS FROM BELOW

- ✚ When the disadvantaged and vulnerable are held accountable to the same rigid measures without the benefit of interpretation that is sensitive to their peculiar circumstances, society unwittingly and unjustly imposes burdens upon them that they do not deserve.
- ✚ 'Bioethics from below' may be contrasted with bioethics imposed from above, tending to uphold the interests of the strong and powerful
- ✚ Upholds primacy of social justice in the analysis of situations and issues





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IS THAT SO?



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