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## FINDINGS

# Failure of Informed Consent in Compensated Non-Related Kidney Donation in the Philippines

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This paper reports selected aspects of the findings of research undertaken on economic and social consequences of compensated non-related kidney donation in the Philippines. The study was conducted on Filipinos who donated transplant organs for material consideration in medical institutions in the Philippines. Specifically, the study sought to find out where organ donors came from, where the transplants were done, how the donors were recruited, how much information they were given about the procedure and its possible consequences, the medical care they received, the manner in which they were treated, and the outcome of the experience for them in terms of self-assessed social and economic indicators. The donors were asked to report their own perception and assessment of their situation. They were not provided an objective scale for assessment.

For the purposes of this paper, specific findings related to the validity of informed consent have been selected. These findings have to do with elements that ought to be present in order to render a patient's consent valid. The selection was made to draw attention to the failure of informed consent and in order to encourage measures to curb the exploitation, and improve the situation for organ donors.

## Methodology

The study was undertaken in several communities in the Philippines between May 2007 and March 2008. The researchers identified the places known for

kidney selling on the basis of television and radio programs, newspaper reports, and statements made by key informants. The key informants included kidney vendors, middlemen, community leaders, local government officials, physicians, nurses, and ordinary persons. Once the communities were identified, the researchers sought the permission of community officials and leaders before approaching key informants. Respondents were individually briefed on the purpose of the research and consent was taken before proceeding with the interviews, which were recorded and documented in writing and by photography. Interviews were conducted by reading from prepared questionnaires.

Relying on snowball sampling, the research team requested respondent-donors and other key informants for referrals to other organ donors. Attempts were made to trace all referrals until they were confirmed and interviewed or were irretrievably lost to follow up. It was through the referrals of the respondents from each of the research sites that the researchers were able to identify other areas in the country where money was being used to recruit donors.

The house of a local official in an economically disadvantaged community in the City of Manila served as the venue for the first interviews to be conducted. Similar private places were sought for subsequent interviews that were conducted in the cities of Mandaluyong and Caloocan, and the provinces of Rizal, Quezon and Surigao. In all the sites, the researchers got prior permission from community authorities to conduct the survey.

The initial respondents referred fellow organ donors to the researchers. It was through the referrals of the respondents from each of the research sites that the researchers were able to identify the other areas in the country where money was being used to recruit donors.

## **The Respondents**

During the study period, the researchers were able to interview 311 respondents, consisting of 292 males and 19 females. When asked to indicate their jobs, 72 (23.2%) said they did not have any. Others mentioned jobs that could not be relied upon for regular pay. A total of 69 (22.2%) said they were drivers, 33 (10.6%) said they were construction workers, 25 (8%) said they were stevedores, 21 (6.8%) said they were farmers, 14 (4.5%) said they were vendors, 12 (3.8%) said they were fishermen, 7 (2.2%) said they were housewives, and 5 (1.6%) said they were scavengers. The rest of the respondents indicated the following jobs: janitor, pedicab operator, community health worker, community watchman, barber, chainsaw operator, diver, security guard, traffic aide, beautician, care giver, cargo checker, carpenter, conductor, domestic helper, factory worker, gardener, helper, housekeeper, junkshop operator, laundrywoman, landfill

assistant, mason, etc. What is most significant about these jobs is that they all indicate temporary daily wage work. None of the donors had a stable occupation that was capable of providing a regular means of income or economic security. Hence, the organ donors who responded to the study were highly vulnerable to monetary incentives, especially since it was clear that their actions were primarily motivated by their poverty.

## **Donor Motivation**

Two hundred and ten (210) respondents explicitly mentioned poverty as the motivating factor. Forty-seven (47) said they entered into the transactions “because of money”. There were six (6) respondents who gave more specific reasons such as “having to reclaim pawned land”, “fix their houses”, and “to buy livestock”. Only 11 mentioned “altruism” together with poverty as their main reasons for donating while 21 explicitly said they wanted to help the patient.

Computed at the exchange rate of 47 pesos to the dollar, the amount of compensation kidney donors reported receiving ranged from an estimated US\$3,571.00 to US\$9,166.67. Since most of the donors reported receiving wages of approximately US\$4 when they were able to find work, the smallest amount received as compensation would have been equivalent to wages for more than two years. From this comparison, one realises the degree of vulnerability of donors to monetary incentives.

The fact that 30% of the respondents decided to make the organ donation without consulting the spouse or a member of the family at all also diminishes the quality of informed consent. In Philippine society, important decisions are usually made in consultation with the family. This behaviour could be interpreted to indicate that the exercise was viewed as illegitimate — something that the rest of the family needed to be kept away from in some way.

## **Involvement of Middlemen**

Two hundred and sixty-seven (267) organ donors (86%) confirmed the involvement of brokers in their transactions. The involvement of middlemen or agents is another negative factor for the validity of informed consent because it represents an interest that could easily come into a direct conflict with those of the donor-patient. The middleman is in a position to withhold payment from the organ donor and use such payment as an undue inducement. More importantly, middlemen do not have a clear responsibility to protect the interests of donors. On the contrary, they have conflicted interests in that they stand to gain only if a donor participates in the transplant procedure. Indeed, there are accounts

of middlemen having actually withheld payment promised to organ donors in order to compel them to first recruit other donors as part of a pyramidal scheme. For these reasons, the involvement of middlemen-agents who make money by facilitating the recruitment of donors for organ transplants should be taken as a *prima facie* proof of the failure of informed consent. With 86% of the donors in the cases surveyed reporting the participation of middlemen-agents, we could see the extent to which informed consent has failed.

The situation could be even worse when doctors themselves get actively involved in the recruitment of donors since they are capable of introducing their own conflicted interests into the picture. In 74 cases (24%) respondent donors reported receiving the monetary compensation from the doctors themselves. (The figure could be even higher since 33% refused to divulge to the researchers the identity of the person who handed over monetary compensation to them.)

In this respect, they are different from professional transplant coordinators whose gain from their own involvement in the process is not dependent on the decision made by organ donors. They do not earn more or less money as professionals whether a prospective donor pushes through with a donation or not.

## **Health Counselling and Postoperative Care**

Twenty-eight per cent (28%) of the respondents claimed that they did not undergo health counselling as part of the process. This figure is indicative of the failure of informed consent since all prospective donors need to be provided full pertinent information in an appropriate way. Only fifty-five per cent (55%) of all donors replied “yes” when asked if they thought the information given to them by the doctor was enough. Thirty-three per cent (33%) wished they had a chance to ask more questions and were given more information by the doctor. Twelve per cent (12%) were not sure whether the information was adequate enough because they were not sure what to ask the doctor.

Thirty per cent (30%) of the organ donors in the study reported that they did not receive advice to return for postoperative medical check-ups. This high figure is consistent with the number of those who said they did not undergo health counselling and supports the assertion of a failure of informed consent. Although sixty-nine per cent (69%) or 214 of the organ donors were advised by the doctor to go back for a postoperative check-up, only 40% actually returned. Sixty per cent (60%) gave financial reasons. The donors said that they felt alright anyway and had no need to spend money on transportation that could be spent on food. Many expressed preference for medical staff to go to their community for routine check-ups. Some felt that the doctors and hospital staff

did not want them back and many were advised by their respective brokers to never go back to the transplant hospital.

## **Economic and Social Consequences**

Although respondents clearly made the organ donation decision because of economic problems, 36% felt that the experience resulted in no remarkable economic improvement in their lives. While 41% of the donors felt that their economic prospects improved, it was only for a brief period after the donation that they had money to spend. Twenty-one per cent (21%) claimed that they lost whatever material investments they made. Some of them got into an informal lending business that flopped because they had to lend money to their neighbours, who were never in a position to repay borrowed money. These results indicate a limitation to the organ donors' understanding of the likely implications of their decision to become transplant donors.

Ninety respondents (29%) felt they were "forced" to make the kidney donation. Eighty said they regretted their decision to sell. Some said they regretted the decision because they felt no economic improvement in their lives even after sacrificing something as important as a kidney. Many of those who didn't feel regret sought refuge in the thought that they were able to have a house, send their kids to school or pay for the hospitalisation of a loved one. In any case, regret is also a negative factor for the validity of informed consent since it constitutes evidence of a failure to accurately anticipate the outcome of the donors' decision to participate.

One finds an explanation of this regret in the fact that 32% of the donors reported feeling that others had a lower regard for them after the donation. Moreover, 182 donors (58.5%) believed they violated the law and 211 (67.85%) believed they committed a sin by giving up a kidney for money. One hundred sixty respondents (51.44%) said they would not recommend kidney donation to others. Taken together, these findings provide further proof of the failure of informed consent.

## **Observations and Conclusions**

A fully informed consent requires full knowledge and understanding of a procedure and its possible consequences. The capability to give fully informed consent also presupposes the ability to assess the possible consequences in relation to one's core values. The results of the study indicate a failure of informed consent in a significant part of the study population. Too many organ donors in the study reported receiving less than what could be considered adequate information.

Although this finding did not reflect the majority of the respondents, anything less than 100% compliance with the requirements for informed consent for a procedure such as the removal of a kidney for organ transplantation should be a serious cause for concern.

The involvement of middlemen (86%) and the apparent complicity of doctors (24%) in commercial transactions (i.e. by being the ones handing over money to the donors) are factors indicative of conflicts of interest that could have an undue influence on the decision of economically vulnerable persons to participate. These factors ought to be eradicated if fully informed consent were to be guaranteed.

The feeling of regret, the sense of having committed a sin and of having violated the law are also indicative of a failure of informed consent in that they reflect the inability of individuals to relate decision-making to values they hold. These should remind us of a need for urgent corrective measures.

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