

# Chapter 12

## On Family Informed Consent in the Legislation of Organ Donation in China

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### 12.1 Introduction

Individual consent is commonly adopted in organ donation legislation worldwide. However, this kind of legislation may cause practice to deviate from law and disparage its authority. Consequently, we have designed an organ donation informed consent system with family informed consent as its basis, whose rationality is not confined to Confucian society. In order to prove its rationality, we need to determine the foundation of the right supporting family-directed organ donation. In addition, such a right needs to be analyzed by reconstructionist Confucian bioethics.

### 12.2 The Status of the Organ Donation Consent System and the Conflict Between Law and Practice

The first successful organ transplant in a human being was a kidney transplant between identical twins in Boston, Massachusetts in 1954. Subsequently, transplant-related technologies developed rapidly and many more transplants were performed throughout the world. Nowadays, the ability to transplant organs successfully is almost taken for granted, and this kind of technology has saved many lives.

Globally, organ donation legislation requires express informed consent of the donor for any living organ donation. For cadaveric organ donation, however, there is a distinction between express consent and presumed consent. Express consent is more in line with the ethical nature of people's autonomy and is divided into strong and weak systems. In the strong system, an individual's willingness to donate during his lifetime can legitimate harvesting his organs, while in the weak system, the

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187

refusal of one's family can override the sentiments expressed by the deceased prior to death.

Few countries have adopted weak express consent laws like Japan and Lebanon have. However, in countries with strong express consent laws, such as China, doctors still tend to solicit opinions from the family, even if the deceased expressed a wish to donate prior to death. Organ harvesting cannot be implemented if the family members oppose it. In other words, practice conflicts with the law in most countries with strong express consent systems; in effect they are actually practicing in line with a weak express consent system.

As for organ donation systems stipulated by law, the most effective is a registration system. Throughout the world, registration systems are different: in countries like Austria, people can opt in and opt out of organ donation; while in some other countries, for instance, the United Kingdom, only those who opt in are recorded, and in Portugal, only those who opt out are recorded.

China began transplanting organs in the 1960s with the practice developing rapidly. Currently, the technological capabilities and success rates related to organ donation in China have caught up to those in developed countries. At present, the major national law regulating organ donation in China is the "Human Organ Transplant Ordinance," promulgated by the State Council in 2007. According to this law, adult organ donation, whether cadaveric or living, only requires consent from the organ donor.

In March 2010, a pilot project on human organ donation was jointly launched by the Red Cross Society of China and the Ministry of Health in 11 provinces and cities throughout China. In those 11 areas, including Tianjin, Liaoning and Shanghai, recruitment, procurement, and allocation practices were fully explored. Any citizen who wished to be a cadaveric organ donor could register as a volunteer donor in the subordinate organ donation office of the Provincial Red Cross Society. One year later, volunteer donors were recruited nationwide. In 2007, the first batch of organ donation cards (for organ and cornea donation) were designed, which included the signature, contact information, names of immediate family members and emergency contact information of the applicant. In the event of accidental death, this card serves as evidence of the person's expressed willingness to serve as an organ donor. This demonstrates significant progress regarding organ donation in China.

Currently, the legal setup for organ donation has not yet been perfected in China. The National People's Congress and its standing committee's legislation, "Organ Transplant Law," is imminent.

### **12.3 Constructing a Family-Based Informed Consent System**

In order to avoid the above-mentioned conflict between law and practice, which has occurred in the Chinese organ donation system, the legislation of the "Chinese Organ Transplant Law" should adopt a family-based informed consent system. Given

that families worldwide can be considered ethical entities linked by the tie of love, the rationality of family-based informed consent can be extended beyond China.

### ***12.3.1 Conceptual Analysis***

The concept of “family” invoked in family-based informed consent for organ donation refers to the “family” constituted by the donor and their next of kin only (namely their spouse, parents and children). As the love between the next of kin is the most natural and real, the fundamental basis of the rationality of family-based informed consent is provided.

So-called “family-based informed consent” refers to the joint decision made by the family on a voluntary basis to embody the spirit of the family ethic and to maximize the family’s interests. Obviously, to realize the family ethic and its benefit maximization, the decision must be based on information communication and mutual agreement. As a joint decision reached by the family members, it is a unified wish of the patient and his/her family where the possible divergence of wishes between them can be healed over by full discussion and mutual concession, once family-based consent is given. If a unified decision cannot be made by the family, it simply means that the family has been split.

### ***12.3.2 The Design of a Family-Based Consent System and its Advantages***

The proposal is to convert individual informed consent into a family-based (common) model where the express consent of the individual citizen during his/her lifetime is a decision jointly made with his/her family and reflected on a consent document signed by the donor and a representative of his/her family. This would allow doctors to remove the donor’s organs without having to seek out informed consent from his/her family after the death.

In such a family-based system, the citizen’s right to dispose of one’s corpse and the family’s right to ownership of the body (organs) can both be respected. In addition, a family-based model would also shorten the time between death and organ harvesting, which helps ensure the successful transplantation of the organ(s). Further, doctors can avoid the embarrassment of having to ask the family if the organs can be harvested and one does not risk harvesting organs without the family’s consent. This contributes to harmony between the doctors and patients. Lastly, derogation of law’s authority is avoided because the doctor is not forced to act against the letter of the law.

It should be noted that in the case where a citizen refuses to register for donation during his/her lifetime, family-based informed consent should not be sought and the individual’s refusal should be taken as final. At the same time, if one has not provided express consent or refusal before death, the family is entitled to dispose of the

organs as they see fit as they belong to the family. As such, the family can choose to donate the organs by having a representative sign an informed consent letter.

In the case of live organ donation, family-based consent is also necessary and an informed consent letter should also be signed jointly by the donor and his/her family representative.

## **12.4 Justification of Family-Based Informed Consent: The Family Affairs Component of Health and Family Ownership of Organs**

The legal foundation of family-based informed consent for organ donation lies in the family component of health and family ownership of organs.

First, further definition of the concept of “family” is necessary. The so-called “family” generally refers only to a family constituted by the next of kin (only including oneself, one’s spouse, one’s parents and one’s children). In such a family, the parents’ kindness to their children, the children’s esteem towards the parents, and the affection between the parents are derived from the most natural, tenacious and enthusiastic force of human nature, constituting the strong and abiding cohesion of the family. In addition, between men and women, marriage is an ethical relationship with a legal protection that eliminates some uncertainties.

### ***12.4.1 The Nature of the Family (A Unified Ethical Entity)***

#### **12.4.1.1 Love**

Undoubtedly, love is the ethical relationship and prescriptive nature of a family. “Love is the desire for union of the separated” (Tillich 1995, p. 38). The “love” among family members means to realize the unity between others and oneself instead of isolating oneself by considering only oneself. On the contrary, only through abandoning one’s independent existence and recognizing oneself as the unity of oneself and another, as well as the other and oneself, can we obtain self-consciousness. The love within families, for example, the father loving his son or the wife loving her husband, is the most natural love. The first component of love is that one does not want to be isolated and lonely, otherwise one will be incomplete. The second component is that one finds oneself in another person, namely by obtaining recognition from others and vice versa. As such, love is a most inconceivable contradiction, which by no means can be solved by reason. Love creates contradiction on one hand and resolves contradiction on the other. As the solution of contradiction, love is the unity of ethics (Hegel 2008, pp. 162–163).

### **12.4.1.2 From “An Independent Person” to “A Member of the Family’s Ethical Union”**

The essence of marriage is that two parties want to voluntarily form “a person” and both are willing to abandon their own natural and individual personalities for that unity. “This union is a self-restriction, but in fact it is their liberation, because in it they attain their substantial self-consciousness” (Hegel 2008, p. 164).

The prescriptive nature of the family is love, a feeling that one is unified with others. Therefore, it’s just because people are aware of this unity that they are no longer an independent person but become a member of the family as an ethical entity. In other words, the independent personality of the individual has already been dispelled in a family and has merged into the direct and natural ethical entity of a family in accordance with the rules of love, as a result of which, affection, kindness, esteem, trust, and the commonality of the individual is experienced. That is to say, the individual and the family (the ethical entity) are directly united as one “person.” Here, no individual personality exists because the family unity is the ethical entity.

In this family unity, freedom is not the ability to do whatever one desires or wants, otherwise everyone will lose their freedom because the desires and wants of family members frequently contradict each other. Acting according to the ethical rule of love enables family members to actualize their real freedom within the family, because their desires and wants are mediated and regulated by the rule so that their decisions and actions will not conflict with each other. The ethical rule of love requires everyone to observe communitarianly-established moral virtues and norms to treat one’s family members with love. Just as the law exists for realizing freedoms (such as a freedom from being robbed) in the state, the ethical rule of love can be understood to function in the ethical union of a family for realizing freedom within the family. Real freedom exists in ethical entities only. That is to say, only when the individual abandons his/her natural personality to live in accordance with love within the ethical entity of a family can he/she obtain true freedom and ontological self-consciousness in the family. The right to live within the ethical union of a family is the basic right one enjoys in the family. Only when a family is disintegrated can the individual break away from the family and become a person with an independent personality existing outside the family again.

### **12.4.2 *The Service Responsibility of Family Members Towards the Family—The Family Affairs Attribute of “Individual Health”***

In the ethical union of a family one is no longer an independent person but a member of the family, a unified ethical entity. Each member of the family must be dedicated to the ethical unity of family. Therefore, physical health and longevity is not an individual matter, but is a common matter for the good of the family unity, that is, personal health is a family matter.

### **12.4.3 From “the Independent Individual’s Right Over One’s Organs” to “the Common Family Right over the Organs of its Members”**

#### **12.4.3.1 The Independent Individual’s Right Over One’s Organs**

A human being is a subject aware of its subjectivity. As a person, I know I’m free inside myself. In order to be an existence in accord with the idea of freedom (the concept of freedom and its actualization), human beings must be provided with an external field of freedom (Hegel 2008, p. 56). While personality is the thing a human being should have qua human being, it should not stay in the abstract ego but be combined with external things to recognize the ego. That is to carry through the free will in the external things, making them a part of oneself. Therefore, possession is the natural existence of personality as well as freedom. To respect one’s possession is to respect his/her personality. In other words, human beings are entitled to embody their will in external things to make them “mine.” “I as a free will am an object to myself in what I possess and thereby also for the first time am an actual will, and this is the aspect which constitutes the determination of property, the true and rightful factor in possession” (Hegel 2008, p. 61).

At the same time, as I’m living in the organism of a body, my body is my external existence. But as a person, I own my life and body as I own other things, as long as my will is inside it. Only when I am willing do I have limbs and life. “I possess the members of my body, my life, only so long as I will to possess them. An animal cannot maim or destroy itself, but a human being can” (Hegel 2008, p. 62). The organs removed from my body are also the natural existence of my personality and freedom and therefore people possess their organs. Just as Audi said, we can assume that the body as a whole is not our property, but still insist that part of the body is our property as long as we do not insist that we have all the parts of the body, as the assumption of possessing all parts of a thing would imply our possession of it (1996, pp. 141–143). Indeed, the Law Reform Commission of the United States found that, if people did not have ownership of the component parts of their own bodies, it would be more difficult for us explain why we can donate organs (Price 2002, p. 237).

#### **12.4.3.2 The Common Family Right Over the Organs of Its Members**

As we discussed previously, a person who has an independent personality and who does not belong to an ethical entity, enjoys the ownership of his/her own body. Will this remain the case if two such persons form a family? In the unified ethical entity of a family, the results are completely different. The organs of the individuals who have lost their independent personalities gain a common family attribute.

The rule that a family is an ethical entity (“a person”) applies at all times in all countries due to its direct and natural nature. As a personality, family has its external reality in possessions, namely family properties. Except for possessions,

as a universal and persistent personality, a family also can establish a stable and lasting industry, namely a resource. Here, the selfish needs and desires of the individual are converted into a kind of caring and gain for the family community (Hegel 2008, p. 171). As family property is a common possession, not any member of the family has special possession but only the co-ownership of common possessions. In this regard, the family members' ownership of their individual organs is also converted into a co-ownership by the family unity of all members' organs. Consequently, the individual has lost one's right to dispose of one's organs and, therefore, it is reasonable that family-based informed consent is necessary for organ donation.

To summarize, family-based informed consent for organ donation is grounded in the family affairs component of "health" and family ownership of organs.

## **12.5 Family-Based Informed Consent for Organ Donation from the Perspective of Reconstructionist Confucian Bioethics**

Laws and regulations are only suitable for the society and culture from which they originate. If one considers the reconstructionist Confucian bioethics of Ruiping Fan, there is powerful support for a family-based informed consent model mentioned above. Furthermore, reconstructionist Confucian bioethicists also share the same understanding of the nature of family, that is, the unified ethical entity.

### ***12.5.1 Reconstructionist Confucian Bioethics***

The reconstructionist Confucian bioethics established by Ruiping Fan is a construction of contemporary Confucianism that faces social reality while mastering the core of Confucianism. Through analysis and comparison Fan properly interprets Confucianism in such a way that his theory provides direct and concrete Confucian resources for reforming modern policies and institutions. Meanwhile, "the core of the reconstructionist Confucian bioethics is its fundamental nature and its most important promise to stick to principles and solve problems in real life." (Fan 2010, p. 2). As such, the Confucian proposal for feasible and spiritually suitable organ donation regulations in China has sought its foundations in reconstructionist Confucian bioethics.

### ***12.5.2 Family-Based Informed Consent for Organ Donation and Confucian Core Values***

Reconstructionist Confucian bioethics is based on close family ties (the love between family members), one of the core values of Confucianism, and is in line with

the essential nature of the family's unified ethical entity. Similarly, since family values and the ethical entity of the family in reconstructionist Confucian bioethics share the same nature, they can provide people with guidance for living correctly. Therefore, "the truth that contemporary Western bioethics fails to comprehend," (Fan 2010, p. 9) is reflected in reconstructionist Confucian bioethics.

### 12.5.2.1 Family-Based Informed Consent for Organ Donation from the Perspective of Family Ties in Confucian Society

One of the core Confucian values is the value of the family. In Confucianism, the core of the family is established through family ties, the source of kindheartedness. In particular, the feature of Confucian kindheartedness is being considerate to those close to you and extending that consideration to others. According to Mencius, one should "revere the elders in one's own family and extend this reverence to all elders; care for the children in one's own family and extend that caring to all children" (*Mencius 1.7*; Chinese Teachers Union Institute of Education Sciences 2005, p. 3). This is the principle of Confucianism, which highlights filial piety and fraternal duty as the basis of kindheartedness. Youruo, disciple of Confucius, said, "The Superior Man concerns himself with the fundamentals. Once the fundamentals are established, the proper way (*tao*) appears. Are not Filial piety and fraternal submission the root of all benevolent actions?" (Confucius 2002, *The Analects 1.2*). According to Mencius, "Every child loves their family members; when they grow up, they show respect for their elderly brothers. Family ties (the love between family members) means kindheartedness; respect for the elderly means obligation. Selflessness helps to reach afar." (*Mencius 13.15*; Xia 2002, p. 417). Therefore, kindheartedness is an extension of family ties while obligation is an extension of respect for the elderly. Furthermore, Confucianism focuses on kindheartedness as the supreme ethic and highlights filial piety and fraternal duty as its basis. Under the filial piety and fraternal duty of Confucianism, the most basic moral ethic is to love your family (Zhang 2009, pp. 80–82).

The family tie is the most natural and stable ethical relation. The components of family ties are to abandon one's independence and to realize the unity between one and one's family and vice versa. For example, the story of cutting off one's flesh to show filial obedience to one's mother in the twenty-four filial exemplars clearly shows the unity between an individual and one's family and the unity within one's family. Through family ties the family becomes a unified ethical entity, "a person," and all assets owned are shared. In this way, the organs of each family member are shared by the family. Consequently, in accord with family ties, an individual will not view their health as their own, but the common affair of the family, as the purpose of health is to add happiness to the family. Naturally, because organ donation harms one's health, family-based informed consent for organ donation is required.

In summary, family-based informed consent rests on ancient Confucian ethical ideas, that is, the theory of "kindheartedness." Confucianism focuses on kindness as the supreme principle, and filial piety and fraternal duty as its basic ethics.



Family-based informed consent for organ donation is in accord with the complete moral essence of Confucianism as filial piety and fraternal duty.

### **12.5.2.2 Family-Based Informed Consent for Organ Donation from the Perspective of Family Values**

Through family ties, or the love between family members, Confucianism has always attached importance to the family, which does not usually view one's life and living as an individual matter, but rather as a link of the family and the life of the family. Therefore, life activities are not only for individual enjoyment, and may not even be enjoyable for the individual, but are rather to increase the happiness of the family and to strengthen the connection between individual's life and that of the family's. As such, Confucianism supports the traditional idea that instructs one to "cultivate the moral self, regulate the family, maintain the state rightly and make all peaceful" (*Book of Rites-Great Learning*). That is, the life of an individual does not only belong to the individual, but to one's family or even one's country.

Such active devotion to and involvement with one's family makes the individual's happiness largely dependent on the family's happiness. Therefore, individual health is not so much a concern of the individual, but a family affair. Additionally, personal belongings do not exist in the traditional Confucian family, only common assets of the family exist. Hidden individual assets (casually called personal funds) are forbidden and, of course, an individual does not have the right to dispose of family assets.

The reconstructionist Confucian bioethics based on the Confucian family values outlined above requires all potential patients and organ donors to be understood as part of a family. Outside of the family it is hard to appropriately understand the individual (Fan 2010, p. 9) because the donor is closely involved with the family and other family members. In Confucianism, the unified family entity makes the concepts of "freedom" and "equality" unnecessary. The individual, whose health and longevity is not an individual matter anymore, has to be dedicated to the ethical entity of the family and better serve the family and the unified family entity. Consequently, as material property due to separation with the body, organs are family property, a common asset, and the individual, therefore, does not have the right to dispose of one's organ and the whole family must decide together.

### **12.5.2.3 Family-Based Informed Consent for Organ Donation from the Perspective of "Concordance"**

Another core Confucian value supported by reconstructionist Confucian bioethics is "concordance." The word "concordance" first appeared in oracle bone inscriptions and inscriptions on ancient bronze objects. "Concordance corresponds to two characters in Chinese, the original meaning of the first one means harmony while the original meaning of the second refers to the upper and lower lips of people's mouth, meaning coordination" (Wu 2005, p. 51).

In China, the traditional idea of concordance is profound, long-standing and well established, consisting of two components: general comprehension and philosophy. General comprehension consists of the relationship between humans and nature, humans and humans, and humans with the nation and society, within which the concordance of humans themselves and that between humans and spirits resides. As for concordance at the philosophical level, Professor Zhang Li-wen defines it as meaning that “the conflicts and harmony of various elements among nature, society, interpersonal relationships, souls and cultures are the aggregation of new structures, new things and new lives formed by quality elements during the conflicts and harmony” (Zhang 1997, p. 51). This indicates that every being consists of conflicts and harmony. Conflicts and harmony are everywhere from astronomical objects to ants and blades of grass. Every phenomenon in the universe has concordance while every concept embodies concordance and every conflict and harmony is the existence of concordance (Yan 1999, pp. 45–47).

“Concordance” is also called “harmony,” meaning the unity in a variety of things with different natures, rather than the “collision-free situation” (Zhang 1999, pp. 10–14). “Harmony” refers to the harmonious existence of elements with different natures while “combination” refers to the mastery and comprehension of things with different natures (Cheng 1998, pp. 29–35). The concept of concordance, which includes harmony, peace, neutralization, fusion, association and cooperation, focuses on mastering the relationship among things in a comprehensive manner. Concordance does not mean removing the differences among things, rather, the premise of its existence is the common difference of things. It tries to reach an overall balanced, harmonious and cooperative state through overcoming and settling conflicts. In short, the concept of concordance is a comprehensive idea focused on harmony, which Chinese traditional cultures deem to be the best state (Li and Liu 2005, pp. 38–40). In addition, concordance is also the best state for the relationship of the family.

In Confucianism the concept of concordance emphasizes that the relationship between people should focus on harmony and pursue unity and coordination within its ranks. Confucius took “harmony” to be a worldly ideal. He states, “harmony is the most precious in practicing etiquette (rituals); the principles of former kings from these were the most ideal, where both the great and small matters depend upon it” (Confucius 2002, *The Analects* 1.12). He also said that the middle way is the basis of the world while harmony is its highest standard (*Doctrine of Mean*). He regarded harmony as the standard of “achievement” and “a man of noble character” would reinforce the extreme importance of harmonious interpersonal relationships.

A Confucian family is the unity formed by combining different individuals who gave up their individual personalities. The unified family entity itself reflects the “combination” of different elements. Family-based informed consent for organ donation reflects the will of the person concerned and the harmonious unity of that person’s family, which displays the “harmony” of the harmonious coexistence of different elements. The pursuit of harmony is one of the traditional features of Chinese culture. However, for Confucians harmony is the supreme ideal. Therefore, family-based informed consent corresponds to the core value of Confucian “concordance” insofar as it represents “unity” and “harmony”.

Concordance is one of the core values espoused by reconstructionist Confucian bioethics. Consequently, it is never possible for reconstructionist Confucian bioethics to support the autonomous decision of an individual to become an organ donor because it may harm the harmony of the family. As such, only when the decision to become an organ donor is made within the family can it be rationalized by reconstructionist Confucian bioethics.

## **12.6 Family-Based Informed Consent for Organ Donation from the Perspective of Etiquette (Ritual)**

It is without question that ancient Chinese ethics held the theory of “kindheartedness” at its core. Confucius focused on kindness as the supreme principle. However, if “self-denial and a return to propriety means kindness,” following the rituals would be the major expression of kindness. In particular, kindness can only be realized in certain interpersonal relationships through loving conduct (Fan 2002, pp. 346–372).

“Etiquette” refers to the family and social rituals commonly practiced in the Confucian community (Fan 2012) “As for Confucianism, the cultivation of virtues, especially the cultivation of virtues through its power, is realized through etiquette (ritual). We should understand that kindheartedness with virtues comes from our following etiquette (ritual). Sound etiquette (ritual) transforms people into real human beings” (Fan 2010, p. 9). Family-based informed consent for organ donation is no doubt the proper behavioral system and norm for practicing the core values of Confucianism.

It should be noted that the reason why the family-based informed consent system is thought of as confirming the family’s consent is because it merely reflects the normal state of the family. The point of creating such a system is so that the law defines the normal state and makes it lawful. Consequently, the embarrassment of not following existing laws and the damage done to the unified family entity by unethical laws are avoided.

It is important to note that Fan’s reconstructionist Confucian bioethics takes the core value of Confucianism as primary while etiquette is that which needs to be reconsidered to adjust to the current situation. When the world changes, outdated etiquette that fails to adjust to the new practical environment has to be replaced by new etiquette or it will dispel or even distort the core value of Confucianism. “A complete picture of Confucian virtue ethics embodies a sophisticated reflective equilibrium between ritual practices and general principles ” (Fan 2012, p. 8).

For example, in Confucianism, the edict stating that the “body is given by one’s parents; doing no damage to it is fundamental to filial piety” (Confucius 2007, *Classic of Filial Piety 1*) is one reason to prevent the Chinese people from donating organs. It also distorts the broader spirit of love embodied by “kindness” in Confucianism. The above edict is an old etiquette adapted for a time period when people could not imagine organ transplantation technologies. In the contemporary world, one should not only define the “body as given by the parents” in a broader manner

(perhaps so that it represents the whole of individual character), but also establish a new etiquette based on it. We can use “body as given by the parents” as the rationale for family-based informed consent. Given that one’s whole being comes from one’s parents one does not possess an independent individual personality in the family, therefore, I am a unity with my parents and other family members. My happiness is their happiness while their sadness is my sadness. I can devote my whole being to them and they will do the same. Because the “body is given by the parents,” the family tie (the love between family members) among family members is the inheritance and association of flesh and blood. As a result, one’s choice to become an organ donor should not be one’s own, but should require the informed consent of the family. Upon getting the “approval” of one’s family, one has preserved filial piety for one’s parents and has discharged one’s responsibility to the unified family entity.

Consequently, Confucian family values make family-based informed consent easy to achieve. From their different perspectives, every family member makes the harmony and continuous development of the family their responsibility, making them willing to participate in family-based informed consent. At the same time, the maximal individual interest of family members and the maximal family interest are easier to coordinate if family-based informed consent is present. That is, family members are more willing to respect family-based informed consent even if it goes against one’s individual interests.

In summary, family-based informed consent for organ donation is an implication of the family as a unified ethical entity. In addition, family-based informed consent is never only applied to Confucian families, but to any family with “home” and “love”.

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