



# Determination of Altruist and Voluntary Donor Attitudes in the Frame of Basic Bioethical Rules in the Management of Kidney Transplantation at Cipto Mangunkusumo Hospital

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## ABSTRACT:

The realization of altruist and voluntary donor attitudes is a measure of the success of kidney transplant management in hospitals and is expected to prevent ethical and legal problems, especially the problem of kidney commercialization. The altruist and voluntary donor attitudes were assessed within the framework of the basic rules of bioethics through interviews, document analysis and field observations. This study aims to assess the altruism and voluntary donor attitudes of kidney donors at Cipto Mangunkusumo Hospital. This study is a qualitative research, using field observation, document analysis and semi-structured interviews. The sample consisted of 3 unrelated donors and 1 related donor who had undergone kidney transplantation at RSCM in 2018 and resided in the Jakarta, Bogor, Depok, Tangerang and Bekasi areas. The study was conducted at the donor's residence or at a place according to the agreement between the subject and the researcher from October to December 2019. In this study, 2 of the 4 subjects who were related and unrelated kidney donors fulfilled the altruist and voluntary descriptions, namely the presence of aspects of empathy, social responsibility, believing in world justice, internal self-control and low ego, which were influenced by psychosocial factors such as the donor's relationship with the recipient, what is expected of the recipient, donation motivation, quality of life, socioeconomic status, religion and openness regarding donation. So it can be concluded that not all unrelated kidney donors at Cipto Hospital Mangunkusumo Hospital in 2018 have altruist and voluntary attitudes.

## INTRODUCTION

Organ transplantation is the transfer of an organ from a donor to a recipient in order to cure and restore the recipient's health problems. Organ donors can come from living donors and deceased donors. The availability of donors is not as fast as the number of patients who need kidneys. The difficulty in selecting deceased donors, and even some doctors cannot always predict how well a kidney will work after transplantation from a deceased donor, makes doctors consider favoring living donors.<sup>1,2</sup>

As of March 2007, it is estimated that organ trafficking accounts for 5% to 10% of kidney transplants achieved annually worldwide. Organ shortages in transplantation governance are becoming a global problem. Commercial transplantation was a growing problem worldwide almost a decade ago and occurs in living donors. Some countries with weak regulatory mechanisms have

participated in the organ buying and selling system such as India, Iran, China, Pakistan, Philippines, Brazil, Turkey, Moldova, Ukraine, Russia, Bulgaria, and Romania. The World Health Organization (WHO) in its statement on organ selling clearly states that this violates the Universal Declaration of Human Rights as well as its constitution. The human body and its parts cannot be the subject of commercial transactions. As such, giving or receiving payment for organs should be prohibited. The WHO advises doctors not to assist with organ transplants if they have good reason to believe that the organ has been the subject of a commercial transaction.<sup>3,4</sup> Obtaining a kidney from a living donor is rare, making kidney transplants expensive. The high demand for kidney donors is not matched by the availability of donors.

Products derived from humans have the potential to violate the principles set out in UNESCO's Universal



Declaration of Bioethics & Human Rights (2005).<sup>5</sup> Therefore, in addition to the health aspects that arise, there will be further problems that need to be watched from the beginning, namely the economic aspects, which can trigger the sale and purchase of kidney organs or commercialization. Hospitals as kidney transplant managers are vulnerable to prosecution and are vulnerable to legal sanctions. In Indonesia, in the last 3 years, investigators have examined a few doctors and hospitals organizing kidney transplants, due to allegations of kidney buying and selling, from the transplant process that has been carried out.<sup>29,56</sup> Kidney donors are expected to be truly voluntary in giving their kidneys to kidney failure patients who need / recipients. A donor is a person who is physically and psychologically healthy, with a transplant then a donor must voluntarily lose one of his kidneys. Whether or not the donor is voluntary is at the heart of the problem of alleged kidney buying and selling. If this problem continues, it will lead to other problems such as falsification of donor documents under the pretext that the transplant process is carried out. This will have a negative impact on the donor's family, which will also have an impact on organ transplantation.<sup>6</sup>

The expectations of a donor may be a measure of how a transplant becomes commercialized and a way to make money. The expectations of a donor may not be known to the transplant organizing team because they are misperceived and undirected. Unrealistic expectations or requests from the donor that the transplant will be free from rejection and failure. Misperception by the donor that if the transplant is unsuccessful, it is due to personal failure as a donor. Financial compensation or provision of a sum of money for donation is against the law. The law prohibits payment to donors for donated organs. Transplant managers do not support the wishes of donors who have a desire for media attention, the wishes of donors who are a necessity for recipients, donors who choose their recipients based on gender, race or ethnicity.<sup>3</sup>

The success of living donor kidney transplantation is the realization of the donor's voluntary desire to help family, loved ones, and others in need by donating a kidney to a stranger out of necessity and to benefit others despite not being related. Although long-term data on donor well-being has been established, it remains unclear what the psychological impact of donation is on donors who may not have the reward of seeing their recipient's health improve.<sup>3</sup> Optimizing the psychosocial status and well-

being of donors both before and after transplantation is one of the main goals of transplant centers.<sup>7</sup>

Healthcare professionals in this case the organ transplant team must manage the transplant system and process carefully. When meeting volunteer donors who are not related to the recipient (unrelated), the host hospital must ensure that thorough informed consent has been achieved in detail and know the risks that will occur, ensure safety, and determine that the goals and expectations of the donor and recipient can be realized.<sup>8,5</sup> Good and correct transplant governance aims to provide protection and legal certainty for donors, recipients, organ transplant host hospitals, and health workers providing organ transplant services. Forensic and medicolegal physicians as medical/legal ethicists play an important role in transplant governance.<sup>1,9</sup> All government agencies including religious affairs must work together to support the program and to provide citizens with good transplant services and avoid commercial transplants.<sup>10,11</sup>

## LITERATURE REVIEW

### Altruist and voluntary

Altruism is a voluntary action taken by a person or group of people to help others without expecting anything in return. According to Myers' theory, altruist behavior is said to pay attention to others, want to help others, and put the interests of others above their own interests. In general, altruism is defined as a voluntary act to help others selflessly, or want to just do good deeds. Altruist behavior is behavior that reflects a consideration of selflessness for the good of others. Every culture in the world recognizes that altruist behavior is an important part of the human process and is considered a universal phenomenon. However, due to many shifts in social, economic, political circumstances and along with the progress of the times, altruist behavior is starting to be rarely found. One of the factors that influence altruist behavior is the presence of empathy, namely a person's ability to feel the feelings or experiences of others.<sup>12</sup> Factors that influence a person to have an altruist attitude, namely: mood, empathy, belief in world justice, sociobiological factors, and situational factors. With a comfortable mood and empathy, a person will be motivated without feeling heavy and voluntarily provide help for others. The aspects of altruist behavior consist of five things, namely: empathy, belief in world justice, social responsibility, internal self-control, and low ego.

13,14



### Basic Rules of Bioethics

The ability to make ethical decisions as one of the lessons of professionalism in clinical governance is expected to be mastered by all disciplines including transplant advocacy. Ethical and medicolegal decision-making is one of transplant governance to avoid ethical and legal issues. One of the main goals of transplant centers is to optimize the psychosocial status and well-being of donors, both before and after transplantation. It must be recognized that kidney donation from living donors still carries risks. Psychosocial issues, in addition to physical health, are of greatest concern in organ donation from living donors. It is expected that the potential donor truly gives informed consent, is of stable psychological status, with the intention of saving lives or improving the quality of life of others.

### Kidney Transplant

Organ transplantation is the transfer of an organ from a donor to a recipient to cure and restore the recipient's health problems.<sup>1</sup> Kidney transplantation was introduced in the 1950s, as a pioneer of solid organ transplantation to treat patients with end-stage renal disease and kidney transplantation is considered the best therapeutic option.<sup>15</sup> Kidney transplantation is the gold standard for patients with end-stage renal disease, but organ availability is an issue. In patients with end-stage renal disease where organ donation from deceased/cadaveric donors is inadequate, transplantation from living donors is considered. The waiting list for kidney transplants continues to increase despite constant efforts to increase the number of organs donated. Given the shortage of available organs, long waiting times for possible transplants, and strict regulations, many patients opt for commercial transplants.<sup>10</sup>

### RESEARCH METHODS

This study is a qualitative research, using observation, documentation and in-depth interviews to explore the opinions, feelings, perceptions and knowledge of kidney donors to determine the truth of altruist and voluntary donors. This research was conducted at the donor's residence or at a place according to the agreement between the subject and the researcher between October and December 2019. The source of data for this study was taken from primary sources, namely kidney donors who have undergone transplantation in 2018, all donor data are stored in the RSCM Transplant team documents.

Sampling in the form of primary data in this study was carried out using purposive sampling and snowball

sampling techniques, namely researchers determining sampling with certain considerations consisting of 3 donors, if necessary, researchers will increase the number of samples. The samples were unrelated donors who had undergone transplantation at RSCM in 2018 and resided in the Jakarta, Bogor, Depok, Tangerang and Bekasi areas. Samples were selected with the criteria of 2 unrelated donors who were suspected of having indications of commercialization, 1 unrelated donor who was suspected of having no indications of commercialization. The suspicion of commercialization was taken from the data of the RSCM transplant team, namely the existence of some members of the advocacy team who did not approve in the full board meeting. Before going to the research location, the researcher will look for the donor's address through the RSCM transplant team data. As an evaluation of the correctness of the answers from the subject, the researcher conducted field observations and document analysis of the predonation transplant team. The research instruments used in this study are:

1. Patient identity sheet / facesheet,
2. Information sheet for prospective subjects
3. A list of semi-structured interview questions, namely
4. The researcher prepares questions without providing alternatives
5. Answers.
6. Post-interview message, impression and suggestion sheet,
7. Stationery,
8. Documentation tool in the form of android phone huawei y611, 5075
9. Recorder brand "rec"

The research subjects are 3 unrelated donors after kidney transplant surgery at the DR Cipto Mangunkusumo National Central General Hospital Jakarta in 2018, who reside in the Jabodetabek / Jakarta, Bogor, Depok, Tangerang and Bekasi areas. Researchers will visit the residences of donors and recipients according to the address listed on the KTP in the RSCM Transplant team document. Data collection methods in this study used interview techniques, observation and documentation. Data analysis used by researchers is analysis according to Spradley. After the researcher conducted an interview, the researcher conducted a domain analysis, with the hope that the researcher would get a general and comprehensive description of the object under study. In determining the domain to be



studied, researchers use sources from various literature and literature. Then the researcher conducted a taxonomic analysis, where the selected domain was described in more detail. From the taxonomic analysis, the researcher conducted a componential analysis where the researcher looked for the internal structure of the domain details through semi-structured interviews. Finally, the researcher will look for relationships among the domains and how they relate to the whole.<sup>16</sup>

## DISCUSSION

Determining the presence or absence of altruism and voluntary donors through interviews, field observations, and document analysis is carried out before donation. The information obtained must be in accordance between before and after the donation to avoid hidden information or incorrect information submitted by the donor. The donor's openness to the family regarding the donation will convince the advocacy team that there is nothing to hide or bad intentions in the donation. So that the element of buying and selling organs can be avoided early.

The relationship between the donor and the recipient will affect the donor's expectations of the recipient, thus affecting the initial motivation to donate the kidney. A close and long relationship will make it easy for the advocacy team to determine altruistic and voluntary donors. It requires knowledge, accuracy, and a lot of time for the advocacy team to determine altruism and voluntarism in newly established relationships. An example is a donor with brain stem death.

The initial motivation to donate a kidney is also influenced by the religion practiced by the donor. In research, it has been found that the purpose of donation is to make amends for past mistakes. With good religion, a person feels that his quality of life is good. A good quality of life will also affect the motivation to donate. Donors feel that all their worldly needs are fulfilled, with donations donors feel more useful to others.

A sense of empathy can arise from the donor's expectations of the recipient, the motivation to donate and good religion. Belief in world justice can arise from religious beliefs, while internal self-control can be generated from religious beliefs, socioeconomic status and donor quality of life. Low ego can be shown from the donor's expectations for the recipient, the religion practiced and the donor's socioeconomic status. A low ego will be shown by the donor by not having unusual expectations of the recipient. The donor does not make

excessive demands on the recipient. Field observations prove to be very important in assessing the veracity of the data submitted and ensuring the donor is not lying. Field observations are needed to ensure:

1. Conformity of residence with the address provided (KTP)
2. Conformity between place of work and employment status (work certificate, permission letter of the official at the workplace, payroll certificate)
3. Conformity of family documents provided (family card, marriage certificate).
4. Openness of the donor regarding the donation to the family
5. Donor's quality of life, socio-economic status, religion
6. Relationship between donor and recipient

A kidney donor is expected to have an altruistic attitude so that they can voluntarily donate their kidneys to help recipients without expecting anything in return. The existence of altruist behavior in donors can be known from (1) Empathy (2) Believe in world justice (3) Social responsibility (4) Internal self-control (5) Low ego.<sup>13,14,12</sup>

Factors that influence a person to have an altruist attitude are seen from his mood, empathy, belief in world justice, sociobiological factors and situational factors. These factors can be assessed from interviews and field observations.<sup>13,14,12</sup>

### 1. Mechanism for determining altruism and voluntarism

Assessing the donor's final decision to donate their kidney is seen from the donor's psychosocial condition. The donor's psychosocial condition must match between the interview, field observation and document analysis both before and after donation. The suitability of data between pre and post donation is a clue that the donor is truly altruistic and voluntary in donating his kidney.

#### a. Relationship with the recipient

The relationship between donor and recipient can be a background for donors to donate their kidney. Especially in long-standing relationships and fraternal relationships. However, the determination of altruism and voluntary in this kind of relationship becomes unclear, because the donor and recipient already have an emotional relationship. Determining altruism and voluntary donors is needed especially for donors and recipients who have just met and are not related by blood. For S2 and S5 it is quite easy for the advocacy team to determine altruism and voluntary donors



because the emotional relationship has been going on for a long time. Unlike S3 and S7 who have not known the recipient for a long time so that other criteria are needed to determine altruism and voluntary donors. Relationships that are not long and not blood relations can occur when transplant management involves donors from patients who experience brain stem death. This relationship can create a sense of empathy due to the pain suffered by the recipient, making the donor have an altruistic attitude and voluntarily donate the kidney. The closeness of the donor and recipient is seen in S2 and S5. However, it does not appear in S3 and S7. To prove the closeness between the donor and the recipient can be asked to the recipient but this cannot be done by the researcher because the recipient is out of town. Information about the relationship between the subject and the recipient that does not match before and after the donation is one of the clues that the subject provides information that is not the same, thus leading to not altruistic and voluntary in making donations.

**b. Quality of life**

Good quality of life through field observations is only possessed by S5. However, donors with poor quality of life can have an altruist attitude if they believe in world justice. This is found in S2 who believes that in this world there is already a regulator and in S3 who believes that what he has belongs to God. With a poor quality of life but voluntarily donating the kidney shows that the subject does not have a high ego. This happened to S2. Information about the quality of life that is different between before and after donation is a clue that the subject is not altruistic and voluntary in carrying out donation is found in S3 and S7.

**c. Initial motivation**

The initial motivation to donate the kidney in the four subjects was to help the recipient. This motivation was recorded in the medical record data. However, this was different when the researchers conducted field observations. From the field data, only S2 and S5 really wanted to help. In S3 and S7, the initial motivation was to fulfill economic needs due to debt problems. This debt problem also occurred in 2 other subjects who were not willing to be interviewed.

**d. Openness of donors regarding donations**

The relationship with the people around the donor will affect whether or not the donor volunteers to donate his kidney. In S5, support for her to donate her kidney came from all her siblings and parents. S5 was not worried if

the surrounding community knew about his donation. This did not happen to the other three subjects nor to the other subjects who were not willing to be interviewed. The fear of being known by others about his donation is an assessment of the existence of something covered up which is the reason for the donor to donate his kidney. This is an indication of the absence of altruism and voluntary donors. The donor's lack of transparency regarding their donation can also occur during the advocacy process. This raises the risk of ethical violations in the management of kidney transplantation.

**e. Religion**

Religious factors also influence a person to donate their kidney. S5 felt that he was diligent in worshiping and his relationship with his worship friends was closer, even his donation intention was known by his pastor. For other subjects, they feel less in worship. With a strong religion, of course, it will have a high social responsibility, the belief in world justice is also getting stronger. This supports the altruist aspect of the donor. It is difficult for researchers to assess how strong the subject is in practicing his religion, because field observations are needed by seeing the religious activities carried out by the subject.

**f. What is expected of the recipient**

What the recipients expect from the donors indicates whether or not there is a low ego. The expectation that the recipient always cares for the donor when the donation has been made is a high ego of the donor. This is not in accordance with the altruist aspect. In contrast to S3 and S7 who expect the recipient to return to a decent life illustrates the low ego and empathy of the donor. The beginning of the donation intention needs to be explored to show whether a donor has social responsibility or not which supports the altruist aspect. In S2 and S5, knowing about donation directly from the recipient. The recipient is a person who has been known for a long time and the subject has long known that the recipient suffers from kidney failure. However, for S3 and S7, they found out about the donation from a third person. Judging from the medical record data, this information is not in accordance with the subject's statement made before the donation. This assessment will be difficult if the subject is not open to researchers and tends to lie.

**g. Socio-economic status**

The economic needs of the subject before donation are known through field observations. The existence of debt

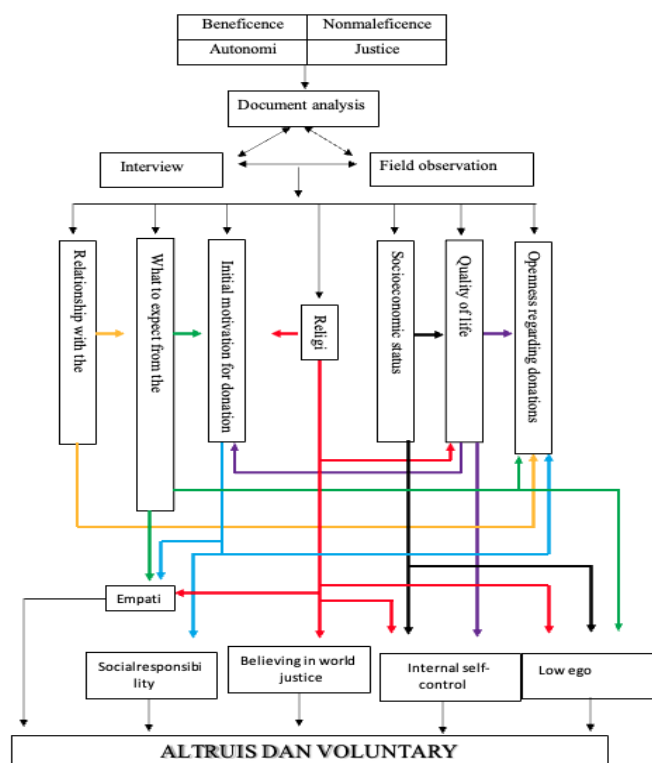




and credit problems was found in S3 and S7, this resulted in the subject's altruist and voluntary attitude being doubted because it would affect his motivation to donate his kidney. The donor's job needs to be assessed to determine whether or not the donor is altruist, whether or not the donor makes a selfless donation. From the interviews obtained, the transplant process takes a long time. For workers who donate, they will leave their work time, so of course they will deal with their superiors or coworkers regarding permission to be absent from work. The donor's job also determines the adequacy of his economic needs. In this study, the four subjects did not

have a boss, and at the time of the transplant the subject's condition was not working. One of the determinations of altruism is the existence of internal self-control. By not having a job and lacking economic status, it is considered that the donor lacks internal self-control. This is not the case with S5, a housewife whose husband died, without children with economic needs fulfilled from investment results. Good internal self-control in S5 supports an altruist attitude so that she is willing to donate her kidney. The existence of poor socio-economic status conditions in S3 and S7 does not match the information provided by the subject before donation.

#### h. Flow of determining altruists and voluntary donors



#### CONCLUSION

In order to determine whether a pre-donation donor is altruistic and voluntary, it is necessary to evaluate by considering basic bioethical principles such as autonomy, beneficence, nonmaleficence, and donor justice. Furthermore, aspects of altruist behavior such as empathy, belief in world justice, social responsibility, internal self-control, and low ego are assessed. Evaluation is also conducted by considering the donor's psychosocial conditions such as openness about donation, initial motivation for donation, quality of life,

socioeconomic status, expectations from the recipient, the relationship between donor and recipient, and religious factors. Meanwhile, to ensure that the donor has an altruistic and voluntary nature, it is necessary to conduct a comprehensive evaluation by considering all relevant aspects and factors. Evaluation can be done through interviews, field observations, and document analysis. In this study, it can be concluded that not all unrelated kidney donors at Cipto Mangunkusumo Hospital in 2018 have altruistic and voluntary traits. Donors who tend not to be altruistic and not voluntary



have characteristics such as socioeconomic status that differs greatly between donors and recipients, lack of relationship between donors and recipients, educational differences between donors and recipients, lack of openness to family, and ego that is not low where donors expect something excessive from recipients.

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