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7

Concept of the Voluntariness in Kidney Transplantation from the Position of Donors and Recipients

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1. Introduction

Organ and tissue transplantation is always a procedure that involves two people, i.e. the donor and the recipient. A patient suffering from chronic renal failure primarily needs a kidney donation and transplantation. The studies and surveys about organ donation demonstrate that the number of organs donated fails to meet the need for organs. Given the studies about organ and tissue transplants, we note that organ donations from related or unrelated living donors have become more widespread due to increasing need for organs. (Lennerling & Nyberg, 2004; Kim et al, 2006, Donelly et al, 1999, Mousavi, 2006, Al-Khader, 2005).

Unfortunately, these sources have so far been unable to keep up with the demand. As a result, there is a large and staidly increasing number of potential recipients awaiting transplantation, some of who dies before an organ is found.

It is widely accepted that the optimal donor for a patient suffering from end-stage renal disease is an adult first-degree relative. However, there is an increasing global-wide tendency to use living donors who have an emotional but not genetic relation with the patient, and this tendency has been supported in the world.(Adorno, 2001, Wilkinson,2007, Chaudry et al, 2007)

The recipient lists and kidney transplantations show that 15% of recipients in waiting lists receive kidneys from their spouses. The success of kidney transplantations with organs received from unrelated donors resulted in the emergence of two donor categories:

1. Donors that have an emotional relationship with the recipient
2. Volunteers that the recipient does not know at all

Although these two categories are different from each other, it is possible to combine them under the concept of altruism. (Spital, 2005)

The life of a single person is valuable because it has a real specific value. As argued by R. Dworkin, religious and non-religious people may compromise on the fact that human life is sacred and hence has a real specific value. However, there is no compromise on why it is sacred. Human life has a specific value in its own rights. This real value emerges when individuals pay attention to the benefit of their own lives in general.

Transplantation is not possible if there is no organ for transplant. There may be transplants from living donors and dead donors. At this point, there is need to distinguish between "non-

directed donation", organ donated by a living donor to any recipient waiting an organ from a cadaver donor, and "directed donation", organ donated by a living donor to a designated recipient. In both types, voluntariness constitutes the basis of donation, and altruistic approach is adopted (Matas et al, 2000). Free and informed choice is an oft-acknowledged ethical basis for living kidney donation. Including parental living kidney donation.

The small number of empirical studies of voluntariness among living donor may be function of elusive nature of ideal voluntariness in a population that can be accepted as medical risk for the benefit of others. Recruitment of living donors represents medical and ethical responsibility. Their motives are often complex. Categories of motives and factors causing concern were taken from the literature and were identified from a various in-dept interview. The purpose of this study is to find out the values and problems used to evaluate the concept of voluntariness from the position of donor and recipient in kidney transplantation. We conducted in-dept, face-to-face interviews with donors and recipients. The interviews lasted for a median of 30(range20-40) minutes. We analyzed the interview transcripts with discourse analysis method used in functional pragmatics. Content analysis is a research technique targeted at systematic and quantitative definitions. Content analysis is related with not only linguistics but also other fields of science based on interpretation.

2. Voluntariness

2.1 The concept of voluntariness

Voluntariness is deciding to do something and doing it willingly in accordance with a purpose, on one's own freewill, without expectation of a reward. In voluntariness, it is not an obligation or pressure that causes an actor to take action. At the basis of voluntariness lies respect for autonomy. (Oğuz et al, 2005)

Donation and donor are words with a strict and extended meaning strictly used, donation means the act of giving or the substance of the gift: the donor is one who gives. The donor is necessarily alive, the moral agent: the one whose decision and act of will make gift. (Dunstan,1997).

Voluntariness is one of the main preconditions for receiving a valid informed consent. The concept of voluntariness involves being autonomous and free from oppressive factors. Some people define voluntariness with the existence of sufficient knowledge and absence of psychological pressure and external constraints. Given these general definitions, voluntariness means a person's, be it male or female, acting willingly without the control of any other factor. However, there are some situations that restrict voluntariness, e.g. physical or psychological diseases and addiction. (Beauchamp & Childress, 1994)

2.2 Voluntariness in terms of ethics

As mentioned above, voluntariness is one of the main components of informed consent. Undoubtedly, for the particular case of organ transplantation, voluntariness constitutes an ethical concern for any operation on both donors and recipients.

As highlighted by J. Harris, the most significant aspect of respect for human beings is the respect for "the desire to live", and all other desires and their well-being depend on respect for this primary desire (Harris, 1998).

When dealing with the issue of voluntariness, it is required to acknowledge that a voluntary person is someone defined by law and holds the authority to give informed consent.

In the context of informed consent, voluntariness may be defined as a patient's making a decision freely without any pressure about healthcare they receive, in accordance with

patient rights. In voluntariness, in addition to the focus on being free of values, it is also required to underline the need for skillful management and elimination of oppressive factors. (Ananda, 2005, Jonsen et al, 2006).

Human beings are creatures that value their own life. Respect for human beings requires two main components: firstly paying attention to the well-being of others, and secondly respecting the desires of others. People working in the health sector acknowledge that their first duty is always to observe the benefit of patients optimally, and argue that this approach does not contradict with respect for human. Well-being is not used in this context as a technical term. The concept here refers to its ordinary meaning, i.e. being good and living under good conditions. The word thus covers happiness, health and good life standards. Paternalism is interference into others' life for their well-being against their will and thoughts. The motto of paternalism is "don't do that, it's not good for you". Moralism is interference into others' life in order to protect their morality. The motto of a moralist is "don't do that, it is sinful". Both paternalism and moralism pay attention to other people's well-being sincerely. Both approaches see people as incompetent, and disregard their control over their own life.

The principle of respect for autonomy underlines the need to inform patients about medical interventions. Today, this approach is widely adopted in bioethical discussions. However, there may be cases where a physician adopts a paternalistic approach for the sake of individuals in line with desires and choices of donors and recipients. Here it is required to make a distinction between strong and weak paternalism. Both types of the paternalistic approach are based on the principle of being helpful.

In weak paternalism, the physician protects the patient against third persons if the patient is incompetent or hesitates about voluntariness. This may be exemplified in the case of protecting potential donors who do not have the competency or authority to give consent for organ and tissue transplant. Contrary to weak paternalism, in strong paternalism, the authority of a person may be violated for the sake of another person. This type of paternalistic approach is unacceptable in terms of medical ethics. With regard to kidney transplantation, the common approach since the first transplantations has been to consider the well-being of recipient more important than the risks that donors may suffer from. However, it is of great importance and priority to establish a balance between gains of recipients and risks of donors (Gutman & Lung, 1999).

The cases where organ donations of living donors are rejected are sometimes referred to as passive paternalism. If physicians have doubts about competency or voluntariness of a potential donor, they may not pay attention to desires and expectations of the recipient (Gutmann & Land, 1999).

Respect for others' will is the most important indicator of recognizing that their life is valuable. Each life has a unique value, and this value is determined by an individual's choices about her/his life (Harris, 1998).

2.2.1 Competency and voluntariness

In organ and tissue transplant, informed consent is required from the donor. To give a valid informed consent, the donor must be competent to donate. Medical practitioners are required to clarify whether a potential donor is competent and voluntary. If there are doubts, weak paternalism may be applied despite expectations and desires of the recipient. Physicians are obliged to complete the informed consent process thoroughly and receive the consent. That is why there is need for a detailed investigation about the organ donation

decision of a donor. The most frequent case in kidney transplant from a living donor is that a family member comes to a transplantation center to volunteer for donation. A recent Scandinavian report shows that donors start the process in 77% of the cases, and recipients request the donation in 13% of the cases. However, it should be taken into consideration that the changing conditions and acceptable donor-recipient relationship definitions may change this dynamics. (Lennerling et al, 2004)

Transplantation centers are required to develop protocols to evaluate potential donors. (Sterner et al,2006) The European Union decision of 1999 also suggests that organs and tissues may not be received from donors who are not competent to give consent.

An informed consent is valid only if the donor is informed thoroughly and makes a decision without any pressure or force. It should be kept in mind that voluntariness is not a presumption or an easy choice.

Voluntariness may be influenced by such internal factors as constrained choice, pain, emotional and psychological problems due to nature of illness as well as external factors such as force, pressure or manipulation from medical team and family members. (Beauchamp & Childress, 1994, Etchells et al, 1996) With regard to treatment, the medical team should support appropriateness of the decision by providing information about possibilities that may affect the decision and by encouraging potential donors to ask questions. The information provided should be free of biases.

Donors and recipients should be given written information about transplantation in the first meeting.(Lennerling & Nyberg, 2004)The information for potential donors should be given separately from general information about transplantation .The language should be easy to understand for most people and rather informal. To catch the reader's interest use illustrations, colour and wide line space. Patients must have a written copy of this information and read it whenever required. The information should be fully understandable for the recipient to be informed about risks and consequences of donation and for the donor to be informed about advantages. However, the evidence about current practices show not all potential donors are provided with reliable information in written form.

2.2.2 Effects on voluntariness

There are some categories of effects that influence voluntariness. Many effects are opposable. Some are pleasing, so they are acceptable. The effects of "effects" on people may vary stunningly. For instance, love, threats, education, lies, manipulative suggestions and emotional affections. It is required to analyze three main categories of effects. These categories may be listed as pressure, persuasion and manipulation (Beauchamp & Childress, 1994). Pressure: Pressure is a limitation imposed upon a person deliberately through physical constraints or conciliation to keep them under control. The emergence of pressure is dependent upon subjective responses as well as the existence of targeted purposes. The subjective obedience reaction to a threat cannot be defined as pressure. Pressure requires a real, believable and intended threat that drives a person to an unwanted action and forces her/his autonomy out of self-control. Threat: Threat is to force someone to do something or to put someone under force by constraining their freedom. Threat principally requires a real, reliable, intended and willful orientation. Some threats may force almost all believers. Persuasion: Persuasion is to lead someone to do an action by making them believe in it. Related to this definition, Loren Roth and Paul Appelbaum suggest the concept of "strong persuasion", which differs only with regard to the degree of persuasion. Manipulation: Manipulation refers to various forms of influencing, e.g. distortion, exaggeration or omission of information in order to produce desired changes in behaviors of the addressee of this information. (Beauchamp & Childress, 1994, Etchells et al, 1996)

Manipulation is neither persuasion nor a forceful act. A person willing to control the process of an event may act according to her/his own will. There are different forms of manipulation regarding decision making. Many forms of manipulation on information hinder autonomous decision making. For instance, deception leads people to believe in wrong things, or hiding or exaggerating information impede people from making autonomous choices. Manipulation may appear in prejudged cases. In such a case, the most useful strategy is to review the information with the patient's own words. If the patient accepts a treatment because of its potential benefits, she/he should be open to possible risks. However, this is not a manipulative situation.

2.2.3 Voluntariness is important

Freedom entered as a ready-made concept into many moral doctrines. Freedom is a mystical concept that may be acquired intuitively. Uninformed freedom is not possible as freedom also means choosing the optimal option among certain limitations. Inasmuch as altruistic acts are not prescribed by rules, these acts are considered positive and are widely believed to be conducted for benevolence purposes.

If an individual doing a favor conducts this act with the assumption that others will know it and thus she/he will take credits, this is not an ethical act. If a volunteer makes a donation to be praised by others, this act would certainly lose its benevolent value. E. Fromm says that only a person who self-devotes herself.himself may be wealthy. In his *Ethics*, Aristotle writes to Nicomachus that the most terrifying thing is death because it is the final end, and that for a dead person nothing seems good or bad; (Denise et al, 2005) An individual may think about her/his acts in a detailed way. After this thorough thinking process, if the individual is willing to donate an organ, she/he will express this willingness. Voluntariness is a characteristic of a generous person and would probably lead to gratitude to him or her. However, a prospective recipient should not be forced to expect favor from a beloved person.

3. What is altruism?

Altruism suggests that the purpose of a moral act is to ensure the well-being of others. Produced from the word *alter* (the other) in Latin, the term altruism was first used by A. Comte in the 19th century, and has since gained a meaning that is opposite to egoism. (Monroe, 1998)

Altruism is the ethical approach upholding love for humans and the humanity without consideration of self-interest, and self-devotion to the welfare of others and society, underlining benevolence, goodwill, tolerance and helpfulness, and adopting the formula of 'living for others' Altruism is the doctrine suggesting that individuals should dedicate themselves to the needs and benefits of others without seeking any self-interest, as opposed to selfishness and individualism. Further reading shows that this concept was defined by the French philosopher A. Comte as loving another person for the sake of that person whereas utilitarianism is to love another person for the sake of the actor herself/himself. Ethical egoism, based on self-interest, asserts that self-interests would be protected only in an organized and stable society and that ethical rules are required to establish such a social order and that it is for the sake of us to preserve an ethical order. Hence, ethical egoism links ethics to self-interest. Opposed to ethical egoism, altruism says that any moral explanation cannot be reduced to self-love and that the precondition for morality is to show interest and goodwill to other people just for their own value, highlighting helpfulness without expectation of any return and sacrifice of self-interests for the well being of others. (Cevizci, 2002) Altruism may be the result of the feeling of responsibility for human beings and the

society as well as the desire to improve and purify morally by coping with selfishness and selfish desires.

3.1 Why is altruism important?

The starting point of the utilitarian doctrines is that human beings by their very nature have selfish needs and tendencies, and that they seek to satisfy these selfish needs and tendencies, bodily and psychic needs and passions and hence reach happiness. According to the utilitarian doctrines, the first attitude of an individual towards others is compatible with selfishness deriving from human nature. Human beings are selfish by their nature, and this selfishness is never completely erased. However, humans are also weak beings of the nature. They do not have sharp teeth or strong claws. Thus, in order to survive as a weak creature, humans have to live with others. In addition to selfish tendencies by nature, they also need to take care of others. This interest in caring others is said either to be inborn or acquired. For instance, Shaftesbury says that we have this interest innately as an altruistic feeling (Ozlem, 2010).

Machiavelli, Hobbes, Bentham and Nietzsche claim that humans take self-interest at the center and that selfishness is both normal and preferable. On the other hand, Rousseau, Hume and Kant treated altruism as a part of human nature. Butler says that human have an innate self-love in addition to the tendency to desire the well-being of others. (Denise et al, 2005)

n discussions about altruism, this concept is commonly defined in terms of giving, sharing, cooperating and helping. Altruism may be defined as the tendency to prefer the welfare of others to our own. We need to mention some critical points when addressing to altruism:

1. An altruistic act should lead to something.
2. The act should be directly linked to the goal.
3. The goal of the act should be to improve the welfare or life quality of another person.
4. If an individual is willing to act for the sake of another person, the fact that the outcome of the said act is negative or that it may lead to negative outcomes in the long term do not reduce the altruistic value of the said act. Numerous evaluations focus on motivation and goodwill of the individual (Monroe, 1998).

3.2 Main components of altruism

Cognitive frame and procedure, religious beliefs and expectations, worldview, empathy and self-perception are the factors that affect altruistic approach. As opposed to emotional meaning that reveals emotional reactions of individual, cognitive meaning is the bare message conveyed by any sentence. Cognitive frame and procedure refers to the act of knowing through intellectual knowledge; the process of the act; the activities such as thinking, understanding and reasoning; and mental behaviors such as symbolization, believing and problem solving. (Cevizci, 2002)

With regard to religious beliefs and expectations, we can say that religion is an institution that is based on individual beliefs and social aspects, is systemized in terms of thought and practice, offers people a way of life and gathers people around a specific worldview. Religion is a way of appraisal and life. Religious evaluation requires profoundness, comprehensiveness and sacredness. Religion is a matter of hearing certain things, believing in them and conducting some voluntary acts according to those beliefs. Studies involving living donors reveal that religious beliefs constitute a strong motivation for kidney donation among both related and unrelated living donors. (Dixon & Abbey, 2000, Dixon & Abbey, 2003).

The donation decisions of donors should definitely be subject to a detailed investigation. The primary purpose of such an investigation is to assure minimal risk for the donor and

provide maximal benefit for the recipient. It is also required to determine to which extent religious beliefs play a role in altruistic acts.

Worldview is the whole of an individual's or a group of individuals' beliefs, thoughts and attitudes about humanity, future and so on. The strongest motivation of a donor is "being helpful to others". No matter whether the recipient is related or unrelated, donors believe that donation would increase the respect to them in the society. However, those who accept the help, i.e. recipients, may feel guilty or indebted. They do not want donors to get harmed. Feeling guilty for whatever we do or do not do, whatever we say or do not say is another way of wasting time unnecessarily. It is required to act honestly in accepting our faults and assuming the results of our choices and the responsibility of our faults. This process entails providing thorough information to both donors and recipients. Good education and sufficient social support may be relieving for both parties.

The sources of information for donors about organ donation are as follows (Lennerling et al, 2004):

40% Recipient
65% Physician of recipient
35% Other health staff
55% Booklets about donation
18% Articles
15% Patient-training programmes
14% Other donors
12% Autobiographies, newspapers, television and Internet

It is obvious that the abovementioned parameters have effects on the worldview of an individual. Thus, it is required to consider them carefully in determining whether a donor acts voluntarily or not and in receiving informed consent without any doubt. The most significant aspect of respect to individuals is the respect to their wish to live. Other wishes and uninterrupted well-being are dependent upon showing respect to this primary wish. Empathy may be defined as understanding the behaviors of other people in the context of their conditions and opportunities by putting oneself into their shoes. (Hojat, 2007).

Patients who need kidney donation experience a long and tough process. It has been observed that most of the donors witness this process. For most donors, it would be heart-breaking not to be involved in this process as a donor in their common life with the patient. (Sanner, 2005) Further, if dialyzing becomes an unbearable process and the patient expresses this suffering, the donor tends to apply to a donation center as soon as possible. According to research findings about donation in organ transplantation, women and men express their intention to donate an organ in different ways. For male donors, donation is a very complicated situation that holds many controversial issues. Male donors expect that their respect in the society would increase after donation. On the other hand, for female donors, donation is an award to the recipient. R. Simmons says that the feeling of family unity is dominant among female donors. With regard to traditional family structure, the woman is located at the center and altruistic approach is generally identified with her. (Gutmann & Land, 1999)

3.3 It is important to evaluate altruistic approach

In kidney donation, donor is the person who donates her/his organ. To donate may be defined as giving or presenting a good or right to another person with no thought or expectation of personal gain. Whether the recipient is related or unrelated, living donors sacrifice their benefit for the sake of another person without expecting any return.

Undoubtedly, this situation requires a thorough ethical examination. The studies on living donors reveal three types of donations in terms of altruistic approach:

1. Direct donation to a beloved or related person
2. To a recipient in the waiting list
3. To a designated recipient (Kim et al, 2006)

There should be no pressure on the donor in terms of ethics. As mentioned in the literature, 'personal willingness' may not be the only reason in indirect donations and requires detailed investigation. (Spital, 2005)

As we mentioned earlier, the quality and quantity of donors is not at the required level in kidney transplantation. Kidney transplantation poses a low level of risk when medical and ethical evaluations are completed thoroughly. Donors may gain a psychological advantage because of the act of donating. Donors have frequently reported to have a feeling of emptiness following the nephrectomy. They have also had depression complaints at times. Despite the efforts to inform donors about any possible negative effects on recipients, many donors may not comprehend potential negative results and underestimate the risk. There is need to evaluate life quality through standardized survey forms. Related surveys reveal that the self-respect of donors have strengthened in the long term. The literature provides perfect results concerning kidney transplants with organs received from living donors. The actions of donors may be based on individual autonomy and altruistic approach. Undoubtedly, related with the decision to donate, in addition to the autonomy and competency to make such a decision as stated by Beauchamp and Childress (Beauchamp & Childress, 1994), there is need to inform the donor thoroughly, realizing the current situation, revising the information given and eliminating any deficiencies as highlighted by Appelbaum and Grisso (Lennerling & Nyberg, 2004).

Today the decision to receive kidney from a living donor is based on the principle of self-devotion to a beloved person. The most common reaction to living donors is usually full support from the majority of community. Human beings are creatures that may value their own lives. Through kidney donation, the individual renounces something that is valuable for her/him, but without which she/he can live, and thus provides a new life opportunity to the recipient. The donor acts for the sake of another person. It is required to respect an individual's willingness to be engaged in such an act. Respect for willingness is the most significant component of the idea that other people's life is valuable. Each life has a unique value and this value is determined by individuals' choices to orientate their lives.

3.3.1 Being a voluntary donor

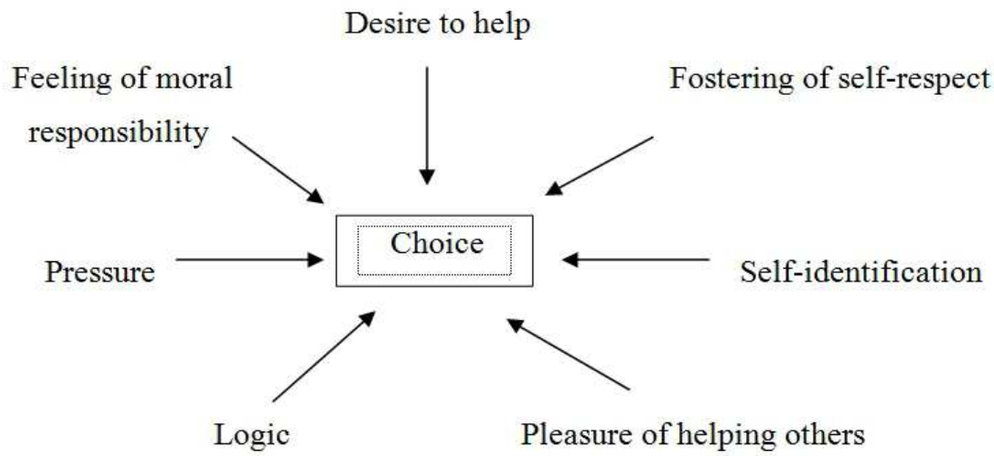
In kidney transplant, only parents and siblings used to be considered as donors initially. However, now the scope of donor group is extended, which gives larger responsibility to health personnel concerning the selection and evaluation of donors.

In transplantation, there should be very low risk for donors, donors should be informed fully, donation should be completely based on the principle of voluntariness, and the success rate for the recipient should be high. Today, it should be assured that donors suffer from minimum psychological and economic burden to the extent possible.

One of the most significant problems in solid organ transplantations is that the waiting period of potential recipients has been extending due to the increase in the number of candidates. Every year, about 7% of prospective recipients waiting for a kidney lose their lives, and long periods of waiting have adverse effects on transplant results. One of the ways to solve problems about waiting is to increase the number of living donors. The early achievements about this were mostly the result of devotion and responsibility. Today there

is need for living donors more than ever because of improvements in transplant results and increasing need for transplants.

In order to expect optimal result from transplantation, it is required to transplant a kidney to the patient as soon as possible following the outset of disease. Thus, doctors are required to discuss choices as early as possible with patients of chronic renal disease, and thus enable patients and families to avoid long waiting periods for kidney transplant from potential living donors. Some studies concerning donation deal with effective criteria about this decision under following titles: (Lennerling et al, 2003, Burruoughs et al, 2003, Elcioglu, 2007)



The majority of donors define "willingness to help" as the strongest factor in their decision for kidney donation. The donor is willing to help a close person who is really in need of a kidney. To exemplify, the expressions such as "I have known him since my childhood" or "I believe my life would be more meaningful if I help him" are noteworthy. (Elcioglu, 2007)

Levinas notes that the relationship between subjects is not symmetrical. In this respect, the subject has a holistic responsibility to account for all others, for anything in others and even for their responsibilities. The subject always has more responsibilities than others. Being subjective arouses the expectation that the actor would always take the right step towards the other. No freedom is absolutely comprehensive or limitless. The way to be released from a restriction is to use another restriction as a lever. Every freedom struggle ends with the replacement of a painful and disturbing restriction by another restriction that looks less evil as it has not been seen or tried before. Every freedom celebrated is a release from the most fearful bond. (Bauman, 1998) It may be said that there is a similar relationship between donor and recipient. While released from the restriction of dialysis, the recipient may be welcoming a new life where she/he is restricted by the donor. Or, on the other hand, the donor may have fluctuations in her/his mind while saving the recipient from dialysis and bestowing her/him a new life. The donor may need time to finalize her/his decision to donate.

Many recent studies reveal that the decision-making process of a voluntary donor is based on moral preferences rather than on conscious grounds. The majority of voluntary donors consider their own situation while considering the benefits of a recipient. Donation to a family member is important for potential donors because of their close relations. However, it should be taken into account that moral considerations may hinder donors from being

fully aware of risks and benefits. Even just for this purpose, informed consent received from a donor is important in its own right. (Valapour, 2008)

Identification may be defined as a process where empathy takes place. With regard to organ donation, "I would not like to be in her/his place, it is an unbearable situation. If I were in need, she/he would undoubtedly do the same," a donor may say to express her/his feelings. At this point, the principle of bestowing is a respectable act. In ethical terms, an individual must have the right not only to make a decision but also to change her/his mind. The most significant issue is to find the most easily-used method that assures minimum error.

During self-questioning, donors are required to make a rational evaluation. At this point, it is important to make the correct reasoning and present it in an understandable way. If a person chooses to live consciously, there are two possible consequences: First, self-responsibility would acquire a different meaning. Life stops being a burden on her/his shoulders and turns into a decision taken alone. In such a case, the donor has only the order she/he establishes. Secondly, the discipline imposed by the external world becomes self-discipline. This may be defined a lesson learned in life struggle by everybody wishing to achieve maturity.

The potential existence of pressure requires a thorough evaluation. The motivation of donors to donate their kidney also requires a detailed investigation, and there is need to clarify that there is no family pressure on their decision-making process. (Mousavi, 2006, Rudlow et al, 2005)

Influence is also a component of persuasion process. When persuaded, an individual accepts and is influenced by an idea. This is not completely against the nature of voluntariness. However, in some cases, a donor may be forced to act without her/his freewill. In this case, we cannot say that the action is fully autonomous. With regard to kidney donation, there are examples of the abuse of donation in the family. Rejecting to donate may lead to isolation of the individual in the family, or an individual may be forced to donate for a family member she/he does not love. Parents usually do not want to receive an organ from their children. If children's decision to make donation is hidden from parents, donors may give up their decision. Children may be willing to donate for their parents in order not to lose their love. This is a difficult choice where moral responsibility is of priority. When a potential donor is making a decision about kidney donation, written information about organ donation and long-term results of organ donation, high-level care during medical examinations, difficulties of organ transplant from cadavers and long periods of waiting for an organ, support of family and friends, appreciation of donors in the eyes of recipients and all other procedures may be helpful.

As the factors summarized above may motivate a donor, there will unavoidably be some concerns. For instance, medical examinations and tests alone cause stress and anxiety. Going to a medical institution and doing those examinations before the donation may be a painful process for donors. Donors also need care and interest. As they become aware of medical risks, hesitations may increase. Donors should be informed thoroughly about long- and short-term consequences of nephrectomy. It is ideally expected that the surgery does not cause mortality or morbidity on the living donor. In any case, the donor should have the right to make her/his own decision. Conflicts among family members may cause problems in family relations. Although the potential donor is aware that she/he is clinically appropriate for donation, she/he may hesitate to make such a decision. In this case, the recipient should be explained that the donor is not appropriate for transplant. The health team should not distort information in order to exclude a potential donor. Based on the donor's right to confidentiality, it should be mentioned that the donor is not appropriate in

general. Honest and open in-family relationship is very important, and potential donors should be encouraged to communicate with family members. (Ross, 2010)
Emotional relations with family and relatives may force individuals to act in a certain way. In case of a disease, family members may feel responsible to donate an organ as if they provide health care or social support. Anxiety is the first reaction given when an individual perceives her/his existence is threatened. The feeling that partially controls the ego of an individual is fear. When the danger reaches at a level to threaten the existence of an individual, anxiety begins to control that person. For a potential donor, what makes donation "anxious" is quality rather than strength of the event. Today's people feel anxiety when they are faced with a threat to their existence. All people have truths that they believe in. Every person has a reason for living whether it be love for success or a person, or love of freedom as in the case of Socrates, or the impetus to listen to inner voices as Joan of Arc did. If this structure of values is subject to an external force, the individual may think her/his existence ends. Given that being accepted and loved is the strongest pressure on people today, anxiety may result from the fear of isolation from society. (May, 2000) Realizing the truth is a function of human wholeness, not of a distinct intelligence. A balanced emotional and moral maturation is required to be sure about voluntariness. The donor's trust in her/his beliefs would strengthen as a result of not abstract principles or others' opinions but her/his own experience.

4. Volunteering: It is not enough to say that "I am voluntary"

Losing one's way in a labyrinth means that the person has lost her/his general perspective about the given situation. We cannot get out of the labyrinth by always repeating the same ideas in mind consistently and then reaching a deadlock every time. We need to be able to put a distance between ourselves and our ideas before revising them. Every movement with an internal aspect may not be an action. If our arm moves up because it is forced by someone else, we just feel this movement but this is not our intentional movement. If we raise our arm on our own will, this movement becomes an action. The difference between the first and second movement is that the former is an action made by us whereas the latter is the product of a movement that we are forced to do. In kidney donation, there is a similar difference between being voluntary and seeming voluntary. What is important is that voluntariness is the product of an action in its own right. For an action to emerge, it should be made by an actor and there should be freewill at the basis of the action. Thus, it is not enough to express voluntariness by words, and a voluntary individual is expected to act in line with the decision to donate her/his organ.
A person may desire to donate her/his kidney. However, for the realization of this desire, it is required that the desire starts guiding behaviors and there is need to concentrate on the selection of ways to be taken. A simple desire does not require such a step. In the expression of voluntariness, it is very important to take required steps rather than just revising ideas about donation. To understand if a person's willpower is strong or weak, we need to find if he/she is determined and prepared to take the steps required to realize the desire and if she/he is still determined despite unexpected obstacles and strenuous efforts required. Bieri mentions that there are two restrictions on will: Firstly, there are limitations posed by possibility or impossibility of existing realities. People may desire to recreate the world; however, this would not be a will. The second factor that restricts willpower is related with the fact that our abilities are restricted; however, we cannot say that an individual desires just whatever she/he is able to do. (Bieri, 2009)

The decision to donate a kidney shows the own intention of a donor. If this intention leads the individual to donate the organ, the donor is required to take an action. In social life, people may feel obliged to do something or prefer to do nothing, going with the flow. In this case, remaining indifferent or doing nothing is also an action. The lack of any sign of voluntariness may also mean that there is an expectation of other donors.

The methods adopted to determine whether a donor is voluntary may be used together. Interviews of health staff with donors and evaluation of survey results would provide detailed information to determine whether a potential donor is really voluntary or not. Organ donation programmes expect to find appropriate well-informed donors even if donors are persuaded, influenced or oppressed. In many cases the feelings of donors may overcome their real intention. There is need to revise and evaluate the donation thoroughly when it is found that donors make such a decision not to lose their job or are persuaded after meeting some family members. (Valopour, 2008) One of the conditions for placing voluntariness on a sound ground is to allow some "time" for potential donors to revise their decision, and thus provide them the chance to renounce the decision to donate an organ. This condition is stipulated within informed consent procedures and has been the strongest principle to determine voluntariness. A person willing to achieve an objective would demand tools and means required to reach that objective. Physicians are required to give importance to the values and objectives of not only patients but also donors. When voluntariness is not expressed clearly and when risks outweigh, there is need to prevent an organ donation. Although experiences about kidney donation have a history of 50 years, certain problems are still up-to-date. Spital asks how we can be sure that a potential donor acts independently and freely, and argues that, in case of profound love and interest, only informed content would not be satisfactory. (Spital, 2000) People may have to benefit from another person's organs or tissues, i.e. organ transplantation, for the sake of the lofty aim of saving human life. However, this act should comply with the principles of seeing human as an aim and saving a life without causing the death of anyone else. In such a case, a donor gives an organ that is very valuable but without which she/he can live in order to assure the recovery of another person, and hence uses her/his ethical right without prejudicing her/his own right to live. Even just the use of this right requires a comprehensive evaluation of voluntariness. A potential donor of kidney has to deal with tiring and painful procedures as well as a surgery, which means a though and undesirable process. However, it should be kept in mind that an individual may demand to donate an organ just because she/he wants to do it. The lack of any effect, in other words, a bare decision to donate an organ, is a proof of altruistic attitude and also an expression of voluntariness.

4.1 Interviews of medical staff with donors – importance of narratives

The medical staff makes interviews with kidney donors in order to find out whether they are really voluntary or not, and the transcriptions of voice recordings of interviews have been evaluated through specific methods. What is narrated at experienced organ transplantation centers constitute significant data for the determination of voluntariness. (Elcioglu, 2007; Lennerling et al, 2004; Kierans, 2005; Pradel et al, 2003)

Not only in medicine but also in nursing, law, history, philosophy, anthropology, sociology and bioethics, narrative knowledge has been increasingly holding a more significant place in the last 20 years. (Charon, 2001) Narratives provide the opportunity to understand the importance of stories. This information provides important findings to reveal mental, symbolic and emotional situation of involved people. Medical ethics seeks solutions to ethical dilemma encountered particularly in medical practices. Narrative knowledge

provides the richest data to solve such ethical dilemmas. One of the important sociological thoughts developed to explain the concept of sickness tries to explain the behavior norms that patients adopt, the comments about disease and how the meanings hidden behind these comments influence human actions and behaviors. According to Talcott Parsons, a disease emerges due to physical reasons that are not under control of the individual. Sick people have certain rights due to their sickness, and are exempt from all duties and behaviors they have to undertake when healthy (Giddens, 2008). Patient role is temporary, and sets the condition that a patient has to exert efforts to recover. The approval of disease by an expert assures that people around the individual accept that she/he is sick. The patient is expected to collaborate with medical staff by following advices of the physician.

Experience with patients would be in different forms according to types of disease and patients. People suffering from a temporary disease are expected to recover as soon as possible. However, patient roles would be different in chronic or mortal diseases that require other people's devotion. Stigma may be defined as any physical or social mark that is considered disgraceful. Dialysis treatment is a factor that prevents the patient from being wholly involved in the society. Certain diseases require periodical treatment or care that affects patients' daily life to a considerable extent. Patients may have to rearrange their daily lives and develop new strategies to cope with their current situation if they are required regularly to receive dialysis treatment, get an insulin injection or take a lot of pills. The disease itself may constrain or change self-perception of the patient. This results from others' actual reactions to the disease and how these reactions are perceived and envisaged by the patient. (Giddens, 2008). Interactions that are ordinary for some people may be full of risks and uncertainties for people suffering from chronic renal failure. Even ordinary situations may be perceived in a different way in case of a disease or disability. For instance, a patient receiving dialysis treatment may not want to seem dependent on family members or other people. Family members may not express their affective or protective feelings to the patient appropriately. A newspaper of February 13, 2011 reads as follows: "Y.Ö. (33 years old) asked her grandfather M.Ö. if he would donate his kidney to her. 'My granddaughter asked me if I would give my kidney to her. She did not say anything else. I have not seen a doctor until this age. I am healthy, everything was alright in tests. I gave my kidney to her,' said M.Ö (86 years old)". In traditional family structure, adults are expected to donate for their children or grandchildren. M.Ö. did not escape from donating his kidney to the granddaughter. Narratives help us understand the spiritual value of experiences and clarify our expectations. For many people, it is virtuous to be among donors rather than be among recipients. Human beings have a mind. They narrate life experiences. A life without language is impossible while we live and sustain human relations. We express our feelings and experiences through language in oral or written form. Detailed analysis of the meaning of verbal expressions may help have a full understanding about the said issue. In the context of kidney transplantation, both donors' and recipients' expressions about transplantation also reflect the history of relationship between two parties. Certainly information about individuals should be narrative.

Narrativity may be defined as a structuring that connects events in a story to each other in a way that they create a meaningful system. According to this approach, the subject of an ethical action conveys in the narrative her/his information about the meaning of life and ethical values. The narration of each individual is original although what is narrated has a bond with the society in which events occur. Medicine cannot survive without narrative knowledge. In medical practices, narrative knowledge is of great importance in diagnosis, treatment planning and applications. (Charon, 2000) Particularly those working in clinics know how important narration, interpretation and conception based on practical mind are. The aim of narrative ethics is to note individual and historical aspects of an issue before

making an ethical judgment about it. Narrations are descriptive as they express human experiences. The described situation is selective because it belongs to the describing person. Further, the expressions of a person need to be binding internally. People provide temporal and spatial information about the situation they narrate. In terms of ethics, time is of particular importance. Each life experience occurs in a period of time. There is need for time for new experiences. In life, fear, anxieties, gratefulness, possible risks or future gains are all dependent on time.

Narratives are the products of the efforts to give meaning to life. Human life is just a series of events, and in order for these events to be meaningful, they should be accounted in a certain order. Narratives contribute to medical ethics through first their content and analysis based on narrative theories. (Adams,2008, Jones,2009) At times, narratives constituted case studies that help us understand the principles and approaches of medical ethics. Further, they were used for suggesting right principles and approaches for a good life. They provide the opportunity to evaluate the events thoroughly as they enable to revise them.

Interviews with donors are based on structured question indexes. They mostly focus on experiences and feelings. The period of interview between medical team member and potential donor is about 1 hour, but may change according to the number of questions and analysis methods used by centers. Interviews are recorded upon receiving permissions required. The most common topics of interviews may be listed as follows:

1. Relationship with the recipient
2. Decision-making process
3. Anxieties and fears about surgical operation
4. Life risks in the long term
5. Gains of the recipient
6. Family members' opinions about donation (Kierans, 2005, Pradel et al,2003).

The content of some narratives provide the opportunity to examine in a detailed way certain topics such as autonomy, respect, telling the truth, consent, being useful, incompetence, negligence of doctors and some specific situations about patient and family members. Whether the interview is made with patients or family members, narratives enable public discussion of an ethical problem. In addition to Mercy's story published by Selzer in 1982, Debbie and Quill cases assumed such functions. In following years, literary discourse analyses were used in medical ethics practices. (Jonas, 1999, Anonimous, 1988, Quill, 1991)

Earlier investigation of attitudes of living kidney donors have been performed retrospect. We saw a need to investigate in depth those motives and feelings that are relevant in potential donors. With a phenomenological approach, interwievs were performed with patients, recipients and potential donors.

The voice records of interviews are transcribed and analyzed. The process is divided into some stages. The evaluation method below was developed by Karlsson in 1993:

1. Transcriptions are read carefully many times.
2. The text is divided into discrete parts. As questions are prepared before the interview, there is already an automatic division.
3. Each part is titled by the researcher.
4. In synthesis, meaning units structured for each interview are used. (desire to help, donation is a humane approach, moral responsibility, external pressures and so on)
5. The general structure of interview is summarized.

As mentioned some papers, the health professionals working with this field have a great responsibility in the task of selection donors. (Lennerling et al, 2003).

Narratives bridge the gap between past and future so that the individual can take action. In this respect, the purpose of phenomenological research is to define past feelings and experiences of participants.
In the history of philosophy, Husserl, Kirkegaard, Heidegger and Sartre contributed to the development of this method. (Monreo, 1996, Lennerling et al, 2004).
The issues dealt with to define altruistic approach from Hume to Trivers have been as follows: family life, group relations, human nature, concept of responsibility, self-perception, empathy, situational factors, costs and expectations. (Monreo, 1996).
Narratives qualify and interpret an event, clarify feelings and thoughts about this event and add meaning to it. These are unique just like the narrating person. They provide starting, middle and end points. This allows presenting an overview about the issue dealt with.
The stories that we think we are living are not necessarily the same as the stories we think we lived when we look back or as the stories that others think we lived. The advantage of looking back is that we (or others) may reevaluate the nature of the narrative that we think we lived and thus redefine whatever we lived.
This is the advantage of looking back: Seeing the importance of an event that emerges after the occurrence of the event.
In kidney transplantation, narratives of donors and recipients are important as they show to which extent we listened to them, we value them, we empathize with them and we give importance to them. Narratives are unavoidably influenced by individuals and their perspectives. As human beings, we have to make choices and live according to these choices. As choices are dependent on moral considerations, they require more detailed evaluation.
Narratives provide an insight into voluntariness for kidney transplantation, involving the periods before and after the decision. Each narrative inherently requires interpretation. Narratives involving donors and recipients connect these two parties to each other, reveal mutual values, and clarify who we are, what we do and what we are responsible for. Thus, it is possible to reevaluate donors and recipients. Through narratives, links and feelings between people become more visible. Sharing experiences may guide other peoples' decisions to be a donor or a recipient.

5. Language and medical language

Language refers to the communication system of human beings. It is a privilege of mankind. The ability to speak is closely connected to the nature, ability to think and structuralism of human beings, which differs us from other creatures. Language is a sign system to express thoughts. Sign refers to any symbol that allows communication between people. It is not possible to isolate language from background and values of the speaker. Language is a mirror of the speaker. It is not possible to say anything about a person who does not speak or who does not do any action. The most concrete indicator of recognizing, meeting, understanding and being understood is using language. (Kayaalp, 2002)
In a society there are distinct groups that have members who are close to each other in terms of vocabulary use, have similar interests, give importance to some concepts not used by others and express certain things in a specific way. The groups in professional associations may be an example. For instance, medical language.
Medical language as the language of the institution of medicine has its own characteristics. It has a complex structure like all other institutional languages. This complexity derives from fields of use as well as styles of language use. The domains where medical language is used are as follows:

1. Language used in classes at medical schools
2. Language used by medical students
3. Language used in congresses, conferences, symposia, etc.
4. Language used in health programmes on TV
5. Language used in magazines and newspapers in writings about health protection
6. Written language used in medical journals
7. Language used by physicians in their conversations with health personnel, i.e. nurses, midwives, caregivers
8. Language used by physicians in their conversations with patients (Duman 2005)

After listing the fields of use of medical language, we need to mention that having a close look at physicians' conversations with patients may be beneficial to help patients to be informed about institutional language and cause physicians to constrain their expectations. Patients do not know medical language. Physicians intentionally try to simplify this language when they are talking to patients. This effort requires the translation of commonly used medical terms into daily language. It is not easy to translate medical language into an understandable daily language. During medical examinations physicians may not always be willing to translate their language into an understandable language because of time limitation. Further, patients with very limited medical knowledge may not understand even if medical terms are fully translated. Further, there are technical tools and machines, and medical procedures conducted through this equipment. Patients may have difficulty in understanding why these technical tools are used. In such a case, patients are faced with a physician who uses medical language and technical terms. This is a very complicated situation.

Patients are generally informed wrongly or incompletely due this complex language use. Thus, it is hard to persuade patients and to create an environment of confidence. Patients have difficulty in understanding that they have to trust physicians and follow their advices. When they tend to go their own way, they put their health and the physician in a difficult position. Further, they are afraid of or anxious about medical interventions due to their limited knowledge. This anxiety and fear naturally influence both patients and their close relations, and cause question marks about treatment. Anxiety and fear may influence psychology of patients and result in psychological problems while there are efforts to restore their bodily health. In such a sensitive situation, the informing process of a donor, who is not a patient but dedication herself/himself for the sake of a patient, requires specific attention.

5.1 Language and gender

Language is a communication tool. It holds many inherent differences. Language may lead to both mutual understanding and conflict. Although we always seem to be speaking the same language, we actually do not always speak the same language. Focusing on why we do not speak the same language would help us reveal the differences. Being aware of differences would help us use language more consciously and accept the differences. This acceptance may contribute to the improvement of communication. We can see language-use differences in conversations between a woman and a man, an educated and an uneducated individual, or a young and an elderly individual.

Studies about language differences between woman and man started to appear first in the US in 1960s, in Germany in 1970s and in Turkey in 1980s. These studies have been involved initially in sociology and then in gender studies, a subfield of sociology. The widely accepted supposition has been that the difference between female and male language is

related with social structure. It has been argued that the patriarchal structure and the status of women in society have reflections on language. It has also been considered that language is male dominant and thus language use of women is restricted. Some argued that in settings where women and men are together, male members orientate and control the communication. Thus, language use is based on social and cultural factors. However, in recent years, the reason for language differences has been sought in different fields. Brain studies constitute one of the primary fields. An argument in brain studies says that the differences between female and male brains lead to differences in feelings, language, eyesight, memory and even sense of smell. Öğrek claimed in 1996 that female and male brains are different in terms of chemistry, hormones and physiology. In the face of a problem, while a man uses only one of the lobs, a woman can use both. That is why a man can be either rational or emotional while a woman can be both rational and emotional and thus provide a more balanced solution (Duman, 2009).

5.2 Fear and language

Each individual has fears. Fears emerge in certain situations. These fears are expressed or not. Even though we do not express our fears verbally, our body language shows we feel fear. This is mostly shown by gestures on our face. The first thing that comes to our mind may be what fear is. We may first explain what fear is, how many types of fear there are and under which conditions fear emerges.

Neidinger defines fear as a restrictive feeling of discomfort that emerges when an individual encounters or imagines a threat that she/he may not overcome. Freud notes that fear is the reproduction of a situation lived previously, that warnings about this situation increase, and that fear takes shapes under certain conditions. He also mentions that fear is a reaction to a threatening situation. The reaction reappears when there is feeling of fear. (Neidinger, 2001, Freud, 1926).

In the communication between patient and physician, the fear is related with disease. In addition to fear, patients have hesitation and anxiety, which puts an excessive burden on patients. (Decker, 2005).

At the basis of fear is lack or insufficiency of information about something. One of our basic fears is fear of death. This fear appears when we are sick or when one of our close relations is sick or when we have to separate from someone close to us. This fear may derive from the fact that we have a single existence which is temporary. Furthermore, it may emanate from the threat in our subconscious that death will overcome us.

Even if fears are not expressed verbally in patient-physician relations, physicians are required to try to reduce the fear of patients based on the supposition that patients may always have fears. They should help patients reduce fear to minimum. The mission of a physician is not constrained with mere communicating with patients, developing strategies to sustain communication and treating the disease. Physicians are required to empathize with patients and keep in mind that their explanations should establish trust with patients so that patients can do what is required for treatment and use medicaments prescribed. Further, they should inform patients about medical interventions and applications. In this information process, physicians should be aware that they are not talking to a medical student, and adapt information to patients' educational background and current knowledge about disease. Another significant point is to answer patients' questions clearly and not to limit the information provided to the extent possible. Physicians should consider to which extent limited information would be helpful for the treatment of a patient who is not informed at all, misinformed or is informed on the basis of merely her/his experiences.

In organ donation, communication entails more attention. The physician is in communication with both an individual making a donation and a patient in need of transplantation. The donor is not an individual who has health problems and seeks a remedy for such problems. Physicians should take into consideration that both patients and donors have anxiety and fears in the process of organ donation, and endeavor to alleviate their fear. Fear is mostly the fear of death, and anxiety is related with problems that may occur after organ transplantation. Fears generally increase on the day of transplant. Neidinger lists as follows the fears that may emerge on the day of surgery:

1. Fear about the fact that life is threatened
2. Fear of pain
3. Fear of an unknown person who the organ will be transplanted
4. Fear of post-operation consequences
5. Fear of narcosis
6. Fear of surgical operation
7. Fear of separation from close people.

Undoubtedly, there may be other different forms of fear according to the sensitivity of patients and donors. Which of the abovementioned fears outweigh the others would depend on the environment of patients and donors, difficulty of surgery and many other factors. Media also plays a role in the emergence of fears. When dealing with problems about organ transplantation, media frequently refers to organ transplant abuses. Such programmes unavoidably have negative impacts on both patients and donors just like on any person.

Organ donation is an important decision. It has been observed that individuals who make this decision and donate their organ voluntarily feel discomfort during the waiting process at hospital and have dilemmas after the operation. Further, it has been seen that donors feel fear and optimism and tend to show depressive behaviors. Even if they are voluntary, organ donation does not always evoke positive feelings in donors.

Looking from the perspective of recipients, we see that they may have fears of non-acceptance of the organ or of any possible complications after the surgery. Further, they feel grateful to the donor. If the donor is not a family member, they may be anxious about not knowing the donor. In other words, the feeling of being reborn after the transplantation may be replaced by many negative feelings. Patients may go into depression, have dilemma or even commit suicide (Reichner, 1999).

It is an undeniable fact that it would be unfair to charge physicians with all negative effects and consequences of organ donation. Unfortunately physicians constitute the most criticized party in organ donation. Responsibility cannot be embarked only on the hospital or health team that realizes organ transplantation. Institutions other than hospitals should also assume responsibility about organ donation and attach more importance to this issue. It is required to raise awareness in the society about organ donation and reduce fears and anxieties about it. In this respect, what specifically needs to be highlighted is that organ donation should not only come from the family, and that donation is not an obligation but a voluntary act. To achieve this purpose, it is required to inform members of the society about organ donation. Organ donation does not only mean life saving. Healthy members of the society need to be aware that they or their family members may also need organ donation.

6. Narratives and meanings

The ethics of transplantation can be expressed in certain requirements or duties. The first is medical integrity. Patients and the public must able to trust their doctors not to sacrifice the

interest of one to that of another, from whatever motive. The second requirement is scientific validity: the basic biology and technology must be sufficiently assured to offer a probability of beneficial outcome, casa by case. The third is consent, based upon information adequately presented, weighed and understood, and unbought, unforced. Without this the contract isunethical: The tension between self and other is skwed. (Dunstan,1997).

Narratives constitute a tool to provide hope for future in voluntariness research for kidney donation. There is no stronger way than speaking and questioning within the scope of a specific context.

In the society, change should start at the point where anxiety is realized. It is not easy to talk mutually about a specific topic. We, as human beings, stop taking action secretly when we cannot talk to each other and renounce changing things. We become passive and allow others to say us what we have to do. We give up our freedom, and begin existing like objects rather than humans. In human relations we are required to maintain our position as subjects and pay careful attention to determination of voluntariness. (Watterman et al, 2006; Wheatley, 2003)

From this point of reference, we conducted interviews through structured surveys with patients receiving hemodialysis treatment, kidney transplant recipients and voluntary donors. The transcriptions of voice records were evaluated in the context of the below specified themes.

6.1 Dialysis and life

People suffering from renal failure continue their lives thanks to dialysis. However, dialysis treatment causes many problems that influence patients' lives significantly. The effects of dialysis on life were exemplified as follows in interviews:

I *couldn't accept disease. I couldn't do housework. My children suffered a lot. (38 years)*

One of the most important fears caused by a disease is not accepting it. This fear is dependent on the progress of disease or may result from the fear of cease of life. Not being able to take care of children and to do housework is not a fear anymore and shows the patient's information about disease based on her experience. This information shows us how her life style has changed due to the disease.

I had blood pressure problems. I didn't know whether I was on earth or on sky. I couldn't leave the dialysis center. It was just a dream to go somewhere else. (35 years)

Information about patients' experiences reveal side effects of disease and how they influence their lives. Certainly every disease or treatment may have side effects. Patients are required to be informed about these effects. The narrative of this patient does not reveal whether they were informed sufficiently. The patient just mentions the side effects resulting from disease or treatment.

I was a stressful period. I couldn't make friends. I wasn't involved in any social activities. (31 years)

The patient was affected psychologically by the disease. He went into stress. Further, the disease impeded him from making friends and participating in social activities. The reasons may be as follows: a) The disease is at the center of his life, b) The patient does not want to occupy friends with his problems, c) The patients does not want his friends to know that he is sick, d) He is not sure whether his healthy friends may understand him, e) He is so preoccupied with his disease that it is not possible for him to be engaged in a social activity, etc.

I was very afraid of machines. At times I couldn't breathe. I suffered from loneliness. (18 years)

The patient has fears about technical devices. We can assume that the patient was not informed sufficiently about technical procedures. The patients can't breathe probably

because of fear. She also suffers from loneliness due to disease, probably when receiving dialysis treatment in the medical center.

It was very difficult in the beginning. All my friends were healthy. I couldn't go anywhere. I was afraid I would look small among my friends. (22 years)

Fear is one of the most important components of disease. This makes it harder to accept the disease. Patients unconsciously tend to compare themselves with healthy friends. The patient above is anxious that his friends may look down on him because of the disease.

Dialysis has been a childhood habit for me. It is just like feeling hungry or thirsty. I have spent many hours in the dialysis center. (23 years)

This patient started receiving dialysis treatment at a very early age. Dialysis is a sort of habit and as vital as water for her. The narratives of the patient show that a life without dialysis has not been possible for her. She has been required to spend a lot of time in the dialysis center to continue her life. The expression of this fact also demonstrates the life struggle of the patient.

Generally dispiritedness. Infirmity, the same bed, the same friends around. Silence and waiting for the hours to pass, just waiting. (28 years)

Continuous dialysis treatment has negative impacts on many patients. Further, the social environment may change due to the disease. Patients commonly make friends with people they meet during treatment. Patients have to wait for hours in dialysis center without talking to anyone. Receiving the same treatment and being with same patients continuously in addition to negative exchanges about disease among patients cause patients to develop negative feelings.

Kidney patients need dialysis to continue their lives. The above patient defines the effects of dialysis on daily life such as long hours of stay at the dialysis center, loneliness, infirmity, long hours spent away from home, scarcity of friends and lack of social life. In brief, dialysis treatment causes many difficulties life.

Donors' narratives about dialysis and life are as follows:

Spending at least twelve hours a week at the dialysis center, excluding travel time and preparation processes. (28 years)

The long period of time required for each dialysis session and the time required arriving to dialysis center undoubtedly cause difficulties. This donor complains that the treatment is repeated every week and takes a lot of time. Close people around patients also suffer from problems caused by these requirements.

Leading a life between short distances. There is no other choice. No traveling. Going on a holiday would be a dream. (31 years)

Dialysis patients cannot organize their lives as they wish because treatment is an ongoing process. Patients may have to spend their life between short distances as they are required to repeat the same treatment every week. There is no other alternative for patients during this obligatory process. This is such a restrictive situation that patients cannot travel or go on a holiday.

We lived with dialysis for long years. We witnessed all problems as a family. Which one shall I tell here? I feel upset whenever I remember. (54 years)

Being dependent on dialysis treatment has negative impacts on family members as well as on patients. The fact that treatment takes long years causes many troubles for patients. Remembering these problems may be painful for sufferers.

If a family member is suffering from a chronic disease, that's the disease of the whole family. You live everything together. There is always someone looking into your eyes, and you sometimes can't look into her eyes. (36 years)

Even though a disease is individual, it affects family members to such an extent that they are involved in the whole treatment process. During the tough treatment process, there are always some people feeling anxiety for the patient. Because of this emotional link between the patient and other family members, the patient may feel discomfort for upsetting the family members because of her disease.
Donors' expressions about dialysis and life are similar to patients'. Family relations may evoke common feelings among family members.

6.2 Dialysis and fears

All our fears are acquired except for the innate fear of heights and falling down. The fears at every moment of our lives emanate from our wish to control the future. Fears related with dialysis are expressed differently in two groups.
Dialysis means lack of sufficient performance in professional life for an employee. I can lose my job at any time. I think this is my greatest fear. (31 years old)
Job is an important component of human life. People may have the anxiety of losing job even when they are healthy. However, anxiety and fear of losing professional performance may increase when they suffer from a chronic disease and require a continuous treatment such as dialysis. This patient also suffers from such a fear.
They take care of me. The life of my family is disrupted. They have to live with my disease. I can see they suffer more than I do. Would they be sick of me one day? (22 years)
Patients are upset when family members always take care of them and their life is disrupted because of the disease. This patient is upset because family members also suffer from the problems caused by the disease. The patient is anxious that family members may be tired of these sufferings.
It is so frightening that my blood is removed from my veins and cleaned. I always think of the insertion of catheters. (37 years)
The cleaning of blood constitutes a great fear for the patient. She has the same fear at each session of dialysis. This means having the same fear continuously. It does not matter that the fear is produced by the patient herself.
The patients receiving dialysis treatment mention have fears of losing job, losing family support and, implicitly, losing their lives.
Are these fears replaced by others after kidney transplant? Does kidney transplant – a gift to life – evoke new fears? Yes, transplantation causes new fears among patients.
I am scared of catching an infection. I have to pay great attention to hygiene after the transplantation. I hope I can be as hygienic as required. Otherwise, everything will be in vain. (23 years)
People usually cannot enjoy the happiness of transplant due to potential complications that may emerge after the transplantation. As it is the case for this patient, they may be afraid of catching an infection. The patient is afraid that all efforts would be in vain if she catches an infection.
I want to think positively about everything. I assumed a great responsibility with this kidney my dad donated. (28 years)
A transplantee is highlighting the need to think positively. Her father gave his kdney to her. She feels not only gratitude but also responsibility and affection to her father. This may put a great burden on her life.
What if my kidney does not function? This is my greatest fear. Then I would have left my mother without a kidney. It will be a pity. (31 years)

The reason behind fear is that the kidney may not function and that the kidney received from mother would be for nothing. In such a case, both the patient and her mother would suffer. The patient is anxious for both herself and her mother.

The fears are mostly related with the rejection of kidney. Return to dialysis treatment is highly undesirable. (Nilsson et al., 2011; Kierans, 2005) Losing an object of love, worsening of bodily health and encountering humiliating situations that injure self-respect may lead to emergence and continuation of affective disorders. Thus, it is required to provide socio-psychological support to patients both suffering from chronic renal failure and undergoing a kidney transplant. (Rios-Martinez et al., 2010; Tong et al., 2011) Chronic renal failure may result in failure to carry out daily activities, weakness, disease symptoms, deterioration of physical well-being and negative effects on life quality. Causing significant problems in family and professional lives, chronic renal failure makes patients, their families and the society pay heavy costs. Donors are anxious that the dialysis patient may have a shorter life due to serious complications. Witnessing patients' life and living the problems together motivate them to donate their organ. (Pascazio et al., 2010)

6.3 Deciding for kidney donation

On one of the days of my peritoneal dialysis, dad said he would donate his kidney to me. "It is enough that you suffered," he said. That was the beginning of my new life.

As it is difficult to find a kidney donor, patients usually get donations from a family member. In the above case, the father says he would donate the kidney as he does not want his child to suffer more. The patient rejoices in this very important decision for her life.

We decided as a family. We read a lot and searched everything we heard and read. On a TV programme, a patient said that he was feeling like a newborn after the transplant. Then my elder brother announced he wanted to donate his kidney.

Families decide on organ donation after they compile positive information about donation. In the above case, the elder brother decides to donate his organ.

My father was always hoping that his kidney would resume functioning. But this did not happen. "Until when will this go on?" my mom asked and said she would donate her kidney to my father.

Mothers and fathers assume a heavy responsibility regarding organ donation. Generally mothers donate their organ. This is an approach usually expected by the mother. Behind mothers' decision lie self-dedication role and fulfillment of social expectations.

Both my elder and I work in a pharmacy. While I was receiving dialysis treatment, my brother was talking to my physician about organ transplantation. After he was informed sufficiently, he said he would donate his kidney to me. We have taken this way together. Now we count the days for the transplant.

This time donor is the elder brother who made this decision after getting adequate information. This is a good example of sharing difficulties.

I am a beloved child of my family. I know that both my parents love me very much. On the first days of my dialysis treatment, my dad said he would donate his kidney to me. He didn't even ask to my mom.

Because of their emotional links, fathers donate an organ to their children with a view to saving their lives. This patient highlights that he is a beloved family member and thus his father decided to give his kidney to him even without asking to the mom.

Family members who witness sufferings of a patient of chronic renal failure feel responsible to solve this problem as healthy individuals. It is a universal fact that parents are motivated to donate an organ for their child. It is acceptable that all family members should be

involved in the decision-making process because this is a problem affecting the whole family. The relationship between spouses is similar to parent-child interaction. Although spouses do not have biological relations, the principles for transplants from living donors should be enhanced to involve spouses (Acıduman & Arda, 2007).

6.4 Potential donors

A willing donor may not be able to give his/her organ. On the other hand, a recipient may wish to receive organ from certain people. Social life and human relations have a highly complex structure. Patients may have to receive organ from a certain donor while there are other potential donors.

My dad wanted to donate his organ. However, he couldn't when medical examination showed he had kidney stones. He was very upset because he couldn't grant a new life to his child. Then I received kidney from my mom. If only we could have found kidney from a cadaver. I wouldn't like to hurt anyone. Are living donors afraid of something?

As it is not always possible to find an organ from cadavers, the kidney is usually received from an appropriate family member. In the above case, the patient says he would have preferred receiving kidney from a cadaver rather than from his mother. He also mentions he does not know what living donors are afraid of.

The patient would have preferred receiving kidney from a cadaver because he did not want anyone to be injured. He also wonders what living donors are afraid of. Has the donor mother revealed her fears? Did the recipient say these because he saw all fears were unnecessary after the transplant?

My dad wanted to donate his kidney. He did. I also have brothers. But I would have preferred receiving kidney from my mom. Mothers have a distinct value.

Although the father is willing to donate his kidney, the patient would prefer receiving kidney from the mother. This is just because of emotional links. As mothers bring us into the world, they are the first person who is expected to help whenever we need.

I received kidney from my mom. I would have preferred receiving from my brothers because they are younger. I sometimes think if it would be better.

The patient received kidney from her mother. Maybe because of the selfishness resulting from disease, the patient wishes to have received kidney from brothers who are younger.

The position of humans is essentially unclear; and none of our acquisitions are permanent. It is normal that such important health problems lead people to think on their lives and possibilities.

My dad will donate kidney to me. My mom will take care of us when we are in the hospital. Dad looks fierce, but I know he isn't. I would like to receive kidney from my dad in any case.

Even though fathers may get tough with children as required by social expectations, they are usually ready to make a sacrifice for the well-being of their children.

Chronic diseases that bring people closer to death influence the lives of both patients and other people sharing their life. Every human action is the product of a subject. Shared experiences constitute the world of human relations. In the family, mothers are firstly expected to donate their organ due to their special relationship with other family members. Secondly, patients may expect their most beloved person to donate.

Sanner states two ways of announcing the donation: 1) immediately, 2) after making the decision. Volunteering process follows a systematic path. The first stage is being aware of the sufferings of the patient, empathizing over time, feeling affection and sometimes feeling

pity for their sufferings. This first stage is followed by approaching to organ transplantaton and regarding oneself as a potential donor. Volunteering first requires being informed about the issue and discussing it with people around. At this point, the individual tries to determine her/his responsibility. This is the point where donation decision is announced. Then it is time for medical examinations and tests. This is a process requiring patience. The final stage is to confront with nephrectomy. (Sanner, 2005)

6.5 Relations between donors-recipients and life

Do family relations change after kidney transplantation? Does the donor start following the recipient more closely? Does the recipient feel gratitude to the donor? How do donor-recipient relations continue after kidney transplantation? It is possible to ask many more questions. The replies to these questions underline various topics.

I sometimes ask her if she has ever regretted. I asked it many times. But she always says no. Now my mother is more valuable for me.

Even though donation is a voluntary act and donor is a close family member, the recipient tries to understand if she has regrets by empathizing with her.

I call him more frequently after the donation. I must be respectful to him as he gave me a new life.

The gratefulness to the donor may continue throughout the life.

I always owe a debt of gratitude to him. What if I were in his place? What he did was not a simple thing.

Empathizing with the donor, the patient tries to put himself in the donor's place and thinks that donation is not a simple decision.

I recovered thanks to him. I don't need dialysis anymore. Would every brother do the same thing? I love him very much.

In addition to the feeling of gratitude, the patient develops emotional links with the donor because he saved him from dialysis and recurring problems.

These expressions show that the patient is indebted to the donor and also tries to find out if he has any anxieties about the donation decision.

The following are the narratives of patients still receiving dialysis treatment:

I sometimes jokingly say to my mother that she doesn't have to give her kidney. But I can see that she is worried for me more than I am. Are we closer to each other now?

A patient may develop a closer and more binding relationship with the individual who will bestow a new life on her?

We have always been two parts of a whole. We are happy to be together. We will continue to be happy after the transplant.

Wholeness and happiness are the same before and after the transplant if bonds of love are strong.

Patients with strong family bonds mentioned that they could overcome problems with family support and solidarity. Kierans also emphasizes that family bonds are effective on the solution of problems. (Kierans, 2005)

Given the reality that the donor is losing something and the recipient is gaining something, there is need to inform donors completely about the whole process and not to put any pressure on the donor. The medical team is required to determine the limit of paternalistic approach that impedes altruistic attitude of a donor. (Banasik, 2006)

6.6 Donors in the eyes of recipients

Do donors have distinctive characteristics? Which characteristics make them outstanding?

My mom has always been a courageous woman. She defends herself to the end when she is right. No one can hinder her when she is willing to do something.

Courage, as a significant characteristic, may motivate people to organ donation. Determination is another significant parameter for donation, which is also expressed by this recipient.

She has always been good to me. Her most significant characteristic is that she is always helpful.

Helpfulness is another significant feature of donors.

My mom is self-devoted. She is patient. I know she loves her children more than anything.

Self-devotion and patience mean enduring something. Mothers show this through donating their organ.

She is very patient. She never hurts anyone. There have been many days when she was upset. You know heaven lies under the feet of mothers.

Here the patients links social expectations fostered by religious connotations to the motherhood role. Islam has a great concern and respect for human life and promotes the preservation and prolongation of life. In this respect, organ donation has became acceptable and practice in many Muslim countries (Goldmaki et al, 2005)

She is determined and prideful. She always takes care of her health. She has given me blood many times. She has made me live for years. She is humorous, joyous. She is sometimes furious with me, but always wants my well-being.

A donor who is protective of her health is expected to care for the health of her family member.

The life of each person has a unique, inevitable, obvious, unquestionable reality, which Gasset defines as "fundamental reality". We feel these realities mainly in vital points of our life. Being a donor is one of these points. Organ donation is an attitude far away from selfishness. In the flow of life there is always a way of escape. However, donors refuse to take this way and offer courage, love and help to another person. Organ donation (from a living donor) is related with the idea of doing favor to a beloved person. The majority of the society support organ donors. There is a tendency to encourage voluntariness for organ and tissue transplantation. At this point, the dominant view is that "giving" is a more honorable act than "receiving".

6.7 How do you understand that a person is voluntary?

Asking this question, we expect to catch some clues showing that a person is voluntary.

We can understand from their acts. She cried whenever she looked at me. Physicians should listen very carefully whatever donors say. They don't look at the ground when they are announcing the donation decision.

Physicians are required to listen carefully to determined volunteers because they are aware of the consequences of their decision.

If they go to hospital for examination and tests before we ask them to do so, they have already volunteered for donation.

This respondent regards taking action as an indicator of voluntariness. Thus, going to the hospital for medical examination on their own will shows that the individual is voluntary.

There is need for sincerity.

Sincerity is one of the important preconditions of voluntariness for this patient.

They also see what is going on. When I started receiving dialysis treatment, my dad also came to the hospital for tests. After getting the test results, he said he wanted to donate his kidney. I know he had been anxious for days about what to do if results were negative.

Not only patients are anxious, but also are their family members. Patients personally observe this.

Donors say the following about determination of voluntariness.

A person who escapes or fears can't be voluntary.

One should be able to insist on being voluntary. The first tests did not provide positive results. I insisted on the repetition of tests. This allowed me to donate my kidney. I am happy.

Being determined and insisting are very important. These two factors push donors to take action.

I didn't even ask to my wife. I decided on my own.

Despite family relations, decisions should be made individually and without the influence of anyone else.

My children could also have donated but I discouraged them.

The donor insists on applying his own decision.

Looking into eyes of the patients during the conversation is generally regarded as the most important sign of voluntariness. Not asking the idea of spouse or children, insisting, taking a step ahead are defined as indicators of a voluntary act.

7. Conclusion

In our study; all the respondents were familiar with kidney transplantation and donation before it became on issue for their relative.

The decision was mainly based on emotion. It is important for the health care professionals involved in living-kidney donation to comprehend how potential kidney donors experience this situation mentioned some papers (Linnerling et al, 2003, Al-Khader, 2005)by showing and interest in motives to donate or not to donate it is possible to support the individual decisions.

Motivation is complex because of the subjective feelings. According to our study Altruism and moral duty were often seen. None of our donors mentioned a sense of guilt as a reason to donate but a small number of our donors were lack of motivation Turkey is a secularized country where altruism is likely to be expressed as a nonreligious motive by most people.

Wishing to communicate with other people and feeling concern for another person are ways of getting beyond personal boundaries. Doing a favor for another person is good for human soul. Choosing a nice gift for a beloved person and seeing her/his happiness is also a gift for the person offering it. This happiness emanating from the act of giving and doing a favor goes back to origins of human beings. Where do helpfulness and joy of doing favor come from? Does this mean that human beings are good by nature? (Precht, 2010) Or does it have different meanings? It is possible to multiply the questions and also the replies. Organ donation, in its most widespread definition "offering a new life" is an invaluable act.

Some scholars give equal weight to organ donation and self-sacrifice whereas some others define self-sacrifice as the reason behind organ donation. The reason for organ donation is generally to do a favor for another person. In society, such an action is usually associated with benevolence. Willingness to donate an organ may also be defined as a motivation for a self-devotion act. In a case of self-sacrifice, the individual aims to provide benefit for another person rather than for herself/himself. In this respect, kidney recipients feel indebted to donors. They mention that they do not want to cause any harm on donors, and that both recipient and donor are disappointed in case of the rejection of kidney. (Nilsson et al., 2011; Waterman et al., 2006)

The recipient may be grateful and indebted to the donor by accepting her/his kidney. Donors deserve to feel good with the credits of their generosity. Thus, donors deserve to

congratulate themselves by giving something. The donor gains, and the recipient gives. As stated by Derrida, we should not be grateful for a gift. (Vernon, 2010)
In every stage of kidney transplant, the psychological life of both donor and recipient should be observed and any complaints should be taken into consideration. (Buldukoğlu et al., 2005).
While carrying out long-term controls on patients after kidney transplant, medical team is also required to evaluate and follow holistically the life quality of donors. We do not know clearly what happens to donors after transplant. In this respect, it is required to set a national data trace bank in order to follow and support donors. This initiative would be an important proof of the fact that voluntariness is supported conceptually and volunteers are supported holistically.
Strong family relations make it difficult for family members to donate their organ as living donors. Kidney donation from a family member is generally regarded as an ordinary act (Zeiler et al., 2010). Friendship, partnership and family create an environment where we feel joyful and safe. Living in such an environment increases our happiness experiences. Thinking future would steal from present moments. Life flows while we are making plans. It is required to make an all-round evaluation of everyone involved in organ transplant. Organ donation is closely linked with education level of the society. A multidisciplinary approach will protect voluntariness of donors and make recipients stronger. (Jowsey & Schneekloth, 2008)
"Time is a remedy for all pains" This statement may be hurtful for sufferers but it is true to a certain extent. As time passes and people endeavor to be saved from their pains, a light would appear in the darkness of life. The emergence of a kidney donor and the start of procedures would show, as stated by A. Camus, that in the midst of winter, there is an invincible summer.
Kidney recipient reported that might not pursue living donation because they felt guilty and in debted to the donor, did not want to harm or inconvenience the donor, did not want to accept a kidney that a family number might need later, and did not want to disappointed the donor of the kidney failed. Recipients were generally unaware that donors could personally benefit from donating and would rather wait for donor volunteer than ask one directly both donors and recipients though that training on how to make the donation request and education about living donors' motivations for donation and transplant experience could help more renal patients pursue living donation.
The small number of empirical studies of informed consent among living donors may be a function of the elusive nature of ideal informed consent in a population that accepts medical risks for the benefit of others. (Valapour, 2008) One study stands out as the only attempt to develop a score to asses a potential donor's willingness to donate. To identify donors who have difficulty admitting to being unwilling to donate because of societal expectations, Al-Khader developed a measure of "Willingness to donate". (Al-khader, 2005). Sample concept such as moral responsibility, desire to help, increase in self-respect of the donor, pressure from family and logic should be taken into consideration diligently in order to detail the voluntariness and choise of donor. Empirical work in these area is encouraged to inform the ethical analysis of the new living donor protocols.

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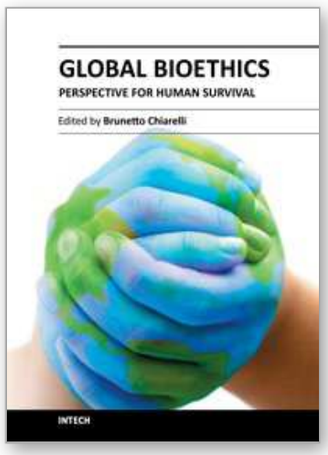
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Global Bioethics - Perspective for Human Survival

Edited by Prof. Brunetto Chiarelli

ISBN 978-953-307-537-2
Hard cover, 152 pages
Publisher InTech
Published online 04, November, 2011
Published in print edition November, 2011

Two new factor have been added to the ideological change in the second half of the past century: the “ecological impact” of humankind on the environment due to the population increase; and the “ innovative impact of science, first with atomic physics, which introduced the scission of the fundamental unit of matter, the atom, and then witch molecular biology, which led to the decoding of genetic information and intervention of biological engineering that annihilate our concepts of individual and species as fundamental units in biology. This stage of fundamental rethinking is however overshadowed by the threat of ecological disaster and catastrophic population increase, which not only impose limits to development, but undermine the very survival of Humankind. The future survival our species in fact depends on the interaction between its reproductive characteristics and the productivity of the territory, which, even if increased by the intellectual capability of the human brain, has intrinsically limits. The adaptive choices (which are also biotechnological and biomedical) of the interaction between human population and the natural ambience is the conceptual basis of the new discipline “Global Bioethics”.

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Omur Elcioglu and Seyyare Duman (2011). Concept of the Voluntariness in Kidney Transplantation from the Position of Donors and Recipients, Global Bioethics - Perspective for Human Survival, Prof. Brunetto Chiarelli (Ed.), ISBN: 978-953-307-537-2, InTech, Available from: http://www.intechopen.com/books/global-bioethics-perspective-for-human-survival/concept-of-the-voluntariness-in-kidney-transplantation-from-the-position-of-donors-and-recipients

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