

# Chapter 5

## The Ideal of Autonomy and Its Misuse

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### 5.1 Introduction

Respecting autonomy has been an important principle for medical ethics since Beauchamp and Childress wrote their famous monograph, *Principles of Biomedical Ethics*. The principle of autonomy often seems to dominate the solutions given for bioethical issues in both Eastern and Western societies. Recently a number of Korean scholars have criticized the principle.

New approaches to autonomy have been proposed in Korea as well as the West. Some suggest a notion of “relational autonomy” which criticizes the individualist perspective. Eastern scholars frequently emphasize the value of family rather than the individual. For example, John Hardwig (1997), an American philosopher, expresses the idea that one may have a moral obligation to die for one’s family member in his article, “Is There a Duty to Die?” In his article, “What About the Family,” Hardwig (1990) also argues that the family should make the treatment decision when the lives of family members would be dramatically affected by the treatment decision.

While I appreciate these new approaches to autonomy and the moral complexity of human relationships they capture, I wonder if these approaches will somehow destroy or devalue autonomy as a moral value, which has played an important role in our moral foundations. Historically, autonomy has been emphasized with the development of an individualistic society. However, at our modern moral foundations, the values of autonomy and freewill cannot be devalued. What then is the proper analysis of autonomy as a moral value?

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In this paper I will distinguish the ideal of autonomy from its practical implementation. Further, I will clarify which of these has been the target of recent criticisms. I will then argue that autonomy is an important moral value, even in Asian cultures, and what we need to be weary of are misinterpretations and misuses of autonomy.

## 5.2 The Ideal of Autonomy

The ideal of autonomy reflects modern enlightenment thinking and its understanding of human beings. The ideology of autonomy presupposes a rational human being capable of reasoning to a conclusion if he/she is given relevant and sufficient information.

Here the notion of a rational human being is not only integral for the ideology of autonomy, but also for constructing modern societies, that is, human-centered societies divorced from the God-centered world. In the secular world, a rational human being is a member of democratic society and is a desirable person for modern societies.

The structure of modern society reflects the ideal of a rational human being. Political decision making usually follows majority rule. This rule cannot be adopted if we do not consider all persons to be equally rational. Education also sets up the ideal of a rational person. When we consider this ideal, we come to recognize the significance of critical thinking in our societies, especially the democratic ones. Economics also presupposes that consumers are rational. Even though many individuals are not in fact rational, our political, educational and economic systems presuppose that they are or at least that they should be. In this respect, rationality is the ideal we have to pursue.

Therefore, the self-determination of a rational human being is to be respected because he/she is the final authority for deciding what's in his/her best interest if he/she is competent. This idea is easily observable in the discourse of bioethics.

Beauchamp and Childress explain autonomy as follows: "We analyze autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action" (Beauchamp and Childress 2009, p. 101). The second condition, "with understanding" is related to the notion of "informed consent," which is required in biomedical contexts. I think that the importance of "informed consent" is related to our assumption that a normal chooser is a rational human being. In other words, a rational human being will determine his/her best interest if sufficient information is given. Beauchamp and Childress say, "To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs" (Beauchamp and Childress 2009, p. 103) Thus, we can simply understand autonomy as a rational person's self-determination on the basis of personal values and beliefs when given sufficient information.

### 5.3 Misinterpretations and Misuses of Autonomy

From a theoretical perspective, the concept of autonomy as it is defined within biomedical ethics (including Beauchamp and Childress' account) is not the same as that set forth by Kant. Kant states, "Act always on such a maxim as thou canst at the same time will to be a universal law" (Kant 1998, p. 301). He continues, "Autonomy of the will is that property of it by which it is a law to itself (independently on any property of the objects of volition). The principle of autonomy then is: Always so to choose that the same volition shall comprehend the maxims of our choice as a universal law" (Kant 1998, p. 303). Here, autonomy is explained as a universal property of the will. Accordingly, autonomy is not mere self-determination. When we discuss autonomy in bioethical contexts, it seems we do not have in mind universalizability. Hardwig outlines the gap between Kant's understanding of autonomy and the general use of autonomy in medical ethics as follows:

Because medical ethics has ignored patient responsibilities, we have come to interpret "autonomy" in a sense very different from Kant's original use of the term. It has come to mean simply the patient's freedom or right to choose treatment he believes is best for himself (Hardwig 1990, p. 8).

In this way, autonomy in biomedical ethics is better understood as Millian rather than Kantian. Beauchamp and Childress explicate Mill's account in *On Liberty* as follows:

Mill concerned himself primarily with the "individuality" of autonomous agents. He argued that society should permit individuals to develop according to their own convictions, as long as they do not interfere with a like expression of freedom by others or unjustifiably harm others; but he also insisted that we sometimes have an obligation to persuade others when they have false or ill-considered views (Beauchamp and Childress 2009, p. 103).

From the above citation we can understand autonomy as mere self-determination.

Autonomy is often understood as synonymous with freedom. However, it is wrong to identify an autonomous decision simply as a free one. When the subject of self-determination is understood as individualistic, his/her decision demonstrates just his/her preference among the other options available. I do not think this decision is necessarily the same as the one a rational person would make after he/she has reviewed the relevant information with moral reflection and consideration.

Autonomy is not freedom or mere self-determination. Autonomy is ethical self-regulation as is evident in the Greek etymology of autonomy: "autos" (self) and "nomos" (rule, governance or law). Thus, one's autonomous decision is not a mere free choice in accord with one's best interest among other options. Hardwig is right to strongly criticize the individualist perspective and to emphasize the responsibility an individual has to and for his/her family. Accordingly, moral reflection should include moral consideration for the lives and wellbeing of others when making moral decisions in bioethical contexts. From a practical perspective, the ideal of autonomy has not been implemented in accord with its theoretical foundations.

Emphasis has often been placed on acquiring a signature to document informed consent rather than, more importantly, considering how the decision is reached.

This reflects our shallow understanding of autonomy. Accordingly, the ideals of autonomy and the rational human being are not realized in a desirable manner. The presence of one's signature does not ensure that an autonomous decision was made. Consequently, practical guidelines need to be developed in order to move closer to realizing the ideal of an autonomous decision made by a rational human being. To realize this goal, efforts should be made to study and develop informed consent practices, how to provide relevant information for consent, and how to identify autonomous decisions.

#### 5.4 Is Family-Oriented Decision Making an Alternative?

As mentioned above, Hardwig criticizes the notion of individual autonomy. Alternatively, he suggests that one's family should be seriously considered in the informed consent process (Hardwig 1997, pp. 36–39). This discussion may be valuable for those Western societies in which an individual's free choice has enjoyed absolute priority even though it may not be a genuine form of autonomous decision making.

However, Hardwig's view is not novel to Eastern cultures. In Korea especially, older generations feel a moral obligation to their offspring. When elders refuse life-sustaining treatment, they do so because they understand it as a waste of money that could be better used for their offspring. This rationale is also not just an economically based compromise between family members, it is also reflective of the view that human life is not endless.

Most Koreans do not subscribe to the individualist perspective. However, some Koreans may feel the burden of tight relationships among family members<sup>1</sup> and feel they are wrongly forced to sacrifice their life plan for family members. Older generations, who lived after the Korean War, often had to sacrifice for older sons or younger siblings by forgoing an education to make money for the family. In this regard, Hardwig's argument for moral obligations to the family might not fit some Eastern societies where the value of autonomy is not fully developed.

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<sup>1</sup> Here I use "family" to refer to a group of people who are related to each other by marriage and/or blood ties, such as grand-parents, parents, their children, the siblings of parents and their children, etc. However, the scope of "family" may vary depending on an individual's perception. According to Article 779 of the Korean Civil Act, family is legally defined as follows: "(1) Family members shall consist of the following persons: 1. The spouse, lineal blood relatives, and brothers and sisters; and 2. Spouses of the lineal blood relatives, lineal blood relatives of the spouse, and brothers and sisters of the spouse. (2) In the case of paragraph (1), subparagraph 2, it shall be limited to those cases where they share living accommodations." Here "lineal blood relatives" means "father, mother, and their father and mother" and "son, daughter, and their son and daughter." Unlike the Act, most Korean people seem to think that family members are persons mentioned in paragraph (1), ignoring paragraph (2). I will use "family" consisting of persons mentioned in the paragraph (1). For reference, Article 777 defines "relatives" as "1. Blood relatives within the eighth degree of relationship. 2. Affinity relatives within the fourth degree of relationship." Here the first degree of relationship is one between parents and their offspring whereas the second is between siblings.

Further, Hardwig's argument that the family should participate in individual decision making requires consideration. He states:

Considerations of fairness and, paradoxically, of autonomy therefore indicate that the family should make the treatment decision, with all competent family members whose lives will be affected participating (Hardwig 1990, p. 9).

This point also does not quite fit Eastern societies because a family is already involved in its members' individual decision making. Too much involvement of the family is problematic.

According to Ruiping Fan, the family plays an important role in decision making in Eastern societies. He states,

It is not a sick family member him/herself but the entire family that has real authority in clinical decision making. Western people might be concerned about this claim of family-sovereignty. But the family under this notion can be viewed as an autonomous social unit from the physician and the state, analogous to the autonomous individual in the West (Fan 1997, p. 317).

Fan is right to notice this difference between Western and Eastern cultures. However, does this difference justify "the East Asian principle of autonomy" Fan (1997, p. 315) presents? Fan's principle appears to be a "principle of family autonomy" because it views the family as an autonomous social unit that should be regarded as such by physicians and the state.

I agree that the family should participate in the process of decision making, but the decision of a family is not the same as that of an individual person in some respects. The latter cannot be reduced to the former for the following reasons.

First, a decision is fundamentally made at the individual level. A family in itself is not a legitimate subject to make a decision. Even though a group makes a decision following a majority rule vote in a democratic society, it is hard to apply this idea to a family. A majority rule vote presupposes autonomous individuals who are equal. This rule may be the best way to resolve a problem when there are conflicts of opinions among equal individuals, but a family is not comprised of equal individuals. Thus, it is not easy to say that a family may adopt a majority rule practice for decision making.

Second, Eastern culture, especially Koreans, may adopt a principle of best interest for family decision making. This principle works best when we do not know the wishes of an individual and others know what is the best for the individual. We may accept a principle of best interest when a decision needs to be made on behalf of an incompetent patient whose wishes we do not know. In such a case, the conditions listed above are met.

But what about family decision making? There is no problem when a proxy decision is a family decision. In this case, a family or its representative plays the role of a proxy. But what if a family knows the individual's wishes? Should we say that a family decision is still better in this case? I would argue that it is not. The principle of family autonomy cannot be considered the same as or similar to that of individual autonomy.

As previously stated, the family should participate in the decision making process and the individual should seriously consider the values of one's family and how their lives and wellbeing might be affected by one's decision. However, the individual should ultimately make the decision if he/she is competent. This view is found in Amitai Etzioni's article, "On a Communitarian Approach to Bioethics," which also addresses Hardwig's point. Etzioni states,

Hardwig leans somewhat in the authoritarian direction when at one point he claims that "considerations of fairness and, paradoxically, of autonomy therefore indicate that the *family* should make the treatment decision, with all competent family members whose lives will be affected participating." Thus, a less authoritarian position would suggest that, for instance, if nine out of ten family members agree that treatment should be stopped for a given member, but the member—who is competent—rejects this conclusion, the family's wishes should not carry. However, the person does owe the family members a careful consideration of their values, reasons, and needs (Etzioni 2011, p. 367).

I agree with Etzioni's position. An individual should appreciate the value of family and take into account the values and needs of family members. However, the final decision should be made by an individual if he/she is competent.

The notion of group autonomy cannot be established if it lacks a formal process for decision making, like the established procedures of a committee or a congress. As such, there is no formal procedure for family decision making. Further, it should be noted that conflicts of interest might be present in family decision making because, in most cases, the family bears the burden of paying medical costs.

Consequently, we should ask, what is the best understanding of autonomy that preserves the ideal of rational human beings as decision makers while also honoring the individual's relationship to other family members?

## 5.5 A Constructive Understanding of Autonomy

How can we maintain the ideal of autonomy and its value while also reflecting the non-individualistic value of the family or community? Problems with the principle of autonomy do not come from the notion of autonomy in itself, but from misunderstanding the concept of autonomy and/or how it implemented. As previously mentioned, in bioethics, the concept of autonomy is conflated with notion of freedom, even though autonomy is not synonymous with freedom. In practice, there are no practical procedures to ensure a decision is made autonomously.

The ideal of autonomous decision making may in fact be internal and personal, causing problems for the principle of autonomy. Even though this ideal may be difficult to realize, this does not necessarily mean we should give it up. This is also true of other human values, such as justice, liberty, and love. I contend, we should still hold to the ideal of autonomy and have reason to pursue it. In its pursuit, we must educate individuals about the true meaning of autonomy and urge them to seriously reconsider what constitutes an autonomous decision.

Bruce Miller's discussion of autonomy is informative for constructing a reasonable theory of autonomous decision making. He explains different types of autonomy as follows.

There are at least four senses of the concept as it is used in medical ethics: autonomy as free action, autonomy as authenticity, autonomy as effective deliberation, and autonomy as moral reflection. . . . *Autonomy as free action* means an action that is voluntary and intentional. . . . *Autonomy as authenticity* means that an action is consistent with the person's attitude, values, dispositions, and life plans. . . . *Autonomy as effective deliberation* means action taken where a person believed that he or she was in a situation calling for a decision, was aware of the alternatives and the consequences of the alternatives, evaluated both, and chose an action based on that evaluation. . . . *Autonomy as moral reflection* means acceptance of the moral values one acts on. The values can be those one was dealt in the socialization process, or they can differ in small or large measure. In any case, one has reflected on these values and now accepts them as one's own (Miller 1981, pp. 24–25, italics mine).

Miller's third and fourth descriptions of autonomy appear to be the most useful for understanding the ideas of "relational autonomy" and "family-oriented consent."

In the third description, autonomy as effective deliberation, one can include consideration of the wellbeing of one's family and community when one considers the consequences of the alternatives. In this way, Hardwig's worries are overcome when one seriously considers the full consequences of one's decision.

In the fourth description, autonomy as moral reflection, one may include the value of family and give consideration to the relationships between one's self and others, including family members or one's community. In addition, one should consider what the desirable and reasonable ways of life are for moral reflection. The individualist perspective Hardwig criticizes is derived from a misunderstanding of human life. It is just a fact of the world that we share our lives with others, including our family members and others in our community. Consideration for the lives of others, especially family members, and their well being should be included in one's moral reflection.

The meaning of "family-oriented consent" is well captured by Miller's description of moral reflection. Most Koreans appreciate the value of family. If one's moral view is that family is valuable to one's life, sacrifices for one's family do not compromise one's integrity. Additionally, if one wants a family member to make a decision in their place, this also does not compromise one's integrity. However, this does not mean we can replace the value of autonomy with others or that we can underestimate its value. In the above cases, the choice of a surrogate decision maker or one's sacrifice for the family must be the outcome of one's own deliberations and the values one accepts.

Daniel Callahan sets forth a communitarian interpretation of autonomy in his statement that "autonomy should be broadened to encompass an analysis of what constitutes morally good and bad free choice. The claim that so-called private choices should be exempt from moral analysis is the death of ethics" (Callahan 2003, p. 505). One should interpret autonomy such that it includes some aspects of Miller's individual approach as well as characteristics of Callahan's communitarian theory.

Further, we can learn from responsive communitarianism, that is, the relationship between autonomy and the common good of a society. Etzioni states,

Although responsive communitarianism's starting point is the recognition that the tense relationship between autonomy and the common good must be worked out rather than assuming a priori that one of these core values trumps the other, it expects treatment to differ from one society to another and among different historical periods. Thus, in totalitarian societies and theocracies, such as in Singapore and Iran, those who advocate the balance that responsive communitarianism favors would need to promote autonomy, while in societies in which individualism is rampant, such as the US was in the 1980s, the advocates of responsive communitarianism would need to promote more attention to the common good. That is, societies often need to move in opposite directions from another to achieve the same end balance (Etzioni 2011, p. 364).

Etzioni's argument holds for the relationship between autonomy and the good of the family. The value of the family, more concretely, the good of family members, should be balanced with the value of autonomy.

At this point, I will argue that autonomy is a universal moral value. What needs to be revised is the individualistic interpretation of autonomy, not autonomy itself or a revised version of "family autonomy." For the Korean way of life, autonomy may still reflect a desirable notion of the moral agent in which family or other members of the community are just as important as the individual. Korean culture emphasizes harmony between an individual and his/her family members. However, harmony should be balanced with the value of autonomy; one cannot replace the other. This is true of the value of the family.

We have a number of values that contingently conflict with one another. The difficulty of ethics lies in balancing the various values we pursue. Consequently, the values of an individual and his/her family should also be balanced. If the value of the family is underestimated, we have to emphasize its importance as Hardwig suggests. If the value of the individual is underestimated, as it is in Korean society, we have to increase its value by emphasizing autonomy. In the East, especially in Korean culture, autonomy is still an important value in need of development.<sup>2</sup>

The individual (the self) and the family (a community) should be balanced. The family can be considered a community in a basic sense. From a traditional Eastern perspective, the family, rather than the individual, has been the basic unit for society and the state. However, it was not long before Korean society began to recognize an individual as having autonomy. We cannot disvalue modernity. In this regard, the value of autonomy should continue to be emphasized, but it must be balanced with other traditional values.

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<sup>2</sup> The 2011 Organ Transplantation Act in Korea allows a family's refusal of organ donation even if a donor has expressed his/her explicit wishes to donate his/her organ(s). This shows that one's autonomous decision is thoroughly disvalued.

## 5.6 Some Practical Suggestions

In order to improve the balance of the relationship between an individual and one's family, or between autonomy and the value of family, I would like to suggest the following practices.

First, sufficient time for decision making should be given. This will help allow patients and research participants the necessary time to weigh and consider one's values in addition to how the values and wellbeing of the relevant family members will be affected.

Second, consultation services providing medical information, psychological comfort, and the like should be provided. Such services will help patients or research participants make their decisions through the processes of effective deliberation and moral reflection.

Third, the legal requirement to ask patients or research participants whether to discuss decisions with his/her family members or to consider their expected responses should be reviewed. Asking this question will allow patients or research participants the chance to consider multiple perspectives, including the values and needs of one's family members.

Finally, society should try to cultivate a social environment in which autonomous decisions can be made. For example, a decent health insurance system is necessary before advance directives can be introduced.

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